DEPARTMENT OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 2021

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
Washington, DC.

[CLERK'S NOTE.—The subcommittee was unable to hold hearings on departmental and nondepartmental witnesses. The statements and letters of those submitting written testimony are as follows:]

DEPARTMENTAL WITNESSES

PREPARED STATEMENT OF THE AMERICA'S PUBLIC TELEVISION STATIONS AND THE PUBLIC BROADCASTING SERVICE

On behalf of America's 159 public television licensees, we appreciate the opportunity to submit testimony for the record on the importance of Federal funding for local public television stations and PBS. We urge the Subcommittee to support $515 million in two-year advance funding for the Corporation for Public Broadcasting (CPB) in fiscal year 2023, $20 million for the Public Television Interconnection System in fiscal year 2021 and $30 million for the Ready To Learn program at the Department of Education in fiscal year 2021.

Corporation for Public Broadcasting: $515 million (fiscal year 2023) two-year advance funded

Public television plays a key role in educating our children; providing job training; preserving our culture and democracy; and keeping Americans informed, safe and healthy. Federal funding for CPB makes these services available to all Americans, including those in rural and underserved areas, and this funding enjoys the overwhelming support of the American people. At about $1.40 per person per year, this funding provides an enormous return on investment for all Americans.

Yet these vital community-based services were level-funded at $445 million for almost a decade—resulting in an approximate $100 million in lost purchasing power.

Recognizing this loss, last year Congress increased the forward funded fiscal year 2022 appropriation for CPB by $20 million. Public television greatly appreciates that much-needed increase.

While public broadcasting is grateful for this increase, without additional increase going forward, the public broadcasting system would still be nearly $80 million, in inflation-adjusted dollars, behind where the system was 10 years ago.

Public broadcasting respectfully requests that Congress take another substantial step toward securing our current and future public service goals in the fiscal year 2021 appropriations process.

The $515 million that public broadcasting is requesting in fiscal year 2021 for fiscal year 2023 will help continue to restore lost purchasing power and enable local stations to leverage advancements in technology and make investments in the future that will educate more children and adults, further enhance public safety and expand the civic leadership work of local stations.

Given the success of public media, and its potential to do so much more for so many, it is sound public policy to increase Federal funding for this valuable service that provides an exceptional return on investment.

EDUCATION

Perhaps now, more than ever as the nation faces unprecedented times, and families all across America are seeking ways to continue educating their children while isolated at home, the power of public media to serve as the nation's largest classroom has never been so important.

Local stations have always served as the nation's largest classroom, meeting their communities' lifelong learning needs by providing the highest quality educational content and resources on multiple media platforms and in-person. That content is available to all Americans for free, delivered directly into their homes, no matter how they receive their television programming.

Public television's educational broadcast content which has helped more than 90 million pre-school age children get ready to learn and succeed in school is also critical in keeping kids educated and engaged in learning while the majority of Americans are now homeschooling due to the COVID–19 pandemic.

Beyond the iconic, proven educational programming, PBS, in partnership with local public television stations and school districts provides additional content directly to classrooms and homes through PBS Learning Media—which provides access to tens of thousands of State curriculum-aligned digital learning objects—including videos, interactives, lesson plans and more—for use in K–12 classrooms and at home. Content is sourced from the best of public television in addition to material from the Library of Congress, National Archives, NASA and other high-quality sources.

Additionally, local public television stations throughout the country have partnered with PBS to bring a first-of-its kind, free PBS KIDS 24/7 channel and live stream to their communities—providing kids throughout the country with the highest level of educational programming, available through local stations any time, over-the-air and streaming. During the COVID–19 pandemic, many stations are using this expanded broadcast capacity to directly serve families and students from Pre-K–12 with state standards aligned educational content.

Public television stations are also leaders in adult education. Public television operates the largest nonprofit GED program in the country, helping tens of thousands of second-chance learners earn their high school equivalency degree. In addition, public television stations are leaders in workforce development, including the retraining of American veterans by providing digital learning opportunities for training, licensing, continuing education credits and more.

PARTNERS IN PUBLIC SAFETY

Public broadcasting stations throughout the country are leading innovators and essential partners to local public safety officers. In partnership with FEMA, the public television interconnection system supports the Wireless Emergency Alert (WEA) system that enables cell subscribers to receive geo-targeted text messages in the event of an emergency—reaching citizens wherever they are. The February 2019 Report from the FEMA National Advisory Council on Modernizing the Nation's Public Alert and Warning System specifically recommends, "Encouraging use of public media broadcast capabilities to expand alert, warning, and interoperable communications capabilities to fill gaps in rural and underserved areas."

In addition, and separate from the WEA system, local public television stations' digital infrastructure and spectrum enable them to provide state and local officials with critical emergency alerts, public safety, first responder and homeland security services and information during emergencies through a process known as datacasting. Datacasting uses broadcast spectrum to send encrypted data and video to first responders with no bandwidth constraints.

In partnership with local public television stations and local law enforcement agencies, the U.S. Department of Homeland Security (DHS) has conducted several successful pilots throughout the country that, in addition to other local initiatives, prove the effectiveness of datacasting in a range of uses cases including: flood warning and response; enhanced 911 responsiveness; over-water communications; faster early earthquake warnings; multiagency interoperability; rural search and rescue; high profile, large event crowd control; and assistance with school safety, including in areas that lack broadband or LTE services.

As a result of the successful pilots, the DHS Science and Technology Directorate has partnered with America's Public Television Stations to maximize and promote datacasting technology and the opportunity to partner with local public television stations in communities nationwide.

To support this nationwide effort, local public television stations have committed to reserve up to 1 megabit per second of their spectrum for the First Responder Network Authority (FirstNet).

Additionally, stations are increasingly partnering with their local emergency responders to customize and utilize public television's infrastructure for public safety in a variety of critical ways, with many serving as their states' Emergency Alert Service (EAS) hub for weather and AMBER alerts.

PROVIDING CIVIC LEADERSHIP

Public television strengthens the American democracy by providing citizens with access to the history, culture and civic affairs of their communities, their states and their country. As the nation grapples with the COVID–19 pandemic, public television is providing essential front-line coverage of the issue to arm citizens with the facts they need to stay healthy and information on where they can turn for help if they need it.

For the 17th year in a row, PBS was ranked the most trusted among national institutions. That trust is more important than ever. At a time when inaccurate information could endanger people's lives, Americans can tune into their local public television station or view their online resources for trusted information that could help keep them safe.

Local public television stations often serve as the state-level "C–SPAN" covering state government actions. Local stations also provide more public affairs programming, forums for discussion of local issues such as the opioid crisis, local history, arts and culture, candidate debates, agricultural news, and citizenship information of all kinds than anyone else. What truly sets public television stations apart is that stations treat their viewers as citizens rather than consumers.

PUBLIC BROADCASTING IS A SMART INVESTMENT

All of this public service is made possible by the Federal funding to CPB. This Federal investment sustains the public service missions of public television, which are distinct from the mission of commercial broadcasting and will not be funded by private sources, as the Government Accountability Office concluded in a 2007 study commissioned by Congress.

The need for Federal investment is particularly acute in small-town and rural America, where lower population density, a lack of corporate and philanthropic support, and challenging topography make the economics of local television and public service more challenging. As a result, public broadcasters are sometimes the only local broadcaster serving rural communities—and only with the help of the Federal investment.

For all stations, Federal funding is the "lifeblood" of public broadcasting, providing indispensable seed money to stations to build additional support from state legislatures, foundations, corporations, and "viewers like you."

For every dollar in Federal funding, local stations raise six dollars in non-Federal funding, creating a strong public-private partnership providing a valuable return on investment and supporting approximately 20,000 jobs across America.

And yet, until last year, this critical funding remained flat for a decade, forcing stations to make difficult programming, staffing and service decisions as operational costs rose with inflation, while CPB funding did not. Despite this severe financial constraint, local public television stations have continued their deep commitments to the communities they serve. If CPB funding had kept up with the rate of inflation over the last 10 years, CPB would be funded at $543 in fiscal year 2023.

The $515 million that public broadcasting is requesting in fiscal year 2023 is both prudent and necessary for the continued health of local stations and the public broadcasting system as a whole—and for long-delayed enhancements of the essential education, public safety and civic leadership services described above.

TWO-YEAR ADVANCE FUNDING

Two-year advance funding is essential to the mission of public broadcasting. This longstanding practice, proposed by President Ford and embraced by Congress in 1976, establishes a firewall insulating programming decisions from political interference, enables the leveraging of funds to ensure a successful public-private partnership, and provides stations with the necessary lead time to plan in-depth programming and accompanying educational materials—all of which contribute to extraordinary levels of public service and public trust.

Local stations leverage the two-year advance funding to raise state, local and private funds, ensuring the continuation of this strong public-private partnership. These Federal funds act as the seed money for fundraising efforts at every local station, no matter its size. Advance funding also benefits the partnership between states and stations since many states operate on two-year budget cycles.

Finally, the two-year advance funding mechanism gives stations and producers, both local and national, the critical lead time needed to raise the additional funds necessary to sustain effective partnerships with local community organizations and engage them around high-quality programs. Producers like Ken Burns spend years developing programs like The Vietnam War and Country Music,. It would be impossible to produce this in-depth programming and the curriculum-aligned educational materials that accompany it without the two-year advance funding.

Public Television Interconnection: $20 million

The public television interconnection system is the infrastructure that connects PBS and national, regional and independent producers to local public television stations around the country. The interconnection system is essential to bringing public television's educational, cultural and civic programming to every American household, no matter how rural or remote. Without interconnection, there is no nationwide public media service. The interconnection system is also critical for public safety, providing key redundancy for the communication of presidential alerts and warnings, and ensuring that cellular customers can receive geo-targeted emergency alerts and warnings.

Congress has always provided Federal funding for periodic improvements of the interconnection system. In fiscal year 2018, Congress moved to fund interconnection for public broadcasting on an annual, rather than decennial, basis to enable dynamic, incremental upgrades in accord with increasingly rapid advances in technology. Public television seeks level funding of $20 million for interconnection in fiscal year 2021.

Ready To Learn: $30 million (Department of Education)

The U.S. Department of Education's Ready To Learn (RTL) competitive grant program, reauthorized in the Every Student Succeeds Act, uses the power of public television's on-air, online, mobile, and on-the-ground educational content to build the literacy and STEM skills of children between the ages of two and eight, especially those from low-income families.

Through their RTL grant, CPB and PBS deliver evidence-based, innovative, high-quality transmedia content to improve the math and literacy skills of high-need children. CPB, PBS, and local stations have ensured that the kids and families that are most in need have access to these groundbreaking and proven effective educational resources. In addition to children, this outreach focuses on adults that care for kids to empower and help them understand the important role they play in their children's educational success.

RTL investments have supported the production and academic rigor of PBS KIDS series: Molly of Denali, Peg + Cat, SuperWhy!, Martha Speaks, Odd Squad and other iconic programming for children.

But this investment does not solely rely on trusted, educational children's programming. CPB, PBS, and local public television stations employ a national-local model to reach parents, teachers, and caregivers on-the-ground in communities to help them make the most of these media resources locally. These include television, online and mobile apps, digital technology, mobile learning labs and on the ground events that provide valuable content and support to local school districts, county non-profits, preschools, homeschools, Head Start and other daycare centers, libraries, museums, and Boys and Girls Clubs, among others.

RESULTS

RTL is rigorously tested and evaluated to assess its impact on children's learning and to ensure that the program continues to offer children the tools they need to succeed in school. Since 2005, more than 100 research and evaluation studies have shown RTL literacy and math content engages children, enhances their early learning skills and allows them to make significant academic gains, helping bridge the achievement gap. Highlights of recent studies show that:

- —Use of PBS KIDS content and games by low-income parents and their preschool children improves math learning and helps prepare children for entry into kindergarten.[1]
- —Children who participated in the RTL Electric Company Summer Learning Program showed significant learning gains from pre- to post-assessment:
  - —41 percent gain in their mathematics vocabulary
  - —20 percent gain in their numeracy skills

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[1] PBS KIDS Mathematics Transmedia Suites in Preschool Homes: A Report to the CPB–PBS Ready To Learn Initiative (WestEd 2012).

—17 percent gain in their phonics skills[2]

—Parents who used RTL math resources in the home became considerably more involved in supporting their children's learning outcomes.[3]

AN EXCELLENT INVESTMENT

In addition to being research-based and teacher tested, RTL also provides excellent value for our Federal dollars. In the last five-year grant round, public broadcasting leveraged an additional $50 million in non-Federal funding to augment the $73 million investment by the Department of Education. RTL exemplifies how the public-private partnership that is public broadcasting can change lives for the better.

A funding level of $30 million is requested in fiscal year 2021 to further enhance the impact of Ready To Learn created content and the quantity and scope of local station outreach to the kids, families, teachers and schools that need it the most.

Given the rigorous, thoughtful educational research and evaluation that goes into the creation of Ready To Learn content, Ready To Learn grants are awarded every 5 years and supported through annual appropriations. Funding in fiscal year 2021 would provide the second year of funding in the latest grant round. Providing $30 million for Ready To Learn in fiscal year 2021 will ensure that the next round of Ready To Learn grants can continue to create the highest quality, proven effective kids educational media content, meeting kids, caregivers and teachers where they are on a variety of platforms, including television, while expanding local, on-the-ground outreach through public television stations and their local partners.

CONCLUSION

Americans across the political spectrum rely on and support Federal funding for public broadcasting because we provide essential local education, public safety, and civic leadership services that are not available anywhere else. And none of this would be possible without the Federal investment in public broadcasting.

Federal funding is the great equalizer that ensures that the best of public broadcasting is available in both the urban centers of our great cities and in Native American communities in America's heartland and everywhere in between.

Federal funding for CPB is what ensures that young children in Appalachia have the same access to the unparalleled PBS KIDS content as their counterparts in Los Angeles. And Federal funding is what ensures that all households, regardless of their ability to pay for cable have access to local programming and the best of NOVA, Masterpiece, NewsHour, Great Performances, and so much more.

Public broadcasters are the only broadcasters that reach nearly 97 percent of U.S. households, and it is CPB funding that makes this possible.

For all of these reasons we request that Congress continue its commitment to the highly successful, hugely popular public-private partnership that is public broadcasting by providing $515 million in fiscal year 2023 for CPB in addition to $20 million in fiscal year 2021 for public broadcasting's interconnection system and $30 million in fiscal year 2021 for the Ready To Learn Program.

PREPARED STATEMENT OF THE CORPORATION FOR PUBLIC BROADCASTING

Chairman Blunt, Ranking Member Murray and distinguished members of the subcommittee, thank you for allowing me to submit this testimony on behalf of America's public media service-public television and public radio-on-air, online and serving communities throughout our country. The Corporation for Public Broadcasting (CPB) requests funding of $515 million for fiscal year 2023, $20 million in fiscal year 2021 for the replacement of the public broadcasting interconnection system and other technologies and services, and $30 million for the Department of Education's Ready To Learn program.

The Corporation provides leadership and stewards the Federal appropriation to ensure a healthy and sustainable public media system. With CPB funding to 1,500 local public television and radio stations across the country, the Federal appropriation guarantees that important educational content and services, news and public affairs programming, and cultural treasures reach Americans living in rural, small town and urban communities. Stations leverage the appropriation, raising, on average, six times more from non-Federal funding sources than they receive from CPB.

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[2] Evaluation of The Electric Company Summer Learning Program (WestEd 2011).

[3] Learning with PBS KIDS: A Study of Family Engagement and Early Mathematics Achievement (WestEd 2015).

While private funding and donations can and do make up a significant portion of the finances of the public media system, the Federal appropriation remains an essential part of the public-private partnership for public media. This seed money pays invaluable dividends to millions of Americans and their families, especially the unserved and underserved. Only through Congressional funding can public media maintain this universal access.

In order to meet the educational needs of young people, public media provides award winning high-quality educational content on all platforms. Through the Department of Education's Ready to Learn grant, public television is preparing our youngest learners for school, especially those in underserved communities, by delivering proven educational resources and experiences to parents, teachers and caregivers. While today's media environment offers abundant content aimed at children, no other outlet provides safe, trusted, educational content that is free of charge and commercial-free. The Federal appropriation to CPB ensures that our children will continue to have access to public media's content over the air, online, through mobile apps and in their community.

Federal support through CPB helps local public media stations provide new services that excite and engage students, teachers and parents. For example, the Mobile Virtual Reality Lab (MVRL) at Georgia Public Broadcasting utilizes virtual reality headsets to immerse students in educational experiences. Through the MVRL, students are transported to key moments in the Civil Rights Movement and can also explore prehistoric cultures of Native American tribes.

Further to ensure that young people can access content of value to their lives, CPB is helping launch TRAX, a new public media network of original podcasts for ages 9 to 13 years old. Beginning this year, TRAX will offer on-demand audio content that is educational and entertaining, and diverse in genre, format and voice. In addition, CPB is funding research at the Joan Ganz Cooney Center to explore new ways public media can connect trusted, educational content to children ages 8 to 18. As learning becomes more personalized, Congress' support is needed to continue to research, develop and test how educational media and technology can improve students' learning outcomes.

Through public media initiatives such as American Graduate, stations provide high-quality educational content and community engagement that helps Americans prepare for success in school and career. Nine years ago, public media addressed the high school dropout crisis-one million students failing to graduate each year. Through national and local content, award-winning documentaries, reporting and town halls, the American Graduate initiative drove dialogue and put a face on a statistic. As a result of the steadfast commitment of initiatives such as American Graduate, the national graduation rate has risen to an unprecedented 84.6 percent. Further, research shows that in 88 percent of those communities where American Graduate was active, schools experienced an almost 10 percent increase in their graduation rates-compared with the national average of 5.5 percent. Moreover, recent government statistics showed that for the first time, black students' graduation rates are on par with white youth. While we are proud of this success, there is still work to be done.

Building on American Graduate's success, CPB expanded the initiative to focus on connecting young people to essential workforce skills and career opportunities. For example, Connecticut Public Broadcasting facilitated a town hall where businesses shared what success looks like for those who enter high-demand, skilled careers and broke down multiple negative perceptions with data and storytelling. With CPB support, Kentucky Educational Television (KET) created Workplace Essential Skills—an online instructional system utilizing videos, interactive learning tools and quizzes to guide learners through the job application process and workplace environment. KET has launched online certification courses in healthcare, manufacturing, transportation/logistics, and in construction and information technology. American Graduate is helping Americans improve their everyday lives and rise to meet the challenges of tomorrow.

CPB seeks to increase the capacity of public radio and television stations to create high-quality original and enterprise journalism by supporting collaborations between public media stations. As local journalism diminishes, public media stations have added more than 700 journalists to their staffs during the past 6 years. Local reporting and community-led conversations on issues such as aging and mental health provide resources and answers for those affected. With the global outbreak of COVID–19 and the need for community information, South Florida PBS is providing public television stations across the country with health reports from medical experts, and is making available a dedicated website that tracks the virus' spread and offers information about treatment and prevention. KUOW–FM in Seattle is providing live updates about the coronavirus online and on air and is explaining who is most at risk for severe illness, as well as where COVID–19 tests are available and its impact on businesses.

Further, CPB's investments in editorial integrity and regional journalism collaborations allow public media to retain the trust of the American people and deliver relevant news and information to local communities and regions. Nationally, programs such as FRONTLINE, PBS NewsHour, NOVA and All Things Considered examine critical issues facing our society, providing trusted content to Americans striving to learn more about our ever-changing world.

CPB supports initiatives that increase understanding of our shared American experience by capturing and elevating the stories of everyday people from differing backgrounds and viewpoints. CPB's Coming Home: Connecting to Community celebrates the people, culture, and stories of rural America through authentic local voices and talent. Working with local partners, public media can uniquely preserve community stories about traditions, aspirations, struggles and what it means to be an American. CPB is also proud to support StoryCorps, including its Military Voices Initiative, which records the stories of military service members and their families to honor and better understand their sacrifice.

Committed to building a pipeline of diverse talent, CPB funds the National Multicultural Alliance, Firelight Media's Documentary Lab, the Jacquie Jones Memorial Scholarship, the Werk It Podcast Festival, and WXXI-Rochester's Move to Include initiative. Each of these efforts increases the numbers of diverse storytellers, ensuring our nation's public media service reflects the faces and voices of Americans.

Interconnection Infrastructure: Interconnection is the backbone of the public media system, delivering content every day from public media producers to public television and radio stations in communities throughout the country. Without it, there is no nationwide public media service. Recognizing its importance, Congress has funded public media's interconnection system since fiscal year 1991 through a separate, periodic appropriation for interconnection. Currently, CPB is investing in new technologies and organizational change to ensure that the public media system continues to provide essential services in the 21st-century. For public media consumers, this will mean increased accessibility and personalization across all public media digital platforms and increased efficiencies for public media stations through unified radio and television content management systems. These efficiencies and technological improvements will advance the entire system and benefit the American people.

CPB's fiscal year 2023 request of $515 million and fiscal year 2021 requests of $20 million and $30 million for interconnection and Ready To Learn, respectively, provides essential support to stations—particularly those serving rural, minority and other underserved communities—and enables innovation and technological advances. We know that Americans value their local public media stations. With your support, CPB will continue to serve as a trusted steward of the Federal appropriation and invest these taxpayer dollars in ways that connect to Americans' daily lives and our shared future. Mr. Chairman and members of the subcommittee, thank you for allowing me, on behalf of America's public media, to submit this testimony. I appreciate your consideration of our funding request.

[This statement was submitted by Patricia de Stacy Harrison, President and CEO, Corporation for Public Broadcasting

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PREPARED STATEMENT OF THE RAILROAD RETIREMENT BOARD

Mr. Chairman and Members of the Committee:

The President's fiscal year 2021 proposed budget for the Railroad Retirement Board (RRB) is $120.225 million. The RRB is requesting $155.824 million. Appropriations for RRB operations are derived from the railroad retirement trust funds and not the general revenue fund. Appropriations language[1] authorizes the RRB to access available funding from its trust funds, in contrast to monies that would otherwise be appropriated from the general revenue fund, to administer comprehensive retirement/survivor and unemployment/sickness insurance benefit programs for railroad workers and their families under the Railroad Retirement (RRA) and Railroad Unemployment Insurance (RUIA) Acts. The RRB also administers certain benefit payments and Medicare coverage for railroad workers under the Social Security Act.

During fiscal year 2019, the RRB paid benefits totaling $13.3 billion, net of recoveries and offsetting collections. Of this amount, payments for the retirement/sur-

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[1] "Such amounts as determined by the Board from the railroad retirement accounts and from moneys credited to the railroad unemployment insurance administration fund." Further Consolidated Appropriations Act, 2020, Public Law 116–94, Div. A, Title IV (December 20, 2019).

vivor benefits program totaled $13.1 billion to about 535,000 beneficiaries. The RRB also paid unemployment-sickness benefits of $93.2 million. About 9,300 railroad workers received unemployment insurance benefits, and approximately 14,700 received sickness insurance benefits. Finally, RRB paid vested dual benefits of $17.3 million to about 9,000 beneficiaries. On behalf of the Social Security Administration, the RRB paid benefits of $1.9 billion to about 125,500 beneficiaries (for which the RRB is reimbursed).

The railroad employer and employee contributions are held in trust funds to pay railroad benefits and support RRB operations. As previously stated, enacted appropriation language authorizes the RRB to access the funds available in the railroad retirement trust fund system in order to finance operations. The Association of American Railroads and the Rail Labor Division of the Transportation Trades Department, American Federation of Labor and Congress of Industrial Organizations (AFL–CIO) continue to support increased appropriations to address the urgent staffing needs and ongoing information technology modernization activities.

PRESIDENT'S PROPOSED FUNDING FOR RRB ADMINISTRATION

The President's proposed budget would provide $120.225 million for RRB operations, to include IT initiatives, and support 672 full-time equivalents (FTEs). The RRB requests $155.824 million, which is $35.599 million above the President's proposed budget. Of the $155.824 million RRB requests, $141.974 million is necessary to support 880 FTEs and $13.850 million in no-year funds to continue IT modernization efforts. For the reasons explained below, the FTE level of 672 proposed in the President's budget would pose too great a risk of failure to meet the agency's mission as early as fiscal year 2021.

The RRB is asking for funding from the railroad retirement trust fund system, not the general revenue fund, sufficient to support 880 FTEs, which is the number that is urgently needed to sustain mission critical activities. The remainder of this testimony will focus on these critical priorities and conclude with an overview of the financial status of the trust funds.

CRITICAL PRIORITY: STAFFING

Since fiscal year 2017, the RRB has been appropriated $113.5 million for personnel and general operating costs to support benefits administration, exclusive of funding for IT modernization despite successive years of unfunded Cost of Living Adjustment (COLA) increases in salary and associated benefits. The COLAs the RRB had to fund with its stagnant budget include $1.388 million in 2017, $1.389 million in 2018, $1.364 million in 2019, and $2.066 million in 2020. Consequently, the RRB has strained to absorb the impact of increases in civilian pay and benefits costs. Roughly, 36 percent of the agency's most knowledgeable and experienced staff will be eligible to retire by fiscal year 2022. In fiscal year 2020, approximately 25 percent of its workforce is eligible to retire. Unfortunately, these seasoned employees are not easily replaced due to the complexity of RRB programs and the tendency of new hires to seek higher paying work outside the agency. Insufficient staffing levels have thus forced the RRB to focus its limited resources on processing initial claim and related payments timely. To date, these are the most visible performance metrics and generally, with the exception of disability payments, RRB has been successful in this regard. Sustained low staffing levels have nevertheless reduced RRB's performance in less visible ways: inadequate staffing levels have created backlogs of post adjudicative actions that serve to ensure ongoing disability or retirement/survivor benefit payments are accurate. Inadequate staffing has also impaired the RRB's core training program, which ensures that new employees obtain an in-depth understanding of the RRA and/or RUIA for effective and efficient benefits administration. It can take one to 2 years for new staff to become competent adjudicators and even longer for new staff to resolve more complex and non-routine administrative issues. On the other hand, RRB customer service metrics associated with deficient staffing levels in the RRB's 53 field offices have sharply declined due to poor customer service availability, unacceptable wait times for telephone assistance and unpredictable temporary office closures. Representatives of both rail management and rail labor have shared negative feedback about and examples of RRB's poor customer service in recent months.

Therefore, the RRB requests $141.974 million to support 880 FTEs. Investment in additional staff would help the RRB revitalize its benefits administration training program, allowing the RRB to better manage the impact of attrition and improve customer service capabilities. After the new staff have been trained, the RRB would begin to realize reductions in the backlog in retirement, survivor, and disability casework and prevent future case build up. Increased staffing levels are necessary until the modernized technology and streamlined business processes can sustain organizational performance at lower staffing levels in the future.

CRITICAL PRIORITY: INFORMATION TECHNOLOGY

We are grateful for the support and $30 million provided thus far for the RRB's IT modernization efforts. Several of the seven initiatives identified early in this modernization journey afforded two major lessons learned. To start with, the RRB's IT Modernization Program focused narrowly on seven initiatives and did not capture significant outdated portions of the enterprise IT environment. Secondly, while IT modernization is still the priority, we will leverage the opportunity to transform core business processes and customer service capabilities, simultaneously. As such, RRB's IT modernization program has evolved into a Transformation that consists of three phases—Stabilize, Modernize, and Perform. From an IT perspective, this Transformation will still target the 70+ legacy applications and transition its platforms to support continuous delivery of capability enhancements securely and reliably. From a business perspective, the Transformation will ensure that core process modernizations span the continuum, to include streamlining the RRB's core training program for claim examiners as well as infusing greater flexibility and efficiency into benefit calculations and/or adjustments.

The progress of the RRB's IT modernization activities is detailed in the quarterly reports submitted to your office. The RRB requests $13.850 million of no-year funding for ongoing modernization efforts, shifting from the Stabilize to the Modernize phase of the Transformation.

FINANCIAL STATUS OF THE TRUST FUNDS

Railroad Retirement Accounts.—The RRB continues to coordinate its activities with the National Railroad Retirement Investment Trust (Trust), which was established by the Railroad Retirement and Survivors' Improvement Act of 2001 (RRSIA) to manage and invest railroad retirement assets for the payment of benefits. The net asset value of Trust-managed assets on September 30, 2019, was $25.4 billion, a decrease of almost $1.2 billion from the previous year.

The RRB's latest report required by the Railroad Retirement Act of 1974 and Railroad Retirement Solvency Act of 1983 was released in June 2018. The overall conclusion was, barring a sudden, unanticipated, large drop in railroad employment or substantial investment losses, the railroad retirement system will experience no cash flow problems during the next 29 years. The report recommended no change in the employer or employee tax rates.

Railroad Unemployment Insurance Account.—The RRB's latest annual report required by Section 7105 of the Technical and Miscellaneous Revenue Act of 1988 was issued in June 2019. The report indicated that even as maximum daily benefit rates are projected to rise approximately 44 percent (from $77 to $111) from 2018 to 2029, experience-based contribution rates are expected to keep the unemployment insurance system solvent. No financing changes were recommended at this time by the report.

Thank you for your consideration of our budget request.

[This statement was submitted by Erhard R. Chorlé, Chairman, John Bragg, Labor Member, and Thomas Jayne, Management Member, Railroad Retirement Board.]

NONDEPARTMENTAL WITNESSES

PREPARED STATEMENT OF THE ACADEMY FOR RADIOLOGY & BIOMEDICAL IMAGING RESEARCH

Mr. Chairman and Members of the Subcommittee, my name is Dr. Mitchell Schnall, and I am privileged to serve as President of the Academy for Radiology & Biomedical Imaging Research ("the Academy"). I am testifying today to thank you for your dedicated support of medical imaging, and to request your support for raising the funding for the National Institutes of Health (NIH) to no less than $44.7 billion and increasing the funding for the National Institute of Biomedical Imaging and Bioengineering (NIBIB) to no less than $428.6 million.

In my "day job" I am Eugene P. Pendergrass Professor and Chair of the Department of Radiology at the Perelman School of Medicine at the University of Pennsylvania, Philadelphia, PA. I am also a member of the American Society of Clinical Investigation and the Association of American Physicians. Throughout my career, I have worked on the interface between basic imaging science and clinical medicine. My work has led to fundamental changes in imaging approaches to breast and prostate cancer, as well to emerging technologies such as optical imaging.

On behalf of the Academy, I would like to begin by thanking you for your generous support for the NIH in the fiscal year 2020 LHHS appropriations bill. The increase in funding of $2.6 billion is critical to the important work of improving our biomedical research infrastructure while also ensuring that the United States remains the leader in medical innovation and technology.

As this subcommittee knows well, funding for NIH is spread throughout the country. Approximately 83 percent of the amount appropriated for NIH budget is used for peer-reviewed extramural grants to researchers at universities, hospitals, and institutes in all 50 states. Approximately 10 percent funds very high-end research and patient care on the NIH campus. Only about 7 percent of funding is used for administrative purposes, maximizing the return on the investment.

Nowhere is the return on investment and impact on healthcare diagnosis and treatment more significant than in the growing field of biomedical imaging and bioengineering.

Our requests of this Subcommittee are critically important to the physical and economic health of the nation, and I would like to state them clearly here:

—Please fund the NIH at no less than $44.7 billion for fiscal year 2021.

—Please fund NIBIB at no less than $428.6 million for fiscal year 2021.

Mr. Chairman, medical imaging plays a unique and substantial role in healthcare, both as an instrumental part of the medical care delivery system and as a catalyst for innovation and technological advancement in service of patient care. Imaging performs increasingly central and irreplaceable roles in early disease detection, diagnosis, treatment planning and monitoring. Precise and personalized care and treatment plans are often developed based on decisions made through imaging analysis and review. The Subcommittee's investment in NIH broadly, and in NIBIB in particular, helps make this possible.

NIBIB's imaging and bioengineering research and development create the vital methodology and tools utilized in so many areas of biomedical research by other institutes, and more generally in America's healthcare delivery system. Imaging and bioengineering research is a significant component of the work of many institutes of the NIH, representing 13 percent of all NIH research, while having a budget that is less than 1 percent of the total NIH budget. It is important to note that NIBIB research itself has led to an impressive number of approved patents. In a study covering the 14-year period from 2000 to 2013, [*]Battelle et al. found that for every $100 million of research funding, NIBIB generated 25 patents and more than $575 million in resulting economic activity and growth.

For nearly every patient—nearly every constituent—who receives a cancer diagnosis, suffers a head injury, or experiences any of thousands of other medical issues, or who cares for family members experiencing such difficulties, the health benefits of imaging and bioengineering research are profoundly felt. Few medical conditions do not already benefit from any of the wide range of clinical imaging modalities, from x-rays to MRI, CT, PET, fluoroscopy, angiography, and ultrasound. Furthermore, scientific discoveries and technological innovations are rapidly expanding the power of biomedical imaging and bioengineering to improve medical care.

In the area of cancer, for example, emerging techniques for molecular imaging will play a key role in realizing the dream of molecularly-targeted treatment. Unlike biopsies, they can give a non-invasive picture of the biological heterogeneity of cancer

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[*] Report available at: https://www.acadrad.org/battelle-report/.

within and across all tumors in a patient. Progress is accelerating rapidly in the use of computer tools, including artificial intelligence (AI) and machine learning (ML). Such tools are utilized to analyze both anatomical and molecular images and identify mathematically defined features not perceptible to the human eye. These tools can predict the presence of cancer, its genetic profile, and how well it is likely to respond to specific treatments. The use of increasingly advanced imaging tools to guide medical interventions is allowing more precise, less invasive procedures, in some cases with immediate assessment of efficacy to enable necessary adjustments before a procedure is concluded. Exploratory surgery is now far less common due to these new advancements.

The Academy is involved in a broad effort to help maximize the efficiency with which medical imaging is applied in research and patient care. Since 2017, when the Interagency Working Group on Medical Imaging (IWGMI) within the White House Office of Science Technology Policy (OSTP) released its Roadmap report, the Academy has been working to advance the report's four key objectives for "high-value" imaging:

—Standardizing image acquisition and storage;
—Applying advanced computation and machine learning to medical imaging;
—Accelerating the development and translation of new, high-value imaging techniques; and
—Promoting best practices in medical imaging.

The Academy is working closely across academia, government, and industry to identify and pursue specific, effective steps to implement the building of the Diagnostic Cockpit (DxCP), as envisioned by IWGMI. The DxCP initiative will empower precision medicine by bringing together the latest diagnostic sensor technology with advanced AI-based computing to match patients to the best treatments. The Academy has convened leaders in biomedical imaging and bioengineering from academia, government, and industry to work collaboratively on this initiative toward the development of tools that will leverage advances in AI and ML to aggregate and synthesize medical data to improve patient care. The DxCP is a vision for today and for the future that will be made possible by a consistent and robust investment in biomedical imaging research. The sooner we invest, the sooner your constituents benefit.

Mr. Chairman, innovation is what keeps America healthy—both physically and economically—and the NIH is a major contributor to our strength. Since its creation, NIBIB has proven to have a significant impact by creating the imaging and bioengineering tools that improve the healthcare of Americans and contribute to our nation's economic vitality and global leadership.

Thank you again for the opportunity to present this testimony to you on behalf of the Academy for Radiology & Biomedical Imaging Research. The Academy welcomes the opportunity to work with the Congress to ensure that the American people benefit from their investment in research and have access to the best technology to address their imaging needs.

[This statement was submitted by Mitchell D. Schnall, M.D., Ph.D., Academy for Radiology & Biomedical Imaging Research.]

PREPARED STATEMENT OF THE ACADEMY OF NUTRITION AND DIETETICS

The Academy of Nutrition and Dietetics appreciates the opportunity to submit outside witness testimony to the Senate Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies. The Academy is the world's largest organization of food and nutrition professionals and is committed to improving the nation's health with nutrition services and interventions provided by registered dietitian nutritionists. Nationwide, the Academy represents over 107,000 registered dietitian nutritionists (RDNs), nutrition and dietetic technicians, registered (NDTRs), and advanced-degree nutritionists.

For fiscal year 2021, we strongly urge you to provide robust funding for Older Americans Act nutrition programs, which are on the front lines of preventing senior hunger and malnutrition and promoting social distancing during the COVID–19 crisis; the CDC Division of Nutrition, Physical Activity, and Obesity; and the National Institute of Diabetes, Digestive, and Kidney Diseases. We also request report language related to obesity treatment within Medicare.

FUNDING: ACL OLDER AMERICANS ACT NUTRITION PROGRAMS

The Older Americans Act authorizes a wide array of service programs through a national network of 56 state agencies on aging, 629 area agencies on aging, nearly

20,000 service providers, 244 Tribal organizations, and 2 Native Hawaiian organizations representing 400 Tribes.[1] These programs are overseen by the HHS Administration for Community Living. Most participants have household incomes below 100 percent of the Federal poverty level.[2]

During the COVID–19 crisis, service providers stopped providing congregate meals and shifted those services to grab-and-go and home-delivered meals to promote social distancing and prevent the spread of the virus among this very vulnerable population. In addition to continuing to combat senior hunger in this time of uncertainty, senior meals programs also help reduce the need for seniors to leave their homes to get food, further helping to limit their potential exposure to COVID–19.

CONGREGATE NUTRITION SERVICES

Academy's Fiscal Year 2021 Request: $562 million—Fiscal Year 2020 Enacted Level: $510 million

Congregate Nutrition Services funds nearly 80 million meals per year for 1.5 million participants and gives seniors access to socialization. More than one-fifth of participants have been deemed to be at high nutrition risk. These funds are also used to provide nutrition screening and counseling to seniors who may be at risk of malnutrition, food insecurity, or other related issues.

A national survey of OAA participants shows that in 2017, 48 percent of congregate nutrition survey respondents were aged 75 and older; 47 percent lived alone; 11 percent had annual income of $10,000 or less; and 51 percent reported that the congregate meals program provided one-half or more of their daily food intake.[3] Furthermore, many congregate nutrition participants reported these meals have fostered greater socialization, with 83 percent saying that they saw friends more often due to meals.

HOME-DELIVERED NUTRITION SERVICES

Academy's Fiscal Year 2021 Request: $285 million—Fiscal Year 2020 Enacted Level: $266 million

Home-Delivered Nutrition Services provides more than 140 million meals per year to 850,000 participants and serves as a safety check for isolated residents.[3] More than one-half of participants have been deemed to be at high nutrition risk. The program is also a primary access point for other home- and community-based services for many seniors. An ACL evaluation found that, compared to congregate meal participants, a larger proportion of home-delivered meal participants reported being in fair or poor health, being underweight, having difficulty eating due to dental issues, and taking multiple medications. For many seniors, Home-Delivered Nutrition Services are their only consistent, dependable source of food.

A national survey of OAA participants shows that in 2017, 62 percent of home-delivered respondents were aged 75 and older; 58 percent lived alone; 23 percent had annual income of $10,000 or less; and 57 percent said that the home-delivered meals program provided at least one-half of their daily food intake.[3] According to the survey, home-delivered meals participants tend to be particularly frail and at risk for institutionalization, in part due to the requirement that participants be home-bound. Almost 4 out of 10 recipients (39 percent) reported needing assistance with one or more activities of daily living (ADLs); 14 percent of these recipients needed assistance with three or more ADLs. In addition, 84 percent reported needing assistance with one or more ADLs.

NUTRITION SERVICES INCENTIVE PROGRAM

Academy's Fiscal Year 2021 Request: $181 million—Fiscal Year 2020 Enacted Level: $160 million

The Nutrition Services Incentive Program provides incentives for providers to serve additional meals through cash and/or commodities grants. Prior to the CIOVID–19 pandemic, more local service providers were reporting waiting lists for home-delivered meals than in previous years.[3] As food insecurity increases across the country in the wake of the COVID–19 pandemic, this incentive program is a key means to reducing waiting lists for senior meals programs.

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[1] https://acl.gov/about-acl/authorizing-statutes/older-americans-act.

[2] https://fas.org/sgp/crs/misc/IF10633.pdf.

[3] https://fas.org/sgp/crs/misc/IF10633.pdf.

DISEASE PREVENTION AND HEALTH PROMOTION SERVICES

Academy's Fiscal Year 2021 Request: $28 million—Fiscal Year 2020 Enacted Level: $25 million

Disease Prevention and Health Promotion Services funds evidence-based prevention programs to improve health and reduce disease and injury among older adults.[4] The program provides grants to states and territories based on their share of the population aged 60 and older for programs that support healthy lifestyles. Common program types include class-based physical activity programs, falls prevention programs, self-management programs, and one-on-one health interventions within the home. Evidence-based disease prevention and health promotion programs can reduce the need for more costly medical interventions.

FUNDING: CDC DIVISION OF NUTRITION, PHYSICAL ACTIVITY AND OBESITY

Academy's Fiscal Year 2021 Request: $125 million—Fiscal Year 2020 Enacted Level: $56.9 million

The CDC Division of Nutrition, Physical Activity, and Obesity (DNPAO) oversees grant programs that provide funds to states and localities to address the obesity epidemic in their communities.[5] According to the CDC, the prevalence of obesity was 42.4 percent in 2017–2018.[6] Obesity-related conditions include heart disease, stroke, type 2 diabetes and certain types of cancer that are some of the leading causes of preventable, premature death. In 2008, the annual medical cost of obesity in the United States was estimated to be $147 billion; the medical cost for people who have obesity was $1,429 higher than those of normal weight.

STATE PHYSICAL ACTIVITY AND NUTRITION PROGRAM

Academy's Fiscal Year 2021 Request: $60 million—Fiscal Year 2020 Enacted Level: $15 million

One of the programs run out of DNPAO is the State Physical Activity and Nutrition (SPAN) grant program, which awards competitive grants to states to implement multi-component, evidence-based strategies at the state and local level to improve nutrition and physical activity.[7] With its current funding level, SPAN is only able to fund 16 states, which is does via 5-year grants (currently fiscal year 2018–2022). DNPAO estimates that it would cost an additional $1.2 million per state to expand the program, so we are requesting $60 million in total funding to allow every state to receive funding through SPAN.

FUNDING: NATIONAL INSTITUTE OF DIABETES, DIGESTIVE AND KIDNEY DISEASES

Academy's Fiscal Year 2021 Request: $2.2 billion—Fiscal Year 2020 Enacted Level: $2.1 billion

The National Institute of Diabetes, Digestive, and Kidney Diseases (NIDDK) conducts and provides grant funding to support research on many of the most common and costly chronic diseases. Key areas of focus include diabetes, digestive diseases such as Celiac, kidney disease, weight management, and more. This research advances clinical knowledge about and treatment for these diseases. The $2.2 billion request would help NIDDK to accelerate scientific understanding of some of the costliest and most common chronic conditions in America:

—30.3 million people have diabetes (9.4 percent of the U.S. population).[8]
—14.5 percent of adults over age 65 have chronic kidney disease and more than 740,000 Americans have kidney failure.[9]
—4.5 million adults have diagnosed liver disease (1.8 percent of adult population).[10]
—60 to 70 million people are affected by all digestive diseases within the United States.[11]

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[4] https://acl.gov/programs/health-wellness/disease-prevention.
[5] https://www.cdc.gov/nccdphp/dnpao/state-local-programs/funding.html.
[6] https://www.cdc.gov/obesity/data/adult.html.
[7] https://www.cdc.gov/nccdphp/dnpao/state-local-programs/span-1807/index.html.
[8] https://www.cdc.gov/diabetes/pdfs/data/statistics/national-diabetes-statistics-report.pdf.
[9] https://www.usrds.org/2019/view/USRDS_2019_ES_final.pdf.
[10] https://www.cdc.gov/nchs/fastats/liver-disease.htm.
[11] https://www.niddk.nih.gov/health-information/health-statistics/digestive-diseases.

REPORT LANGUAGE: OBESITY TREATMENT IN MEDICARE

We ask that you include report language that encourages CMS to exercise their existing authority to provide full access to anti-obesity medications under Medicare Part D and intensive behavioral therapy for obesity under Medicare Part B. The language requested below reflects the major provisions of the Treat and Reduce Obesity Act (H.R.1530/S.595).

Obesity is a chronic disease and a public health crisis that continues to strain the economy and health outcomes. According to the Centers for Disease Control and Prevention, about 41 percent of adults aged 60 and over had obesity in the period of 2015 through 2016, representing more than 27 million people. The National Institutes of Health has reported that obesity and overweight are now the second leading cause of death nationally, with an estimated 300,000 deaths a year attributed to the epidemic. Obesity increases the risk for chronic diseases and conditions, including high blood pressure, heart disease, certain cancers, nonalcoholic steatohepatitis (NASH), arthritis, mental illness, lipid disorders, sleep apnea and type 2 diabetes.

To help address the high costs of comorbidities associated with the chronic disease of obesity and to promote access to treatment of the disease of obesity and chronic weight management, the Committee encourages CMS to provide access to the full continuum of care with obesity, including to anti-obesity medications under Medicare Part D consistent with CMS's approach to pharmacotherapy agents used for weight gain to treat AIDS wasting and cachexia.

The Committee also encourages CMS to update its Medicare Part B national coverage determination for intensive behavioral therapy (IBT) for obesity to be consistent with current United States Preventive Services Task Force recommendations that IBT for obesity can be provided, through referral, outside of the primary care setting and by a broader range of qualified providers than are currently permitted to bill under Part B for this service.

Recent research shows that obesity is the second greatest risk factor, after older age, for hospitalization among COVID–19 patients. For these reasons, the Centers for Disease Control and Prevention now state that older people and younger adults with serious medical conditions, such as obesity, heart disease, diabetes, lung disease and asthma have a greater risk of becoming severely ill if they are infected with the SARS-CoV–2 virus.

This crisis has also magnified the health disparities experienced by minority communities. Minority populations have long faced chronic disease health disparities due to socioeconomic inequalities and reduced access to healthcare, healthy foods and safe places to be active. It is these same groups that are now disproportionately impacted by COVID–19. We encourage you to help reduce this important driver of COVID–19 morbidity, mortality, and related disparities by using report language to encourage CMS to offer full access to evidence-based obesity treatments within Medicare.

Contact

Please feel free to contact me at hmartin@eatright.org with any questions. Thank you for the opportunity to submit testimony to the Subcommittee.

[This statement was prepared by Hannah Martin, MPH, RDN, Director, Legislative and Government Affairs, Academy of Nutrition and Dietetics.]

PREPARED STATEMENT OF THE AD HOC GROUP

The Ad Hoc Group for Medical Research is a coalition of more than 330 patient and voluntary health groups, medical and scientific societies, academic and research organizations, and industry. We appreciate the opportunity to submit this statement in support of strengthening the Federal investment in biomedical, behavioral, social, and population-based research conducted and supported by the National Institutes of Health (NIH) through a recommendation of $44.7 billion for NIH in fiscal year 2021.

As a result of the strong, bipartisan vision of Senate and House Labor-HHS-Education Appropriations Subcommittees over the last 5 years, Congress has helped the agency regain some of the ground lost after years of effectively flat budgets. This renewed investment in NIH has advanced discovery toward promising therapies and diagnostics, reenergized existing and aspiring scientists nationwide, and restored hope for patients and their families.

We are also grateful for the recent bipartisan agreements to provide supplemental appropriations for NIH and other key health programs as the healthcare and research community responds to the ongoing coronavirus pandemic. To maximize our country's ability to develop countermeasures against COVID–19 and sustain the research momentum across all NIH research, the Ad Hoc Group recommends $44.7 billion for the NIH in fiscal year 2021, a $3 billion increase over the NIH's program level funding in fiscal year 2020. This funding level, supported by more than 330 stakeholder organizations, would allow for meaningful growth above inflation in the base budget that would expand NIH's capacity to support promising science in all disciplines in addition to special initiatives. It also would ensure that funding from the Innovation Account established in the 21st Century Cures Act would supplement the agency's base budget, as intended, through dedicated funding for specific programs.

In addition, due to the strain COVID–19 is placing on our researchers and research infrastructure, and the strict limits of the fiscal year 2021 discretionary spending caps, the Ad Hoc Group supports bipartisan proposals to exempt key health programs, including NIH, from the fiscal year 2021 budget caps. We believe that investments in science and innovation are essential if we are to continue to meet current and future health challenges, improve our nation's physical and fiscal health, and sustain our leadership in medical research. As the Subcommittee has recognized, to remain a global leader in accelerating the development of life-changing cures, pioneering treatments, and innovative prevention strategies, and in this time of unprecedented scientific opportunity, it is essential that Congress sustain robust increases in the NIH budget.

NIH: A Partnership to Save Lives and Provide Hope. The partnership between NIH and America's scientists, medical schools, teaching hospitals, universities, and research institutions is a unique and highly productive relationship, leveraging the full strength of our nation's research enterprise to translate this knowledge into the next generation of diagnostics, therapeutics, and cures. More than 80 percent of the NIH's budget is competitively awarded through nearly 50,000 research and training grants to more than 300,000 researchers at over 2,500 universities and research institutions located in every state and Washington, D.C. The Federal Government has an essential and irreplaceable role in supporting medical research. No other public, corporate or charitable entity is willing or able to provide the broad and sustained funding for the cutting-edge basic research necessary to yield new innovations and technologies of the future.

NIH has supported biomedical research to enhance health, lengthen life, respond to emerging health threats, and reduce illness and disability for more than 100 years. The following are a few of the many examples of how NIH research has contributed to improvements in the nation's health.

—Amidst a global pandemic, steady investment over the past few years in NIH has enabled NIH to rapidly scale up clinical trials of candidates for a SARS–COV–2 vaccine. The record speed at which we are seeing progress toward a vaccine is a testament to the value of supporting basic and clinical research over time. Vaccines continue to be one our most cost-effective public health tools. Every $1 spent on routine childhood vaccinations is estimated to save $5 in direct costs, and $11 in broader costs to society.

—Breakthroughs in the treatment of depression came in 2019 with FDA approval of two new drugs—one for treatment-resistant depression and the first ever treatment for postpartum depression. These approvals follow nearly three decades of research funded by the NIH to identify novel mechanisms of drug action.

—The NIH has supported research on sickle cell disease (SCD) since 1948, and the disease currently affects about 100,000 Americans. Today, an ongoing multicenter clinical trial is using gene therapy to replace the defective gene that causes SCD, beta globin, in patient's blood cells and effectively curing them of disease.

—In 2007, induced pluripotent stem cells (iPSC) were discovered when adult cells were re-engineered into early non-differentiated versions of themselves. In late 2019, the National Eye Institute launched a first-in-human clinical trial to test the safety of a novel patient-specific iPSC therapy to treat the "dry" form of Age-related Macular Degeneration (AMD), the most common form of the disease and the leading cause of vision loss in the age 65+ population.

—NIH-supported researchers continue to work toward strategies to better prevent, identify, and treat pain and substance use disorders through the HEAL (Helping to End Addiction Long-term) Initiative. HEAL aims to support research into new, non-addictive medication and to establish public and private partnerships to develop best practices in communities.

—Today, treatments can suppress HIV to undetectable levels, and a 20-year-old HIV-positive adult living in the U.S. who receives these treatments is expected to live into his or her early 70s, nearly as long as someone without HIV.

- —NIH funding supported research that contributed to all of the 210 new drugs approved by the FDA between 2010 and 2016.
- —The death rate for all cancers combined has been declining since the early 1990s for adults and since the 1970s for children. Overall cancer death rates have dropped by nearly 29 percent with more than 2.9 million deaths avoided in total between 1991 and 2017. Research in cancer immunotherapy has led to the development of several new methods of treating cancer by restoring or enhancing the immune system's ability to fight the disease.

For patients and their families, NIH is the "National Institutes of Hope."

Sustaining Scientific Momentum Requires Sustained Funding. The leadership and staff at NIH and its Institutes and Centers have engaged the broader community to identify emerging research opportunities and urgent health needs and to prioritize precious Federal dollars to areas demonstrating the greatest promise. Sustained robust increases in NIH funding are needed if we are to continue to take full advantage of these opportunities to accelerate the development of pioneering treatments and innovative prevention strategies.

One long-lasting potential impact of investments in NIH is on the next generation of scientists. Sustained increases in NIH funding over the last 5 years has allowed NIH to double the investment in early stage investigators (ESIs). In 2015, NIH only funded about 600 grants for ESIs and the career outlook for early career researchers seemed grim. This past year, NIH was able to fund about 1300 grants for ESIs reinvigorating the spirits of researchers in the biomedical workforce. Sustained increases will allow NIH to continue support of new talent and innovation in biomedical research.

Even with the recent investment in NIH, nearly 4 of every 5 research ideas that are proposed to NIH every year cannot be funded. Additional funding is needed if we are to strengthen our nation's research capacity, ensure a medical research workforce that reflects the racial and gender diversity of our citizenry, and inspire a passion for science in current and future generations of researchers.

NIH is Critical to U.S. Competitiveness. Our country still has the most robust medical research capacity in the world; however, other countries have significantly increased their investment in biomedical science, which leaves us vulnerable to the risk that talented medical researchers from all over the world may return to better opportunities in their home countries. We cannot afford to lose that intellectual capacity, much less the jobs and industries fueled by medical research. The U.S. has been the global leader in medical research because of Congress's bipartisan recognition of NIH's critical role. To continue our dominance, we must reaffirm this commitment to provide NIH the funds needed to maintain our competitive edge.

NIH: An Answer to Challenging Times. Research supported by NIH drives local and national economic activity, creating skilled, high-paying jobs and fostering new products and industries, and catalyzes increases in private sector investment. A $1 increase in public basic research stimulates an additional $8.38 investment from the private sector after 8 years. A $1 increase in public clinical research stimulates an additional $2.35 in private sector investments after 3 years. According to a United for Medical Research report, in 2019, NIH-funded research supported more than 476,000 jobs across the U.S. and generated more than $81 billion in new economic activity.

The Ad Hoc Group's members recognize the tremendous challenges facing our nation and acknowledge the difficult decisions that must be made to restore our country's fiscal health. Strengthening our commitment to medical research, through robust funding of the NIH, is a critical element in ensuring the health and well-being of the American people and our economy. Therefore, for fiscal year 2021, the Ad Hoc Group for Medical Research recommends that NIH receive $44.7 billion to continue the momentum in our nation's investment in medical research.

PREPARED STATEMENT OF THE AIDS ALLIANCE FOR WOMEN, INFANTS, CHILDREN, YOUTH & FAMILIES

Dear Chairman Blunt and Members of the Subcommittee:

AIDS Alliance for Women, Infants, Children, Youth & Families (AIDS Alliance) was founded in 1994 to help respond to the unique concerns of HIV-positive and at-risk women, infants, children, youth, and families. AIDS Alliance conducts policy research, education, and advocacy on a broad range of HIV/AIDS prevention, care, and research issues. We are pleased to offer written testimony for the record as part of the fiscal year 2021 Labor, Health and Human Services, Education, and Related Agencies appropriations measure and endorse maintaining separate funding and support for Part D of the Ryan White Program.

RYAN WHITE PART D FUNDING REQUEST

Sufficient funding of Ryan White Part D, the program funded solely to provide family-centered primary medical care and support services for women, infants, children, and youth with HIV/AIDS has successfully identified, linked, and retained these vulnerable populations in much needed care and treatment, resulting in optimum health outcomes. We thank the Subcommittee for its continuous support of the Ryan White Program and respectfully request that the Subcommittee maintain its commitment to the Ryan White Part D and increase Ryan White Part D funding by $9.9 million in fiscal year 2021.

RYAN WHITE PART D BACKGROUND AND HISTORY

Congress first acted to address pediatric AIDS in 1987, due to the alarming increase in the number of reported pediatric AIDS cases by providing $5 million for the Pediatric AIDS Demonstration Projects in the fiscal year 1988 budget. Those demonstration projects became part of the Ryan White CARE Act of 1990 and today are known as Ryan White Part D. Since the program's inception in 1988, Part D programs have served approximately 200,000 women, infants, children, youth, and family members. These programs have been and continue to be the entry point into medical care for these vulnerable populations. The family-centered primary medical and supportive services provided by Part D are uniquely tailored to address the needs of women, including HIV positive pregnant women, HIV exposed infants, children and youth. Part D programs are the only perinatal clinical service available to serve HIV-positive pregnant women and HIV exposed infants, when payments for such services are unavailable from other sources. Ryan White Part D programs have been extremely effective in bringing the most vulnerable populations into and retained in care and is the lifeline for women, infants, children and youth living with HIV/AIDS. The Part D programs continue to be instrumental in preventing mother-to-child transmission of HIV and for ensuring that women, including HIV-positive pregnant women, HIV exposed infants, children and youth have access to quality HIV care. The program is built on a foundation of combining medical care and essential support services that are coordinated, comprehensive, and culturally and linguistically competent. This model of care addresses the healthcare needs of the most vulnerable populations living with HIV/AIDS in order to achieve optimal health outcomes.

Approximately $75.1 million was appropriated to Ryan White Part D in fiscal year 2019 to provide comprehensive outpatient ambulatory family-centered primary and specialty medical care and support services for women, infants, children and youth with HIV. Ryan White Part D provided funding to 115 community-based organizations, including academic medical centers and hospitals, federally qualified health centers, and health departments in 39 states and Puerto Rico. These grant recipients also provide case management services (medical and non-medical); referrals for inpatient hospital services; treatment for substance use, and mental health services. Part D recipients also receive assistance from other parts of the Ryan White Program that help support HIV testing and linkage to care services; provide access to medication; additional medical care, such as dental services; and key support services, such as case management and transportation, which all are essential components of the highly effective Ryan White HIV care model. This model has continuously provided comprehensive quality healthcare delivery systems that have been responsive to women, infants, children, youth and families for three decades.

A RESPONSE TO WOMEN, INFANTS, CHILDREN, AND YOUTH

Ryan White Part D programs have been extremely effective in bringing our most vulnerable populations into care and developing medical care and support services especially designed to reach women, infants, children, and youth. The groundbreaking results of the AIDS Clinical Trial Group study 076 that proved the efficacy of AZT in preventing mother-to-child transmission of HIV was significant for Ryan White Part D programs as these programs played a leading role in reducing mother-to-child transmission of HIV-from as many as 2000 babies born HIV-positive in 1990 to roughly 181 cases in 2012. As appropriate funding is critical to maintain and improve upon this success, AIDS Alliance was pleased that the President's fiscal year 2019 budget focused on accelerating the elimination of perinatal HIV infection in the United States. Appropriate funding is critical to maintain and improve upon this success, as an estimate for 2006 suggested that approximately 8,500 HIV-positive women that need counseling services and support to prevent pediatric HIV infections were giving birth every year in the United States. The most recent available data reports that 11,355 infants (including HIV exposed infants) and children were served by Ryan White Part D in 2010. According to the CDC, youth aged 13–24 made up 21 percent of all new HIV diagnoses in the country in 2017. Eighty-seven percent of those new diagnoses among young men and thirteen percent were among young women. Gay and bisexual men accounted for 69 percent of the 37,832 new HIV diagnoses in 2018 and heterosexual men accounted for 7 percent of new HIV diagnoses. Ryan White Part D programs are the entry point into medical care for many of these HIV-positive youth as this is the age group least likely to have access to quality healthcare. Though HIV diagnoses among women have declined in recent years, more than 7,000 women received an HIV diagnosis in 2017. According to the Health Resources and Services Administration, approximately 26.5 percent of women received medical care from Ryan White Programs in 2018. Part D provides medical and supportive services to a large number of women over 50 who are HIV survivors which is a testament to the high standard of care provided to Ryan White Part D programs. Support and care through the Ryan White Part D program was and continues to be funding of last resort for the most vulnerable women and children, who often have fallen through the cracks of other public health safety nets. The Ryan White Part D program will dramatically improve health access and outcomes for many more women, infants, children, and youth living with HIV disease.

ENDING THE HIV EPIDEMIC

New efforts to end the HIV epidemic in the United States focus on four key strategies: Diagnose Treat, Prevent, and Respond, in order to reduce new HIV infections by 2030. Ryan White Part D programs are essential to the success of the Ending the HIV epidemic as Ryan White Part D is an effective model of care and has been extremely effective in retaining our most vulnerable populations in care and treatment. The comprehensive coordinated medical care and support services provided by Ryan White Part D are uniquely tailored to address the needs of women, including HIV positive pregnant women, HIV exposed infants, children and youth living with HIV/AIDS and are central components of a highly effective model of care designed to achieve optimal health outcomes. The family-centered primary medical and specialty care along with supportive services provided by Ryan White Part D funded programs have enabled these programs to successfully engage and retain vulnerable populations in much needed care and treatment, resulting in positive health outcomes. Ryan White Part D is extremely cost effective relative to the care and treatment services provided to populations highly impacted by HIV and remain a critical component of the overall Ryan White Program as their vast networks of service providers are fully engaged in addressing and meeting the critical healthcare needs of women, infants, children and youth with HIV and AIDS.

CONCLUSION

The requested increase of $9.9 million in fiscal year 2021 will enable Ryan White Part D programs, across the country to continue to deliver life-saving HIV/AIDS care and treatment for women, infants, children and youth with HIV and to ensure that these populations are fully engaged and retained in care. We thank the Subcommittee for its work in ensuring that women, infants, children, and youth, living with HIV receive the much needed care and treatment services necessary to sustain their lives.

[This statement was submitted by Dr. Ivy Turnbull, Deputy Executive Director, Aids Alliance for Women, Infants, Children, Youth & Families.]

PREPARED STATEMENT OF THE AIDS INSTITUTE

Dear Chairman Blunt and Members of the Subcommittee:

The AIDS Institute, a national public policy, research, advocacy, and education organization, is pleased to offer testimony in support of domestic HIV and hepatitis programs in the fiscal year 2021 Labor, Health and Human Services, Education, and Related Agencies appropriation measure. Last year, you and your colleagues showed incredible leadership by increasing funding for domestic HIV programs by over $300 million. This funding will allow jurisdictions across the United States to begin planning the Ending the HIV Epidemic Initiative (ETE Initiative). We urge you to fully fund the request for year two of the Initiative so that these jurisdictions can transition from planning to implementation. We also request that core public health programs that provide essential HIV prevention and treatment services are adequately funded, and we request significant new funding for viral hepatitis programs in order to combat the skyrocketing cases of viral hepatitis in the country.

Finally, we urge you to provide immediate supplemental funding for HIV and hepatitis programs in order to mitigate the impact COVID–19 has on people living with and at risk of HIV and hepatitis.

HIV IN THE UNITED STATES

There are currently over 1.1 million people living with HIV in the United States. Since the height of the epidemic, there have been tremendous advancements in HIV treatment and prevention. A person living with HIV on treatment can expect to live a near full life, and if they achieve an undetectable viral load, are unable to pass HIV on to a partner. The toolbox for HIV prevention is ever expanding, with pre-exposure prophylaxis (PrEP) now available in addition to traditional prevention techniques like condoms and syringe service programs. Despite these advancements, new cases of HIV have been stagnant at around 39,000 cases a year since 2013, although we are concerned that the disruption of in-person outreach and care caused by COVID–19 may result in HIV outbreaks. Ending the HIV epidemic will require increased Federal investments in the public health infrastructure that serves people living with and at risk of HIV.

ENDING THE HIV EPIDEMIC INITIATIVE

In last year's State of the Union Address, the president announced the Ending the HIV Epidemic Initiative. This initiative has the goal of reducing new HIV infections by 75 percent in the first 5 years and 90 percent by the tenth year. To do so, the Initiative focuses on 57 jurisdictions across the nation that have the highest burden of new infections. We thank your Subcommittee for leading Congressional action last year which resulted in $261 million for the first year of this Initiative. Jurisdictions across the nation have been eagerly developing plans to combat the HIV epidemics that cater to the unique needs of their populations. A significant increase in funding is necessary for year two of the EHE Initiative so that these jurisdictions can transition from planning to implementation, directing resources to areas at most need.

We urge you to fund year two of the EHE Initiative at the administration's requested levels: $371 million for the CDC Division of HIV/AIDS Prevention to do targeted testing, connection to treatment, and robust surveillance; $165 million for the Ryan White HIV/AIDS Program to increase access to high-quality HIV care and treatment; $137 million for HRSA's Community Health Center program to provide prevention services emphasizing PrEP; $16 million for NIH's Centers for AIDS Research to provide best practices to guide the plan; and $27 million for the Indian Health Service to provide HIV prevention, treatment, education, and hepatitis C (HCV) elimination in Indian Country.

CDC HIV PREVENTION

CDC's Division of HIV/AIDS Prevention focuses resources on those populations and communities most affected by investing in high-impact prevention. One in seven people living with HIV in the United States are unaware of their status, and many people newly diagnosed with HIV have been living with HIV for many years. There is no single way to prevent HIV, but jurisdictions use a combination of effective evidence-based approaches including testing, linkage to care, education, condoms, syringe service programs, and PrEP. We urge the Subcommittee to fund CDC's HIV Prevention program at $1.293 billion, which includes $100 million for school-based HIV prevention efforts and $371 million for the Ending the HIV Epidemic Plan.

THE RYAN WHITE HIV/AIDS PROGRAM

The Ryan White HIV/AIDS Program provides medications, medical care, and essential coverage completion services to almost half of all people living with HIV in the United States, many of whom are uninsured or underinsured. With people living longer and continued new diagnoses, the demands on the program continue to grow. The Ryan White Program successfully engages individuals in care and treatment, increases access to HIV medications, and helps over 86 percent of clients achieve viral suppression. Science has proven that if a person achieves viral suppression, they cannot transmit HIV to another person, making the Ryan White Program also integral for preventing new HIV infections. The AIDS Drug Assistance Program (ADAP), provides people access to lifesaving medications by helping clients afford insurance premiums, deductibles, and high cost-sharing of their medications, and is an important component in the successful health outcomes for Ryan White clients.

The AIDS Institute requests that the Subcommittee fund the Ryan White HIV/AIDS Program at a total of $2.652 billion in fiscal year 2020, distributed in the following manner:

Part A at $686.7 million; Part B (Care) at $437 million; Part B (ADAP) at $943.3 million; Part C at $225.1 million; Part D at $85 million; Part F/AETC at $35.5 million; Part F/Dental at $18 million; and Part F/SPNS at $34 million; Ending the HIV Epidemic Plan at $165 million.

MINORITY AIDS INITIATIVE

As racial and ethnic minorities in the U.S. are disproportionately impacted by HIV/AIDS, it is critical that the Subcommittee continue to fund the Minority HIV/AIDS Fund and Minority AIDS programs at SAMHSA. We urge the Subcommittee to appropriate $105 million for the Minority HIV/AIDS Fund; and $160 million for SAMHSA's Minority AIDS Initiative Program.

VIRAL HEPATITIS IN THE U.S

Over the past decade, there has been a resurgence of viral hepatitis in the United States, largely driven by the opioid epidemic. CDC data modeling suggests that approximately 3.2 million people are currently living with HBV or HCV. However, because of insufficient funding for testing and surveillance, only about half of those individuals are aware of their infection. Annual diagnoses have increased substantially, with a more than 400 percent increase in new infections of HCV from 2010 to 2018. The CDC estimates that over 70 percent of the approximately 44,000 new cases identified in 2018 alone were the result of injection drug use. Despite the availability of a highly effective vaccine for HAV and HBV, there have been recent HAV outbreaks in multiple states across the country, and an increase in HBV cases nationwide, which are also related to the opioid epidemic. Despite the availability of a cure for HCV, some 2.4 million people are currently living with the disease. Left untreated, HBV and HCV can cause liver damage, cirrhosis, and liver cancer. The Federal Government must invest in testing, surveillance, and linkage to treatment in order to staunch the viral hepatitis epidemics.

INFECTIOUS DISEASE IMPACT OF THE OPIOID CRISIS

The clear link between viral hepatitis, HIV, and opioid use indicate that there should be better coordination between programs designed to combat opioid use and to address the HIV and viral hepatitis epidemics.

Starting in fiscal year 2019, Congress allocated new funds to enhance the nation's efforts to prevent and treat infectious diseases commonly associated with injection drug use. That legislation also authorizes CDC to expand surveillance for those diseases, which includes viral hepatitis and HIV. The AIDS Institute supports the administration's proposed $58 million for CDC's infectious diseases and opioid epidemic efforts. This new funding would allow CDC to work collaboratively with state and local health departments to improve knowledge of the full scope and burden of these infectious diseases.

CDC VIRAL HEPATITIS PROGRAM

Despite the large increase in the number of cases, the CDC's Viral Hepatitis program is only funded at $39 million in fiscal year 2020, which is a far cry from the $393 million the CDC estimated it would need for a national program focused on decreasing mortality and reducing the spread of the disease.[1] Unfortunately, the administration did not request an increase in its fiscal year 2021 budget proposal. We cannot begin to address the rise in viral hepatitis and combat the impact of the opioid crisis without a significant increase in funding commensurate with the importance of eradicating the epidemic. The AIDS Institute recommends $134 million for CDC viral hepatitis prevention activities.

SYRINGE SERVICE PROGRAMS

Syringe service programs (SSPs) are an important tool in the fight to end the opioid, HIV, and hepatitis epidemics because they have been proven to reduce the incidence of new HIV and viral hepatitis among people who inject drugs: The presence of SSPs has been associated with a 50 percent decline in new HIV and viral hepatitis incidence. When these SSPs are combined with medication-assisted treatment, there is a two-thirds reduction in HIV and HCV transmission. In order to en-

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[1] Centers for Disease Control and Prevention's Pathway to Eliminating Hepatitis B and Hepatitis C and Professional Judgment Budget, fiscal year 2018–fiscal year 2027.

sure that local jurisdictions have the capacity and flexibility to expand SSPs in areas that could benefit from these services, Congress must remove the restrictions on the use of Federal funds for the purchase of sterile syringes. Sterile syringes are a large part of SSPs budgets and removing this ban will encourage state and local governments to expand these life-saving and effective programs.

One of our nation's most effective tools in fighting opioid-related infectious diseases is syringe service programs. We urge your Subcommittee to remove all restrictions on Federal funding for syringe service programs, including for the purchase of sterile syringes.

HIV, HEPATITIS, AND THE IMPACT OF COVID–19

The COVID–19 pandemic has significantly impacted the public health infrastructure in the United States. Public health programs have had to reckon with scarce resources, reassigned staff, and disruption of in-person outreach and provision of services in order to protect their staff and clients from the spread of COVID–19. Experts in HIV and viral hepatitis are worried that these disruptions are resulting in new HIV and hepatitis outbreaks because people are not able to access effective preventive services during the pandemic. We urge your Subcommittee to provide supplemental funding for these programs immediately to enable them to grapple more effectively with these challenges and minimize the damage to people in vulnerable communities and to our nation's effort to eliminate these epidemics.

We urge you to provide $500 million in supplemental funding for the Ryan White HIV/AIDS Program to meet the pressing needs of Ryan White clients during the COVID–19 pandemic. Ryan White programs have been simultaneously shifting their service delivery model to incorporate telehealth services, increase case management, cover new costs for their existing clients, and ensure that they have the capacity to care for the many new clients they are likely to see as a result of the economic downturn. Demand for Ryan White services, including the AIDS Drug and Assistance Program (ADAP), will increase in the next year because millions of people have lost their jobs and their job-based health insurance; additional funding is needed immediately to ensure continued access to care and uninterrupted HIV treatment.

HIV prevention programs across the United States have had to reduce or suspend in-person testing, reassign staff to COVID–19 response, suspend PrEP initiations, and transition to telehealth prevention models. In order for these programs to continue to provide HIV prevention services, and to reach the goals of the Ending the HIV Epidemic Initiative, we urge your Subcommittee to provide $100 million in supplemental funding to the CDC's Division of HIV/AIDS Prevention, so that HIV prevention programs can expand the infrastructure needed to provide telehealth prevention services including at-home testing, and backfill gaps in programming that have occurred because resources and personnel have been reassigned to COVID–19 response.

[This statement was submitted by Rachel Klein, Deputy Executive Director, The AIDS Institute.]

PREPARED STATEMENT OF AIDS UNITED

As the committee continues its important deliberations on the fiscal year 2021 Labor, Health and Human Services, Education, and Related Agencies (Labor-HHS) appropriation bill, we thank you for your continued commitment to addressing HIV/AIDS in the United States and request that you maintain the Federal Government's commitment to safety net programs that protect the public health. Specifically, we ask that you adequately fund the CDC Division of HIV prevention and surveillance activities at $1.24 billion to prevent new infections, the Ryan White Program at $2.65 billion to better ensure that all people living with HIV (PLWH) receive treatment and are retained in care, and HIV/AIDS Research at the National Institutes of Health at $3.5 billion to support innovative research moving us ever-closer to a vaccine, better prevention methods, or a cure. We also urge the committee to end the ban on the use of Federal funds for syringe exchange to prevent HIV outbreaks that many parts of the country are at greatly increased risk of experiencing due to the opioid & overdose epidemics.

We can end the HIV epidemic in the United States. Once, this sentiment would have been unthinkable, but now, nearly forty years since the first identified cases, it is a concept endorsed by all major public health agencies in the country. Recent scientific advances and groundbreaking HIV research have shown us that not only is it possible for people living with HIV to live long, healthy lives while on antiretroviral medication, but that people living with undetectable viral load cannot transmit the virus to their partners. We are in possession of the science and the tools that are necessary to end the HIV epidemic the United States, and the Federal Government has committed to & developed plans to do so across administrations in the 2010 National HIV/AIDS Strategy and the A Plan for America: Ending the HIV Epidemic initiative announced in 2018. But this knowledge and planning alone will not affect the change we need; we must commit the resources to make plans a reality.

Over one million Americans are living with HIV, and annual HIV incidence continues to hover at 37,600 new HIV transmissions each year, due in part to increases in injection drug use across the country related to the opioid epidemic that are resulting in new HIV outbreaks, especially in areas with scarce public health resources. It is only through significant Federal investment and an unyielding commitment to providing access to the support services needed to ensure communities impacted by HIV are empowered to prioritize to their care and treatment that we will be able to end the HIV epidemic.

We are encouraged by the Administration's increased funding request for HIV prevention, care and treatment for the Ryan White HIV/AIDS Program, HIV prevention programs at the Centers for Disease Control and Prevention (CDC), and HRSA's Community Health Centers Program and urge the Labor-HHS subcommittee to build upon these proposed funding increases in your fiscal year 2021 budget. However, we also encourage you to diverge with the Administration's budget request by providing adequate funding for HIV/AIDS research at the National Institutes of Health (NIH) and the Substance Abuse and Mental Health Services Administration (SAMHSA). Below are specific discretionary programs we ask you to support, along with accompanying justifications.

THE RYAN WHITE HIV/AIDS PROGRAM

The Ryan White HIV/AIDS Program, acting as the payer of last resort, provides medications, medical care, supportive services, and essential coverage completion services to almost 550,000 low-income, uninsured, or underinsured individuals living with HIV. Those living with HIV who are in care and on treatment have a much higher chance of being virally suppressed, leading to reduced transmission of the virus, and the Ryan White Program boasts significantly higher rates of viral suppression than other care programs: over 85 percent of Ryan White clients have achieved viral suppression, compared to just 49 percent of all PLWH nationwide. It is precisely because Ryan White Program clients can access high-quality, patient-centered, comprehensive care that is financially accessible and culturally competent that they can remain in care and adhere to treatment.

The Ryan White Program continues to serve populations that are disproportionally impacted by HIV, including racial and ethnic minorities, who make up three-quarters of Ryan White clients. Almost two-thirds of Ryan White clients are living at or below 100 percent of the Federal Poverty Level. To improve the continuum of care and progress toward an HIV/AIDS-free generation, sustained funding for all parts of the Ryan White Program is needed. With a changing and uncertain healthcare landscape, continued funding for the Ryan White Program is critically important to ensure that those at risk of or living with HIV have uninterrupted access to healthcare, medications, and services.

Funding for the Ryan White Program is critical to improving health coverage and outcomes for people living with HIV, therefore, we urge you to fund the Ryan White Program at a total of $2.652 billion in fiscal year 2021, an increase of $263 million over fiscal year 2020, distributed as follows: Part A, $686.7 million; Part B/Care, $437 million; Part B/ADAP, $943.3 million; Part C, $225.1 million; Part D, $85 million; Part F/AIDS Education Training Centers, $58 million; Part F/Dental, $18 million; Part F/Special Projects of National Significance, $34 million; and $165 million in additional funding to support activities in the Ending the HIV Epidemic initiative.

DIVISION OF HIV/AIDS PREVENTION AND THE CDC

Over the almost forty years since the beginning of the epidemic, there has been incredible progress in the fight against HIV/AIDS. Because of the efforts by CDC's National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention (NCHHSTP) and its grantees, hundreds of thousands of new infections have been averted and billions of dollars in treatment costs have been saved. This confirms that HIV prevention efforts are working. Through expanded HIV testing efforts, largely funded by the CDC, the number of people who are aware of their HIV status has increased from 81 percent in 2006 to 87 percent in 2018; while all progress is worth celebrating, new testing expansion opportunities in the Plan for America initiative should equally energize us to support new and existing, successful testing programs, to the extent that Congress will fund them.

Continued funding for CDC's HIV prevention programs will support HIV testing, targeted prevention interventions, public education campaigns, and surveillance activities. Ending HIV will take a multifaceted approach. This funding supports a combination of effective evidence-based approaches including testing, linkage to care, condoms, and syringe services programs; it also supports access to pre-exposure prophylaxis (PrEP), the FDA-approved medication that keeps HIV negative people from acquiring HIV in sexual encounters.

For fiscal year 2021, we urge you to fund the Division of HIV/AIDS Prevention and the CDC at $1.293 billion.

HIV/AIDS RESEARCH AT THE NATIONAL INSTITUTES OF HEALTH

Building on recent progress, robust support for HIV research must continue until better, more effective and affordable prevention & treatment regimens—and eventually a cure—are developed and universally available. For the U.S. to maintain its position as the global leader in HIV/AIDS research for the 35 million people globally and 1.2 million people living with HIV in the U.S., we must invest adequate resources in HIV research at the NIH. HIV/AIDS research supported by the NIH is far-reaching and has supported innovative basic science for better drug therapies, and behavioral and biomedical prevention interventions, saving and improving the lives of millions around the world. Specifically, AIDS research supported by the NIH has proved the efficacy of PrEP, the groundbreaking effectiveness of treatment as prevention, and the first partially effective AIDS vaccine. We are appreciative of the Committee's work to increase funding for the NIH in recent years and urge you to direct some of these resources and language to protect such funding to continued HIV/AIDS research so that more effective HIV treatments and ultimately a cure can be realized.

We request that HIV/AIDS research at the NIH receive a total $3.502 billion in fiscal year 2021.

COMBATING VIRAL HEPATITIS AND PROTECTING ACCESS TO STERILE SYRINGES

AIDS United strongly urges the Committee to maintain current language allowing the use of Federal funds for syringe services programs, and expand eligibility beyond current, limiting allowances for jurisdictions experiencing or at risk for an HIV outbreak or elevated levels of HCV and where local public health or local law enforcement authorities deem a site to be appropriate. People with HIV infection in the United States are often affected by chronic viral hepatitis; about one-third experience coinfection with either Hepatitis B (HBV) or HCV, and viral hepatitis progresses faster and causes more liver-related health problems among people with HIV than among those who do not have HIV. Over the last several years, the opioid crisis has led to concerning numbers of new infections tied to injection drug use, resulting in nearly 55,000 new hepatitis cases each year. Throttled at just $39 million a year for the past many years, CDC's viral hepatitis programs do not have the needed resources to combat the infectious diseases associated with the opioid epidemic.

The CDC has identified 220 counties that are most vulnerable to outbreaks of HCV and HIV related to injection drug use. These counties are spread across 26 states and represent only the top 5 percent of vulnerable counties overall. At present, more than 93 percent of those 220 counties vulnerable to HIV/HCV outbreaks do not have comprehensive syringe services programs. Over the past thirty years, the CDC has collected compelling evidence of syringe services programs' effectiveness, safety, and cost-effectiveness for HIV prevention among program participants and for reductions in HIV, HCV, and HBV incidence rates community-wide. Syringe services programs increase access to comprehensive resources such as HIV and Hepatitis testing and linkage to treatment, referral to substance use treatment and assistance, behavioral health services, primary care, overdose treatment and education, Hepatitis A and B vaccinations, connections and referrals to other supportive services, and more.

Syringe services programs are recommended by AIDS United as a key component of the Department of Health and Human Services' response to the opioid crisis in CDC, HRSA, and SAMHSA appropriations, and as an indispensable tool in any efforts to end the domestic HIV epidemic.

AIDS United urges the Committee to adequately fund the CDC Division of HIV Prevention's surveillance activities at $872.7 million and to increase funding for the CDC Division of Viral Hepatitis activities to $134 million for the purpose of ensuring appropriate levels of testing, education, screening and linkage to care, surveillance, and on-the-ground syringe services programs that reduce the infectious disease consequences of the nation's opioid crisis.

A comprehensive accounting of the community's fiscal year 2021 funding priorities may be accessed at bit.ly/ABACFY21 (note: case sensitive link). Please do not hesitate to be in touch for more information regarding HIV appropriations with our Vice President for Policy & Advocacy, Carl Baloney, Jr., at cbaloney@aidsunited.org.

AIDS United looks forward to a positive outcome for the funding request for HIV/AIDS domestic programs that will enable us to end the HIV epidemic in the United States. We thank you for your continued leadership and support of these critical programs for so many people living with HIV, and the organizations and communities that serve them nationwide.

Sincerely.

[This statement was submitted by Jesse Milan, Jr., JD, President & CEO, AIDS United.]

PREPARED STATEMENT OF THE ALLIANCE TO END SLAVERY AND TRAFFICKING

The Alliance to End Slavery and Trafficking (ATEST) thanks you for your leadership in the fight to end child labor, forced labor and human trafficking. We appreciate your efforts to pass legislation and provide resources to Federal agencies engaged in combating these horrific crimes. We seek your assistance in funding essential programs in the fiscal year 2021 Labor, Health and Human Services, Education, and Related Agencies Appropriations bill. The number of trafficking victims significantly exceeds the availability of services at the Departments of Labor (DOL), Health and Human Services (HHS) and Education (ED). ATEST recommends robust funding and accountability for programs at these key departments to fulfill the highest priority mandates of the Trafficking Victims Protection Act (TVPA) and related legislation.

ATEST FISCAL YEAR 2021 APPROPRIATIONS REQUEST SUMMARY: LHHS

Department	Program	Fiscal Year 2020 Enacted	Authorized Funding	Fiscal Year 2021 Appropriation Request
Labor	International Labor Affairs Bureau.	$96,000,000		$130,040,000
	Employment & Training Administration.			Report Language (see below)
Health & Human Services	Administration for Children and Families, Victim Services.	$28,255,000	$24,000,000	$38,000,000
	Administration for Children and Families, National Human Trafficking Hotline.	$3,500,000	$3,500,000	$3,500,000
	Administration for Children and Families, Runaway and Homeless Youth Act.	$147,421,000	$152,420,000	$165,000,000 and Report Language (see below)
	Administration for Children and Families Office of Trafficking in Persons.			Report Language (see below)

DEPARTMENT OF LABOR

International Labor Affairs Bureau: $130,040,000.—The Bureau of International Labor Affairs (ILAB) is an essential part of the U.S. government's international response to forced labor, human trafficking and child labor. ILAB's mandates touch on key elements of partnership, prevention, protection and prosecution, such as child labor, international labor diplomacy, international economic affairs, and labor-related trade policy. Through highly respected research, grant making and policy development work, ILAB identifies cases of goods reported on the annual "List of Goods Produced by Child Labor or Forced Labor." ATEST was pleased that Congress recognized the need for increased resources for ILAB's critical work in fiscal year 2020 and encouraged Congress to continue to enhance efforts to identify . In fiscal year 2021, we request $27,000,000 for the administration of ILAB, $59,000,000 for the Child Labor and Forced Labor program, $36,000,000 for the Workers' Rights program, and $8,040,000 for program evaluation.

Employment and Training Administration: Report Language.—Labor trafficking affects both U.S. citizens and foreign nationals working across many industries, most commonly domestic work, agriculture, manufacturing, janitorial services, hotel services, construction, health and elder care, hair and nail salons, and strip club dancing. DOL needs resources to protect and support victims, particularly with much needed skills training and job placement services, as well as providing referrals to shelter, medical care, mental health services, legal services, and case management. Proposed Report Language: The Committee encourages the Employment and Training Administration to increase access and eligibility to employment and training services for survivors of all forms of human trafficking as required by Sec. 107(b) of the Trafficking Victims Protection Act (Public Law 106–386). The Committee also encourages the development and integration of training to identify potential signs of trafficking and referral options as a regular activity for State Farmworker Monitor Advocates, and during the provision of relevant services to particular at-risk populations, including through the Youth Build, Job Corps and Reentry Employment Opportunity programs. The Committee also encourages the Department to continue and expand its pilot initiative to develop and support networks of service providers in collaboration with HHS and DOJ.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Administration for Children and Families, Victim Services (ACF): $38,000,000.—ACF fulfills mandates of the Trafficking Victims Protection Act to (1) Identify and serve victims who are foreign nationals; and, (2) Create specialized case management programs to assist U.S. citizen victims. The number of trafficking victims certified as needing comprehensive, trauma-informed, gender-specific services has risen dramatically but funding for services has not kept pace. We encourage ACF to use a portion of increased funding for legal services for victims. We request that increased funds be utilized equally for services for both foreign national victims and U.S. citizen and legal permanent resident victims, consistent with demonstrated need.

Administration for Children and Families, the National Human Trafficking Hotline (NHTH): $3,500,000.—The NHTH is a toll-free 24/7 center available to answer calls, online tips and email queries. The NHTH collects tips on human trafficking cases, connects victims with anti-trafficking services in their area (such as shelter, case management, and legal services), and, where appropriate, reports actionable tips to law enforcement. The NHTH serves both domestic and foreign victims inside the U.S. Since 2007, NHTH has received reports of 51,919 cases. The NHTH also collects and provides valuable data on human trafficking trends and the prevalence of victims in the U.S. We request that $3,500,000 be appropriated consistent with the authorization levels, while preserving existing victim services funding.

Administration for Children and Families, Runaway and Homeless Youth Act: $165,000,000.—The Runaway and Homeless Youth Act has laid the foundation for a national system of services for vulnerable young people who are at risk of becoming or have already been victims of exploitation and trafficking. These programs provide homeless and victimized youth with hope, safety, healing, and opportunities for a new life through: emergency shelters, family reunification when safe, aftercare, outreach, education and employment, healthcare, behavioral and mental health, transitional housing, and independent housing options. These programs are often in the best position to prevent trafficking and commercial sexual exploitation and provide early identification of victims of these crimes. Congress recognized the critical role that programs funded through RHYA serve to prevent trafficking, identify survivors, and provide services to runaway, homeless and disconnected youth by including a 2 year reauthorization of RHYA in the Juvenile Justice & Delinquency Prevention Act of 2018. We request $165,000,000, the level previously authorized, to increase the capacity of programs that serve runaway and homeless youth to address human trafficking ($140,000,000 for the Consolidated Runaway, Homeless Youth Programs and $25,000,000 for Prevention Grants to Reduce Abuse of Runaway Youth), and within these funds designate $5,000,000 to increase capacity and provide training for service providers to identify and serve exploited and trafficked youth, and $2,000,000 to conduct the National Study on the Prevalence, Needs and Characteristics of Homeless Youth.

Administration for Children and Families, Office of Trafficking in Persons: Report Language.—In establishing the Office of Trafficking in Persons (OTIP), HHS underscored the importance of coordinating trafficking efforts across the Administration for Children and Families (ACF). ACF works directly with all victims of human trafficking—men, women, children, LGBTQ, foreign nationals and domestic clients—and the diverse needs and vulnerabilities of these populations can only be met by an effective coordinating body networked agency-wide. Proposed Report Language: Within the funds provided, the Committee encourages ACF to hire sufficient full time employees to support the Office of Trafficking in Persons and coordinate trafficking efforts across ACF.

Administration for Children and Families, Family Youth Services Bureau: Report Language.—The process of informing RHYA grantees has restricted the ways in which service providers are able to continue to provide services to vulnerable youth. For the past several years, RHYA grantees have been notified if they will receive a grant or not within one day before a grant period is to begin. This lack of sufficient notice is extremely problematic for agencies and community based organizations working to serve runaway and homeless youth who face higher risks of trafficking and violence. We recommend that the current bureaucratic process be streamlined, so that RHYA grant applicants are notified regarding whether they will receive a grant or not within at least 3 months in advance of the start date of a grant. Proposed Report Language: That when awarding funds under the Runaway and Homeless Youth Act program, the Secretary shall notify all applicants if they were successful or not at least 30 days before the grant is to begin as well as 30 days before an existing grant is set to end.

As a champion for the victims of child labor, forced labor and sex trafficking, you understand the complexities of these issues and the resources needed to respond. We have carefully vetted our requests to focus on the most important and effective programs. We thank you for your consideration of these requests and your continued leadership. If you have any questions, please contact ATEST Coalition Co-Chairs Anita Teekah (Anita.Teekah@safehorizon.org) or Terry FitzPatrick (terry.fitzpatrick@freetheslaves.net).

Sincerely.

Coalition to Abolish Slavery and Trafficking (CAST)
Coalition of Immokalee Workers (CIW)
Free the Slaves
Human Trafficking Institute
National Network for Youth (NN4Y)
Polaris
Safe Horizon
Solidarity Center
T'ruah: The Rabbinic Call for Human Rights
United Way Worldwide
Verité
Vital Voices Global Partnership

ATEST is a U.S.-based coalition that advocates for solutions to prevent and end all forms of human trafficking and modern slavery around the world.

PREPARED STATEMENT OF THE ALZHEIMER'S ASSOCIATION AND ALZHEIMER'S IMPACT MOVEMENT

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) appreciate the opportunity to submit written testimony on the fiscal year 2021 appropriations for Alzheimer's research and public health activities at the U.S. Department of Health and Human Services. Specifically, we respectfully request a $354 million increase for Alzheimer's research at the National Institutes of Health (NIH) and $20 million for implementation of the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act (Public Law 115–406) at the Centers for Disease Control and Prevention (CDC). We detail these requests below but first want to thank the Subcommittee for it's crucial and timely work to support Americans affected by COVID–19.

As you know, people living with Alzheimer's and other dementia are at increased risk of having serious complications relating to COVID–19 due to their typical age and likelihood of coexisting conditions. According to the CDC, older adults and those with serious chronic medical conditions like heart disease, diabetes and lung disease are at higher risk of getting very sick from this virus. There are currently 5.8 million Americans age 65 or older living with Alzheimer's dementia and more than 95 percent of people with the disease have one or more other chronic conditions. This includes 38 percent of people with Alzheimer's that also have heart disease and 37 percent that also have diabetes. Thank you for your quick, bipartisan work to address and support this vulnerable population, and all Americans, during this pandemic.

ALZHEIMER'S ASSOCIATION/AIM

Founded in 1980, the Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support, and research. The Alzheimer's Association is the nonprofit with the highest impact in Alzheimer's research worldwide and is committed to accelerating research toward methods of treatment, prevention, and, ultimately, a cure. The Alzheimer's Impact Movement (AIM) is the advocacy arm of the Alzheimer's Association, working in strategic partnership to make Alzheimer's a national priority. Together, the Alzheimer's Association and AIM advocate for policies to fight Alzheimer's disease, including increased investment in research, improved care and support, and development of approaches to reduce the risk of developing dementia.

ALZHEIMER'S IMPACT ON AMERICAN FAMILIES AND THE ECONOMY

The most important reason to address Alzheimer's is because of the suffering it causes to millions of Americans and their families. Alzheimer's is a progressive brain disorder that damages and eventually destroys brain cells, leading to a loss of memory, thinking, and other brain functions. Ultimately, Alzheimer's is fatal. We have yet to celebrate the first survivor of this devastating disease.

In addition to the suffering caused by the disease, however, Alzheimer's is also creating an enormous strain on the healthcare system, families, and Federal and state budgets. While there are over 5 million Americans currently living with the disease, without significant action, as many as 14 million Americans will have Alzheimer's by 2050 and costs will exceed $1.1 trillion (in 2020 dollars). As the current generation of baby boomers age, near-term costs for caring for those with Alzheimer's will balloon, as Medicare and Medicaid will cover more than two-thirds of the costs for their care.

Caring for people with Alzheimer's will cost all payers—Medicare, Medicaid, individuals, private insurers, and HMOs—nearly $20 trillion over the next 30 years. As noted in the 2020 Alzheimer's Disease Facts and Figures report, in 2020 America will spend an estimated $305 billion in direct costs for those with Alzheimer's, including $206 billion in costs to Medicare and Medicaid. Average per person Medicare costs for those with Alzheimer's and other dementias are more than three times higher than those without these conditions. Average per senior Medicaid spending is 23 times higher.

INVESTING IN ALZHEIMER'S TREATMENTS

Congress unanimously passed the National Alzheimer's Project Act (NAPA) (Public Law 111–375) in 2010, requiring the creation of an annually-updated strategic National Plan to Address Alzheimer's Disease (National Plan). The National Plan must include an evaluation of all federally-funded efforts in Alzheimer's research, care, and services—along with their outcomes. The primary research goal of the National Plan is to prevent and effectively treat the disease by 2025.

If America is going to succeed in the fight against Alzheimer's, Congress must continue to provide the resources scientists need to do their work. Understanding this, in 2014 Congress passed the Consolidated and Further Continuing Appropriations Act of 2015 (Public Law 113–235), which included the Alzheimer's Accountability Act (S. 2192/H.R. 4351). The Alzheimer's Accountability Act requires NIH to develop a Professional Judgment Budget focused on the research milestones established by the National Plan. This provides Congress with an account of the resources that NIH has confirmed are needed to reach the 2025 goal. The Alzheimer's Association and AIM urge Congress to fund the research targets outlined in the Professional Judgment Budget by supporting an additional $354 million for NIH Alzheimer's funding in fiscal year 2021.

Recent funding increases have been critical to progress toward the primary research goal to effectively treat and prevent Alzheimer's by 2025—including advances into new biomarkers to detect the disease; building better animal models to enable preclinical testing of promising therapeutics; and bolstering the Alzheimer's research workforce to enable the expertise, experience, and new thinking needed to understand the complex causes of Alzheimer's disease and related dementias.

However, Alzheimer's continues to be the only leading cause of death in the United States without a way to prevent, cure, or even slow its progression. The primary reason this remains true is that investment in Alzheimer's research is still only a fraction of what's been applied over time to address other major diseases. Between 2000 and 2017, the number of people dying from Alzheimer's increased by 145 percent while deaths from other major diseases have decreased significantly or remained approximately the same.

It is vitally important that NIH continues to increase the investment in Alzheimer's research so we can see the same promising advances that other major diseases have realized with sustained, robust funding. An increase of $354 million in fiscal year 2021 would allow scientists to target a precision medicine approach to deliver the right treatments at the right stage of the disease; enable NIH to follow up on successful Phase I drug trials by initiating more Phase II trials focused on new therapeutic targets; and support the inclusion of Alzheimer's phenotype and environmental exposure measures in non-Alzheimer's cohorts, like cardiovascular disease and cancer, which have a wealth of data that could unlock new discovery research and accelerate cross-validation of discoveries made in Alzheimer's cohorts.

A disease-modifying or preventive therapy would not only save millions of lives but would save billions of dollars in healthcare costs. Specifically, if a treatment became available in 2025 that delayed onset of Alzheimer's for 5 years (a treatment similar in effect to anti-cholesterol drugs), savings would be seen almost immediately, with Medicare and Medicaid saving a cumulative $535 billion in the first 10 years.

PUBLIC HEALTH APPROACH TO ADDRESSING ALZHEIMER'S

As scientists continue to search for a way to cure, treat, or slow the progression of Alzheimer's through medical research, public health plays an important role in promoting cognitive function and reducing the risk of cognitive decline. Investing in a nationwide Alzheimer's public health response will help create population-level improvements, achieve a higher quality of life for those living with the disease and their caregivers, and reduce associated costs.

In 2018, Congress acted decisively to address Alzheimer's through the passage of the BOLD Infrastructure for Alzheimer's Act (Public Law 115–406). This strong bipartisan law authorizes $100 million over 5 years for the CDC to build a robust Alzheimer's public health infrastructure across the country. We were glad to see CDC receive $10 million in fiscal year 2020 for the first year of BOLD's implementation. While this funding is an important step forward, CDC must receive the full $20 million authorized for fiscal year 2021 to ensure the meaningful impact that Congress intended. The Alzheimer's Association and AIM urge Congress to include the full $20 million for the second year of BOLD's implementation at CDC in fiscal year 2021.

With this funding, CDC will establish Alzheimer's and Related Dementias Public Health Centers of Excellence across the country and fund state, local, and tribal public health departments to increase early detection and diagnosis, reduce risk, prevent avoidable hospitalizations, reduce health disparities, support the needs of caregivers, and provide care planning for people living with the disease. These important public health actions can allow individuals with Alzheimer's to live in their homes longer and delay costly long-term nursing home care. The law also aims to increase the analysis and timely reporting of data. This data is critical to identifying opportunities for public health interventions, helping stakeholders track progress in the public health response, and enabling state and Federal policymakers to make informed decisions when developing plans and policies.

CONCLUSION

The Alzheimer's Association and AIM appreciate the steadfast support of the Subcommittee and its priority setting activities, especially during this time. We thank the Subcommittee and Congress for previous increases in Alzheimer's research activities at NIH, but the current funding level is still short of the total investment needed to meet the National Plan's primary research goal of finding a treatment or cure for Alzheimer's and other dementias by 2025. We ask Congress to continue to address Alzheimer's with the bipartisan collaboration demonstrated in previous years by providing an additional $354 million for Alzheimer's research activities at NIH and $20 million for implementation of the BOLD Infrastructure for Alzheimer's Act at CDC in fiscal year 2021.

PREPARED STATEMENT OF THE ALZHEIMER'S FOUNDATION OF AMERICA

Dear Chairman Blunt, Ranking Member Murray and Members of the Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies:

On behalf of the Alzheimer's Foundation of America (AFA), a national organization whose mission is to provide support, services and education to individuals, families and caregivers affected by Alzheimer's disease and related dementias nationwide, and fund research for better treatment and a cure, I am submitting the following appropriation requests to the Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies (the "Subcommittee") for programs impacting persons living with dementia and their care partners in fiscal year 2021:

—an additional $354 million for a total $3.2 billion appropriation for Alzheimer's disease clinical research at the National Institutes of Health (NIH);

—$500 million to fund the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative, a trans-agency effort to arm researchers with revolutionary tools to fundamentally understand the neural circuits that underlie the healthy and diseased brain;

—$44.7 billion (a $3 billion increase over fiscal year 2020) for total spending at the NIH;

—an additional $50 million to fund caregiver supports and services provided by programs administered by the Administration for Community Living (ACL), including a $8.5 million increase for the Alzheimer's Disease Program for a total expenditure of $35 million in fiscal year 2021;

—$20 million to support BOLD Act initiatives at the Centers for Disease Control and Prevention (CDC); and

—$120 million over fiscal year 2020 spending at the Food and Drug Administration (FDA) to almost $3.3 billion.

National Institutes of Health (NIH)

AFA is extremely grateful to the Subommittee for approving an increase in funding for Alzheimer's disease research at NIH for fiscal year 2020. The $350 million in additional resources for fighting Alzheimer's disease and related dementias at NIH, coupled with other increases in recent past fiscal years, will greatly increase our chances that promising research gets funded as we move closer to the goal of finding a cure or disease-modifying treatment by 2025 as articulated in the National Plan to Address Alzheimer's Disease.

Yet, meaningful treatment is still some ways off and basic science into dementia—the type of research funded through NIH—remains vital to finding a cure.

AFA asks the Subcommittee to build upon past progress and continue making the battle against Alzheimer's disease a national priority. To this end, AFA urges the Subcommittee to provide an additional $354 million, for a total of approximately $3.2 billion for Alzheimer's disease clinical research at NIH in fiscal year 2021.

The BRAIN Initiative is a large-scale effort to accelerate neuroscience research by equipping researchers with the tools and insights necessary for treating a wide variety of brain disorders, including Alzheimer's disease, schizophrenia, autism, epilepsy, and traumatic brain injury. By mapping whole brains in action, the ability to identify thousands of brain cells at a time and development of innovative brain scanners, BRAIN Initiative research advances and tools are needed to better understand the brain and cognitive functioning. AFA is asking that $500 million be allocated to conduct BRAIN Initiative research for fiscal year 2021.

AFA also urges the Subcommittee appropriate at least $44.7 billion for total NIH spending in fiscal year 2021, a $3 billion increase over the NIH's program level funding in fiscal year 2020, as recommended by the Ad Hoc Group for Medical Research. This funding level would allow for meaningful growth above inflation in the base budget that would expand NIH's capacity to support promising science in all disciplines. It also would ensure that funding from the Innovation Account established in the 21st Century Cures Act would supplement the agency's base budget, as intended, through dedicated funding for specific programs.

Centers for Disease Control and Prevention (CDC)

Last year Congress passed, and the President signed, the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act which calls for the Centers for Disease Control and Prevention (CDC) to establish Centers of Excellence in Public Health Practice dedicated to promoting Alzheimer's disease management and caregiving interventions, as well as educating the public on Alzheimer's disease and brain health, will establish Alzheimer's disease a public health issue increasing American awareness and care training around the disease. To fund BOLD Act initiatives at CDC, AFA is requesting $20 million in appropriations for fiscal year 2021.

Food and Drug Administration (FDA)

AFA is calling for a $120 million increase at FDA in fiscal year 2021. Such an increase would strengthen FDA systems that guide and support agency decision-making and stimulate innovation for medical products, including improvements in drug and device manufacturing, advances in the use of real world evidence in medical product development, revisions to the regulatory framework for digital health technology, enhancements to research on rare diseases such as less common forms of dementia, and new systems that could speed the introduction of cost-saving generic drugs.

Administration on Community Living (ACL)

AFA is requesting a $50 million increase for vital ACL programming across-the-board, including an $8.5 million increase to the Alzheimer's Disease Program for a total funding of $35 million in fiscal year 2021. In addition, AFA is requesting that the following amounts be allocated to these programs that directly impact those living with dementia:

—*National Family Caregiver Support Program (NFCSP):* NFCSP provides grants to states and territories, based on their share of the population aged 70 and over, to fund a range of supportive services that assist family and informal caregivers in caring for those with dementia at home for as long as possible, thus providing a more person-friendly and cost-effective approach to institutionalization. AFA urges that an additional $27.2 million (for a total of $213.2 million) be appropriated in fiscal year 2021 to support this important program.

—*RAISE Act Family Caregiver Advisory Board:* AFA recommends that the Subcommittee allocate $300,000 fund and staff a Family Caregiver Advisory Board to develop a national family caregiver plan as envisioned under the RAISE Family Caregiver Act.

—*Lifespan Respite Care Program (LRCP):* AFA urges the Subcommittee to allocate $20 million—a $14 million increase—to LRCP in fiscal year 2021. LRCP provides competitive grants to state agencies working with Aging and Disability Resource Centers and non-profit state respite coalitions and organizations to make quality respite care available and accessible to family caregivers regardless of age or disability.

AFA understands that during this time of crisis, Congress is working hard to stem fallout of both the human and fiscal toll of COVID–19. We are grateful for your efforts and urge that the Subcommittee continues making services and supports available to our nation's most vulnerable populations- including those older Americans with chronic conditions—a priority. We know that through determination, sacrifice and resilience, Americans will rise to the challenge and take the necessary steps to mitigate the fallout of this public health emergency.

Again, AFA thanks the Subcommittee for the opportunity to present our recommendations and looks forward to working with you through the appropriations process. Please contact me at cfuschillo@alzfdn.org or Eric Sokol, AFA's senior vice president of public policy, at esokol@alzfdn.org, if you have any questions or require further information.

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF ALLERGY, ASTHMA, & IMMUNOLOGY

Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee, the American Academy of Allergy, Asthma, & Immunology (AAAAI) thanks you for the opportunity to submit written testimony on the U.S. Department of Health and Human Services (HHS) fiscal year 2021 appropriations bill. AAAAI respectfully requests the subcommittee to include a $6.1 million increase in funding for the Consortium on Food Allergy Research (CoFAR) which is within the National Institute of Allergy and Infectious Disease (NIAID) at the National Institutes of Health (NIH). In addition, we request report language reflecting the importance of NIH engaging in trans-NIH research on food allergies. Established in 1943, AAAAI is a professional organization with more than 7,000 members in the United States, Canada, and 72 other countries. This membership includes board certified allergist/immunologists, other medical specialists, allied health and related healthcare professionals—all with a special interest in the research and treatment of patients with allergic and immunological diseases.

FOOD ALLERGIES

Food allergies affect 32 million Americans, including 6 million children. Each year, more than 200,000 Americans require emergency medical care for allergic reactions to food—equivalent to one trip to the emergency room every three minutes.

The Consortium on Food Allergy Research—CoFAR—was established by the National Institutes of Health (NIH) within the National Institute of Allergy and Infectious Disease (NIAID) in 2005. Over the following 15 years, CoFAR discovered genes associated with an increased risk for peanut allergy and has also identified the most promising potential treatments for egg and peanut immunotherapy, among many other accomplishments. Breakthroughs like these, scaled across other major food allergies, can significantly improve the quality of life for tens of millions of Americans. Its annual $6.1 million budget is a relatively small portion within NIH's almost $40 billion budget, yet CoFAR has been able to achieve massive strides in the study of food allergy prevention and treatment.

AAAAI enthusiastically supports an increase in funding for CoFAR of $6.1 million, annually, bringing its yearly budget up to $12.2 million. With its relatively low current level of funding, CoFAR has been able to accomplish breakthroughs in the under-researched field of food allergies. It is crucial that we continue investing at proportional levels given the scale of this condition which impacts 10.8 percent of the U.S. population.

AAAAI also requests that the Subcommittee's report accompanying the fiscal year 2021 Labor/HHS appropriation reflects the importance of trans-NIH research on food allergies. AAAAI strongly supports the following NIAID report language submitted by Sen. Richard Blumenthal (D–CT) that acknowledges the groundbreaking work of CoFAR and encourages robust investment to expand its research breadth and network.

Food Allergies.-The Committee recognizes the serious issue of food allergies which affect approximately 8 percent of children and 10 percent of adults in the United States. The Committee commends the ongoing work of NIAID in supporting a total of 17 clinical sites for this critical research, including seven sites as part of the Consortium of Food Allergy Research (CoFAR). The Committee includes $12,200,000, an increase of $6,100,000, for CoFAR to expand its clinical research network to add new centers of excellence in food allergy clinical care and to select such centers from those with a proven expertise in food allergy research.

In addition to AAAAI, the CoFAR funding request and report language are supported by the American College of Allergy, Asthma & Immunology; Allergy & Asthma Network; Asthma and Allergy Foundation of America; Food Allergy & Anaphylaxis Connection Team; Food Allergy Research and Education; and International FPIES Association.

PENICILLIN ALLERGY TESTING

AAAAI also wishes to express its appreciation to the subcommittee for the inclusion of language regarding the importance of penicillin allergy testing in the fiscal year 2020 appropriations bill. The discovery of penicillin opened the door to medical innovation allowing surgeries to be performed, organs to be transplanted, as well as combat wounds and burn victims to be treated. AAAAI encourages more widespread and routine performance of penicillin skin testing for patients with a history of allergy to penicillin or another beta-lactam drug (e.g, ampicillin or amoxicillin). Penicillin allergy testing can accurately identify the approximately 9 of 10 patients who, despite reporting a history of penicillin allergy, can safely receive penicillin. On behalf of the patients we serve, thank you for your leadership in giving penicillin allergy testing the attention it deserves.

Thank you for your consideration of these requests. Please contact Sheila Heitzig, JD, MNM, CAE, AAAAI Director of Practice and Policy, at sheitzig@aaaai.org if you have any questions or would like additional information.

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF FAMILY PHYSICIANS

On behalf of the American Academy of Family Physicians (AAFP), which represents 136,700 family physicians and medical students across the country, I urge you to prioritize primary care in your fiscal year 2021 spending bills. Family physicians are specialists with training to provide the full scope of care to patients of all ages and are caring for the populations most vulnerable to COVID–19. According to a recent survey,[1] 47 percent of primary care clinicians report they have laid off/furloughed staff, two-thirds report that less than half of what they do is reimbursable, and 45 percent are unsure if they have the funds to stay open for the next four weeks. Primary care practices already have financially thin operating margins, The AAFP therefore asks that the Committee provide the following appropriations for the agencies and programs in the Department of Health and Human Services (HHS) which our members and their patients rely on for access to care, the research to improve efficacy and safety, essential family physician workforce programs, and disease prevention and health promotion efforts.

CENTERS FOR MEDICARE & MEDICAID SERVICES

We appreciate the swift action of the Congress to enact programs to respond to the pandemic and steps taken by HHS and the Centers for Medicare & Medicaid Services (CMS), but more support is needed for primary care if we wish to maintain a viable healthcare system throughout the pandemic and into the future.

The AAFP urges Congress to codify the Medicare Accelerated and Advanced Payment (AAP) program for Part B providers and extend it until at least the end of 2020. The abrupt suspension of the AAP for Part B providers negatively impacted primary care physicians and hindered their ability to maintain practice operations in the midst of this pandemic. This mechanism, which was voluntary, provided an ability to stem some of the losses that primary care physicians are experiencing. While we were concerned with the short repayment deadline and high interest rate, we believe that the program was an important component of a multi-faceted strategy to get critical support to primary care and we urge you to reinstate and extend it.

The COVID–19 pandemic has underscored that fee-for-service is an inappropriate structure to meaningfully resource primary care. This public health emergency should accelerate shifts to more sustainable models of care such as prospective, global payments for primary care. Several models have shown promise by resourcing practices in a prospective manner to allow for investments and resources to treat their population while balancing the need to deliver specialized care based on unique patient needs. Primary Care First, which has been approved by HHS for implementation in January 2021 on a limited scale, is one such model for achieving this. Congress should direct the Secretary of HHS to immediately expand Primary Care First (PCF) as a national model and allow all primary care physicians, on a voluntary basis, to begin participating in the model beginning January 1, 2021.

Payment rates in PCF should reflect the final 2020 Medicare Physician Fee Schedule (MPFS) rule, in which CMS wisely adopted payment changes to address the undervaluation of E/M office/outpatient visit services to take effect in 2021. In addition to reopening and expanding PCF participation for 2021, the AAFP also recommend that CMS add a 2022 program start date for physicians who are eager to move into the model but require more time to do so. It is time that we fundamentally change how primary care is financed by providing prospective payments to all primary care physicians participating in Medicare coupled with expanding Primary Care First as an appropriate bridge to a new future.

CMS will require an adequate appropriation for program management to meet the current and future needs of the millions of Americans enrolled in Medicare, Medicaid, the Children's Health Insurance Program and private insurance coverage in the Marketplace. The AAFP asks that the Committee provide CMS with at least $3.7 billion for program management.

Immediate Financial Relief for Primary Care

Congress should authorize an additional $20 billion for HHS' Provider Relief Fund or direct HHS to set-aside $20 billion of the current Fund specifically for physicians and physician practices. The AAFP recommends that HHS prioritize financial support to primary care physicians—defined as family medicine, pediatrics, general internal medicine and geriatrics—by distributing provider relief funds using the foundation of the previously used model as follows:

> Provide a one-time payment that is equal to the total Medicare fee-for-service payments distributed to each eligible NPI and/or TIN for July through December 2019 multiplied by 3 to accommodate for lost revenue from traditional Medicare, Medicaid, Medicare Advantage and commercial insurers.
>
> [Total Medicare FFS Payments (July—December 2019) × 3 = Payment per primary care physician]

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[1] Etz, Rebecca "Quick COVID–19 Primary Care Survey" https://www.pcpcc.org/2020/04/23/primary-care-covid-19-week-6-survey.

We believe that building on this existing formula allows HHS to quickly and efficiently distribute financial support to primary care practices.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

The AAFP opposes the proposed cuts of $742 million in HRSA's discretionary fiscal year 2021 budget proposal and calls for $8.8 billion for HRSA programs in fiscal year 2021. The AAFP supports the bipartisan request of $512 million for the HRSA Title VII health professions programs in fiscal year 2021. In particular, we recommend $125 million for the Title VII Primary Care Training & Enhancement which supports family medicine residencies and departments. These funds are needed to support faculty retention, recruit and retain students into primary care, develop new curriculum related to pandemic, and meet the need to increase the number of full scope primary care physicians to care for patients throughout the nation.

In addition, the AAFP requests that the Committee fund the Title VII Diversity Pipeline Programs, Health Careers Opportunity Program, Centers of Excellence, Faculty Loan Repayment, and Scholarships for Disadvantaged Students at $100 million in fiscal year 2021. The AAFP also requests $45.4 million for the Title VII Area Health Education Centers to provide grant support for health professions workforce development in shortage areas.

Another important health professions workforce initiative administered by HRSA is the Rural Residency Planning and Development Program. The AAFP asks that the Committee provide $11 million for the HRSA Rural Residency Planning and Development Program to support the development of new rural residency programs or Rural Training Tracks in family medicine, internal medicine and psychiatry. Most of the 62 million people living in a rural community or county depend on a family physician for their healthcare. The AAFP welcomes this important initiative to address rural training challenges as a way to reduce healthcare disparities facing rural communities.

The programs administered by HRSA's Office of Rural Health Policy work to reduce the unique obstacles faced by physicians and patients in rural areas. The impact of COVID–19 has been and will continue to be devastating for the nation, but rural communities and the family physicians who care for them are uniquely challenged by this pandemic in significant and consequential ways. The AAFP strongly supports an increased investment in the Office of Rural Health Policy to support the following programs:

—Rural Outreach Network Grants ($87.5 million), a community-based grant program aimed towards promoting rural healthcare services by enhancing healthcare delivery in rural communities.

—Rural Research and Policy Analysis ($11.4 million), the only Federal research program entirely dedicated to producing policy-relevant research on healthcare and population health in rural areas.

—State Offices of Rural Health ($12.5 million), a grant program is to assist states in strengthening rural healthcare delivery systems.

—Rural Communities Opioid Response ($121 million), funds multi-sector consortia to enhance their ability to implement and sustain SUD/OUD prevention, treatment, and recovery services in underserved rural areas.

—Rural Hospital Flexibility Grants Program ($59 million) to support critical access hospitals (CAHs) in quality improvement, quality reporting, performance improvement, and benchmarking; to assist facilities seeking designation as CAHs; and to create a program to establish or expand the provision of rural emergency medical services.

The AAFP commends the Committee for expanding in fiscal year 2020 the Rural Maternity and Obstetrics Management Strategies (RMOMS) Program and urge that it be increased again to $9.9 million. In addition, we recommend that the Committee provide $31.9 million for the Office for the Advancement of Telehealth, including the telehealth Network Grant Program for telehealth funding for the Small Rural Hospital Improvement Grant Program as recommended by the National Rural Health Association.

HRSA also administers the National Health Service Corps (NHSC) which is plays a vital role in addressing the challenge of regional health disparities arising from physician workforce shortages by offering financial assistance to meet the workforce needs of communities designated as health professional shortage areas. The AAFP recommends that the Committee provide $132 million in discretionary funding for the NHSC in fiscal year 2021, and we are working with NHSC stakeholders to strongly urge Congress to provide a long term extension of the program's mandatory trust fund.

The AAFP supports continued funding for HRSA's Title X Federal grant program dedicated to providing women and men with comprehensive family planning and related preventive health services. The AAFP strongly recommends adequate funding to support Title X clinics which offer necessary screening for sexually transmissible infections, cancer screenings, HIV testing, and contraceptive care of $286.5 million for HRSA's Family Planning Grants in fiscal year 2021.

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

Expanding the capacity for practice-based research supported by the Agency for Healthcare Research and Quality (AHRQ) is particularly critical in the face of the changes in medical practice brought on by COVID–19. AHRQ-supported research has long been important to providing the evidence basis for the comprehensive primary care medicine practiced by America's family physicians. While the AAFP initially supported the Friends of AHRQ request for fiscal year 2021 of $471 million in budget authority for AHRQ, which is consistent with the fiscal year 2010 level adjusted for inflation, Congress must do more than just allow AHRQ to rebuild portfolios terminated as a result of years of past cuts.

The AAFP urges the Committee to provide an additional $71 million to AHRQ in the next COVID–19 relief measure to allow the agency to assess how physicians, healthcare professionals, hospitals, and health systems are responding to COVID–19. It is critical to evaluate the impact on healthcare of the rapid expansion of telemedicine during the outbreak and to explore strategies to reduce needless administrative burden related to telemedicine. Clearly, COVID–19 has had an impact on medical practice, and AHRQ is uniquely qualified to research its impact on quality, safety, and value of health systems' response. Further, AHRQ-support research should examine the role of primary care practices and professionals during the pandemic. Since patients have put off going to see their family physician during the pandemic for non-coronavirus-related needs, the impact on patients from deferred primary care must also be studied. In addition, it is imperative that AHRQ explore how to alleviate physical and emotional burdens on physicians, patients, and communities.

CENTERS FOR DISEASE CONTROL AND PREVENTION

In the midst of the COVID–19 pandemic, Congress must reject the proposed $693 million in cuts to the Centers for Disease Control and Prevention (CDC) in the fiscal year 2021 budget request. The AAFP urges that the Committee provide at least $8.3 billion in your fiscal year 2021 bill for the broad portfolio of prevention and public health programs administered by the CDC. Family physicians provide preventive care, including routine checkups, health risk assessments, immunization and screening tests, and personalized counseling on maintaining a healthy lifestyle. The AAFP is one of over 100 organizations supporting the 22 by 22 campaign urging Congress to increase funding for the CDC by 22 percent by fiscal year 2022.

The COVID–19 pandemic is changing rapidly and requires different strategies to maintain clinical preventive services, including immunization. The AAFP supports the important role in of the CDC's National Center for Immunization and Respiratory Diseases programs and urge that the Committee provide at least $830 million for current programs and such sums as are needed when a COVID–19 vaccine is approved.

Although CDC has a high profile role in addressing the COVID–19 pandemic, it continues to work on a wide variety of unrelated projects that are designed to improve the nation's health. The AAFP recently promoted to our members the many public awareness campaigns available from the CDC's Division of STD Prevention. In February of 2020, we provided the CDC's first comprehensive guidelines for the treatment of latent tuberculosis infection. So, we were pleased that the fiscal year 2021 budget proposal included an increase for the CDC HIV/AIDS, Viral Hepatitis, Sexually Transmitted Infections and Tuberculosis line to $1.55 billion to increase the investment in both domestic HIV/AIDS prevention and research and infectious diseases and the opioid epidemic. We ask that the Committee provide at least $1.55 billion for the CDC HIV/AIDS, Viral Hepatitis, Sexually Transmitted Infections and Tuberculosis.

The AAFP values the CDC Chronic Disease Prevention and Health Promotion funding to support our efforts to prevent and control chronic diseases and associated risk factors and reduce health disparities. We appreciate that the Committee rejected the eliminations proposed in fiscal year 2020 for this important activity and increased its appropriation to $1.24 billion and encourage the Committee to provide $1.25 billion for CDC Chronic Disease Prevention and Health Promotion in fiscal year 2021.

Smoking directly contributes to the deaths of more than 440,000 Americans annually, and the AAFP has called for bold new initiatives are necessary to decrease the harm caused by tobacco and nicotine use. We appreciate that the Committee increased funding for CDC Office on Smoking and Health (OSH) by $20 million in fiscal year 2020 to $230 million, and we believe that additional investments in tobacco prevention and cessation will save lives and reduce the cost of treating tobacco-caused disease. The AAFP recommends that you to increase funding for CDC's OSH to $310 million to enable CDC to address the new challenges posed by e-cigarettes while continuing to make progress reducing the death and disease caused by other tobacco products.

The United States nationally is in the acceleration phase of the pandemic. On behalf of our patients and our communities, the AAFP urges the Committee to take prompt action on these vital priorities so that we can return to our important work of providing preventive medical care—including vaccinations, managing chronic diseases, and promoting overall population health and wellness in our communities.

[This statement was submitted by Gary LeRoy, MD, FAAFP, President, American Academy of Family Physicians.]

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF PEDIATRICS

The American Academy of Pediatrics (AAP), a non-profit professional organization of 67,000 primary care pediatricians, pediatric medical subspecialists, and pediatric surgical specialists dedicated to the health, safety, and well-being of infants, children, adolescents, and young adults, appreciates the opportunity to submit this statement for the record in support of strong Federal investments in children's health in fiscal year 2021 and beyond. AAP urges all Members of Congress to put children first when considering short and long-term Federal spending decisions, and supports funding levels for the following programs: $50 million for Firearm Injury and Mortality Prevention Research at the Centers for Disease Control and Prevention (CDC) and National Institutes of Health (NIH), $60 million for the Administration for Children and Families (ACF)'s Child Abuse Prevention and Treatment Act Plans of Safe Care Grants, $50 million for Pediatric Subspecialty Loan Repayment at the Health Resources and Services Administration (HRSA), $22.334 million for Emergency Medical Services for Children (HRSA), $20 million for the Assistant Secretary for Preparedness and Response (ASPR)'s Pediatric Disaster Care Pilot Program, $168.5 million for CDC's National Center for Birth Defects and Developmental Disabilities, $10 million for Pediatric Mental Health Care Access Grants (HRSA), $8 million for Screening and Treatment for Maternal Depression (HRSA), and $226 million for Global Immunizations at CDC, as well as report language for Research on Adolescent E-Cigarette Cessation at NIH.

FIREARM INJURY AND MORTALITY PREVENTION RESEARCH (CDC AND NIH)

The AAP is tremendously appreciative of and applauds Congress for providing $25 million total, split evenly between CDC and NIH, for firearm injury and mortality prevention research in fiscal year 2020. federally funded public health research has a proven track record of reducing public health-related deaths, whether from motor vehicle crashes, smoking, or Sudden Infant Death Syndrome. This same approach should be applied to increasing gun safety and reducing firearm-related injuries and deaths, including suicides, and CDC and NIH research will be as critical to that effort as it was to these previous public health achievements. The dearth of research on how best to prevent firearm-related morbidity and mortality makes it difficult to address this public health problem.

Fiscal Year 2021 Request: $50 million total ($25 million to both CDC and NIH); Fiscal Year 2020 Level: $25 million total ($12.5 million to both CDC and NIH).

CHILD ABUSE PREVENTION AND TREATMENT ACT (CAPTA) PLANS OF SAFE CARE GRANTS (ACF)

The AAP appreciates the continued $60 million designated for CAPTA Plans of Safe Care Grants in fiscal year 2020. CAPTA is the only Federal law dedicated to primary prevention of child abuse. CAPTA requires states to refer families to child welfare services if an infant is identified at birth as affected by prenatal substance exposure, withdrawal symptoms, or a Fetal Alcohol Spectrum Disorder. Plans of safe care follow the best evidence for treating maternal substance use, including early identification and screening, appropriate treatment, consistent hospital screening of mothers and their infants, and information sharing across systems. These expanded requirements represent an opportunity to address the child health impact of the opioid epidemic.

Fiscal Year 2021 Request: $60 million dedicated to Plans of Safe Care; Fiscal Year 2020 Level: $60 million dedicated to Plans of Safe Care.

PEDIATRIC SUBSPECIALTY LOAN REPAYMENT PROGRAM (HRSA)

The AAP requests $50 million in initial funding for the Pediatric Subspecialty Loan Repayment Program, a Title VII health professions program to improve access to care for children with special healthcare needs by offering loan repayment to pediatric subspecialists and child mental health providers who agree to serve in an underserved area. This program was recently reauthorized for 5 years as part of the Coronavirus Aid, Relief, and Economic Security (CARES) Act. The United States' supply of pediatric subspecialists is inadequate to meet children's health needs. Many children must wait more than 3 months for an appointment with a pediatric subspecialist, and approximately 1 in 3 children must travel 40 miles or more to receive care from a pediatrician certified in certain subspecialties such as developmental behavioral pediatrics.

Fiscal Year 2021 Request: $50 million; Fiscal Year 2020 Level: Never funded.

EMERGENCY MEDICAL SERVICES FOR CHILDREN (HRSA)

The AAP urges the committee to maintain $22.334 million in funding for the Emergency Medical Services for Children (EMSC) Program in fiscal year 2021. EMSC is the only Federal program that focuses specifically on improving the pediatric components of the emergency medical services (EMS) system. EMSC aims to ensure state of the art emergency medical care is available for the ill and injured child or adolescent, pediatric services are well integrated into an EMS system backed by optimal resources, and that the entire spectrum of emergency services is provided to all children and adolescents no matter where they live.

Fiscal Year 2021 Request: $22.334 million; Fiscal Year 2020 Level: $22.334 million.

PEDIATRIC DISASTER CARE PILOT PROGRAM (ASPR)

The Academy urges the Subcommittee to provide $20 million to ASPR's National Disaster Medical System to continue and expand the Pediatric Disaster Care pilot program. This funding will build on lessons learned and expand local and statewide capabilities to develop a regional and nationwide capability to respond to the needs of pediatric patients in the ongoing COVID–19 pandemic and any future public health emergency. The two Pediatric Disaster Centers of Excellence in California and Ohio funded under this pilot are addressing appropriate planning and response capabilities that support the specific needs of children during public health emergencies and disasters, such as mass casualty events. As the nation grapples with the impacts of the COVID–19 pandemic, including on children, the importance of this program and ensuring increased, continued funding cannot be understated.

Fiscal Year 2021 Request: $20 million (also the level of the President's Fiscal Year 2021 Budget Request); Fiscal Year 2020 Level: $6 million.

NATIONAL CENTER FOR BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES (CDC)

The AAP requests $168.5 million for fiscal year 2021 for the National Center for Birth Defects and Developmental Disabilities (NCBDDD). According to the CDC, birth defects affect 1 in 33 babies and are a leading cause of infant death in the United States. NCBDDD conducts important research on fetal alcohol syndrome, infant health, autism, attention deficit and hyperactivity disorders, congenital heart defects, and other conditions like Tourette Syndrome, Fragile X, Spina Bifida and Hemophilia. NCBDDD supports extramural research in every State and has played a crucial role in the country's response to the Zika virus. Furthermore, staff from NCBDDD are assisting in the nation's response to the ongoing COVID–19 public health emergency.

Fiscal Year 2021 Request: $168.5 million; Fiscal Year 2020 Level: $160.81 million.

PEDIATRIC MENTAL HEALTH CARE ACCESS GRANTS (HRSA)

The AAP appreciates the $10 million in fiscal year 2020 and urges Congress to maintain funding at $10 million in fiscal year 2021 for Pediatric Mental Health Care Access Grants, which support the development of new statewide or regional pediatric mental healthcare telehealth access programs, as well as the improvement of already existing programs. Research shows pervasive shortages of child and adolescent mental/behavioral health specialists throughout the U.S. Integrating mental health and primary care has been shown to substantially expand access to mental healthcare, improve health and functional outcomes, increase satisfaction with care, and achieve costs savings.

Fiscal Year 2021 Request: $10 million; Fiscal Year 2020 Level: $10 million.

SCREENING AND TREATMENT FOR MATERNAL DEPRESSION (HRSA)

The AAP thanks the committee for providing $5 million in fiscal year 2020 for the Screening and Treatment for Maternal Depression grant program, which helps to establish, improve, or maintain programs that increase screening, assessment, and treatment services for maternal depression for women who are pregnant or have given birth within the preceding 12 months. Maternal depression can lead to increased costs of medical care, inappropriate medical care, child abuse and neglect, discontinuation of breastfeeding, family dysfunction, and may adversely affect early brain development in children.

Fiscal Year 2021 Request: $8 million; Fiscal Year 2020 Level: $5 million.

GLOBAL IMMUNIZATION—POLIO AND MEASLES/OTHER (CDC)

Vaccines are one of the most cost-effective and successful public health solutions available, saving the lives of two to three million children each year. The CDC provides countries with technical assistance and disease surveillance support, with a focus on eradicating polio, reducing measles deaths, and strengthening routine vaccine delivery. Global mortality attributed to measles, one of the top five diseases killing children, declined by 79 percent between 2000 and 2015 thanks to expanded immunization, saving an estimated 20.3 million lives. A global immunization campaign has reduced the number of polio cases by more than 99 percent since 1988. However, until the world is free of measles and polio, all children, even those in the United States, remain at risk. In 2019, there were 1,282 individual confirmed measles cases in 31 states. This was the highest number of confirmed cases reported nationally since 1992, despite measles being declared eliminated in the United States in 2000. This outbreak was in part due to unvaccinated travelers importing the virus from parts of the world where it remains common. Only two countries had indigenous transmission of wild polio virus in 2018: Afghanistan and Pakistan. We must complete polio eradication or face a potential global resurgence, which could result in as many as 200,000 cases of polio annually within a decade.

Fiscal Year 2021 Request: $226 million ($176 million for Polio and $50 million for Measles/Other); Fiscal Year 2020 Level: $226 million ($176 million for Polio and $50 million for Measles/Other).

RESEARCH TO HELP ADOLESCENTS QUIT E-CIGARETTES (NIH)

The rise of JUUL and similar pod-based e-cigarettes has fueled continued dramatic increases in adolescent e-cigarette use, with recent surveys finding more than 5 million middle and high school students are current users. The AAP urges Congress to include report language to encourage research at the National Cancer Institute on adolescent e-cigarette cessation as there is virtually no data on how to treat an adolescent with e-cigarette dependence, and no randomized controlled trials specific to adolescent e-cigarette cessation have been conducted to date. The pediatric community is in urgent need of research to conclusively identify the most effective tobacco cessation modalities for adolescents addicted to e-cigarettes.

Fiscal Year 2021 Request: Report language—"Youth Tobacco Cessation.—The committee is concerned about the increase in youth e-cigarette addiction and the significant lack of research to inform effective therapies to help youth quit. The United States Preventive Services Task Force has determined that there is not sufficient evidence to recommend adolescent use of existing pharmacological tobacco cessation treatments that are currently approved for adults. There is great need for additional clinical trials and other research to determine if new or existing pharmacological treatments, behavioral interventions, or combination therapies have the potential to benefit adolescents in quitting cigarettes and other forms of tobacco, including e-cigarettes."

There are many ways Congress can help meet children's needs and protect their health and well-being. Adequate funding for children's health programs is one of them. The American Academy of Pediatrics looks forward to working with Members of Congress to prioritize the health of our nation's children in fiscal year 2021 and beyond. If we may be of further assistance, please contact the AAP Department of

Federal Affairs, Patrick Johnson at pjohnson@aap.org. Thank you for your consideration.

[This statement was submitted by Sally Goza, MD, FAAP, President, American Academy of Pediatrics.]

PREPARED STATEMENT OF THE AMERICAN ALLIANCE OF MUSEUMS

Chairman Blunt, Ranking Member Murray, and members of the subcommittee, thank you for the opportunity to submit this testimony. My name is Laura Lott, and I am President and CEO of the American Alliance of Museums (AAM). I urge you to provide the Office of Museum Services (OMS) within the Institute of Museum and Library Services (IMLS) with at least $42.7 million for fiscal year 2021, the amount approved by the House of Representatives last year.

I want to express the museum field's gratitude for the $38.5 million in funding for OMS in fiscal year 2020, and we applaud the bipartisan group of 41 Senators who wrote to you in support of fiscal year 2021 OMS funding. This small program is a vital investment in protecting our nation's cultural treasures, educating students and lifelong learners alike, and bolstering local economies. The American Alliance of Museums, representing more than 35,000 individual museum professionals and volunteers, institutions of all types, and corporate partners serving the museum field, stands for the broad scope of the museum community.

In addition to regular appropriations, we request at least $6 billion in supplemental appropriations for IMLS-Office of Museum Services to administer specifically for nonprofit museums in COVID–19 economic relief to provide emergency assistance.* This would include assisting museums in developing and sharing distance learning content, as well as pandemic recovery planning and implementation. (Please see this request letter from more than 50 national, regional, and state museum associations.) Museums will be vital to our nation's recovery from this pandemic, and after sudden and long-term closures, they will require financial assistance to reopen, maintain their staffs, provide educational programs to communities, and assist in rebuilding local tourism economies.

Even as museums are experiencing closures and significant losses in revenue, they are meeting an increase in demand for their services and safeguarding and supporting their communities. They are contributing to the ongoing education of our country's children by providing free lesson plans, online learning opportunities, and drop-off learning kits to teachers and families. They are using their outdoor spaces to grow and donate produce to area food banks and are maintaining these spaces for individuals to safely relax, enjoy nature, and recover from the mental health impacts of social isolation. They are donating their PPE and scientific equipment to fight COVID–19, and providing access to child care and meals to families of healthcare workers and first responders. In the midst of financial distress, they are even raising funds for community relief. Museums are pivotal to our nation's ability to manage through the pandemic and recover from it as our nation opens back up.

Museums are a robust and diverse business sector, including African American museums, aquariums, arboreta, art museums, botanic gardens, children's museums, culturally-specific museums, historic sites, historical societies, history museums, maritime museums, military museums, natural history museums, planetariums, presidential libraries, public gardens, railway museums, science and technology centers, and zoos.

Museums are economic engines and job creators: According to Museums as Economic Engines: A National Report, U.S. museums support more than 726,000 jobs and contribute $50 billion to the U.S. economy per year. For example, the total financial impact that museums have on the economy in the state of Missouri is $852 million, including 13,653 jobs. For Washington, it is a $1.01 billion impact supporting 14,145 jobs. Museums spend more than $2 billion yearly on education activities and the typical museum devotes 75 percent of its education budget to K–12 students.

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* The $6 billion figure is a conservative estimate based on budget numbers from several museum associations and data from the Oxford Economics/AAM's "Museums as Economic Engines" study. The American Alliance of Museums calculates that museums are losing at least $33 million a day due to closures as a result of COVID–19, will be in desperate need of significant Federal support, and that the U.S. Congress needs to include at least $6 billion for nonprofit museums in economic relief legislation to provide emergency assistance through December. The study shows the museum field directly employs 372,100 people and generates $15.9 billion in income each year. It costs $1.3 billion to keep 370,000 people employed per month so the estimated cost through December 2020 is approximately $6 billion minus the 2 months of expected assistance from SBA-related loan programs.

IMLS is the primary Federal agency responsible for helping museums connect people to information and ideas. Its Office of Museum Services (OMS) supports all types of museums by awarding grants that help them better serve their communities. The 2018–2022 IMLS strategic plan focuses on promoting lifelong learning, strengthening the capacity of museums and libraries to serve their communities, increasing access to information and ideas, and strategically aligning resources to maximize public value.

OMS awards grants in every state to help museums digitize, enhance, and preserve collections; provide teacher professional development; and create innovative, cross-cultural, and multi-disciplinary programs and exhibits for schools and the public. Congress reauthorized IMLS at the end of 2018, by enacting the Museum and Library Services Act of 2018 (Public Law 115–410). This legislation was adopted with widespread bipartisan support, including unanimous consent in the Senate and a vote of 331 to 28 in the House, showing Congress' renewed support for the agency's programs and commitment to its funding. IMLS grants to museums are highly competitive and awarded through a rigorous peer-review process.

In addition to the dollar-for-dollar match generally required of museums, grants often spur more giving by private foundations and individual donors. But current funding allows the agency to fund only a small fraction of the highly rated grant applications it receives. For example, in fiscal year 2019, the OMS received 938 applications requesting nearly $134 million. Despite this funding shortfall the need has never been greater: museum attendance prior to the pandemic had increased, collections are subject to increasing risk, and museum staff members need professional development in conservation, education, and technology.

The Inspire! Grants for Small Museums program, designed to encourage small institutions to apply for OMS funding, generated 202 applications in its first year. OMS awarded 30 grants totaling $1.1 million, representing 15 percent of the applicants and demonstrating a need for continued support for the nation's small museums. In 2014, IMLS launched Museums for All, a national access initiative. Today, more than 500 participating museums offer deeply discounted admission to visitors who receive Supplemental Nutrition Assistance Program benefits. More than 1 million people visited a Museums for All museum in 2019 and more than 2.5 million visits have occurred since 2014.

Here are just a few examples of how OMS helps museums better serve their communities:

In 2018, The University of Missouri in Saint Louis received a $49,979 National Leadership Grant to support a leadership team from the university to partner with nine cultural heritage organizations, including museums, to prototype a collaborative model for internships that offers peer support and fosters mentorship to students from faculty and site coordinators. The project team will bring students, faculty, and site supervisors together for a project team kick-off meeting to design a micro-internship program allowing diverse students to participate in 2–3 week fully-paid internships at heritage sites across the U.S. For two to three weeks, six to ten students will work in pairs at preselected internship sites with the support of mentors. The project activities will result in a curriculum and guide for future micro-internships that attract diverse students into the heritage museum workforce with additional opportunities and added career-building potential.

In 2019, the Missouri History Museum in St. Louis was awarded a $250,000 Museums for America Office of Museum Services grant to process, survey, and make publicly accessible the 1,894 objects in its Charles A. Lindbergh Collection. Objects include diverse personal items, gifts associated with Lindbergh's 1927 transatlantic flight and publicity tours, and wedding gifts presented to Charles and his wife Anne. The museum will hire two collections specialists and one special projects photographer, overseen by its collections manager, to perform the work. Conservators specializing in objects, paintings, paper, and textiles will perform detailed conservation surveys. Full records with digitized images will be made publicly accessible via the museum's online collections portal. The project will be the first phase of an 8-year, multistage collections initiative culminating in 2027 with the centennial of Lindbergh's legendary transatlantic flight.

In 2019, the Contemporary Art Museum St. Louis in Missouri was awarded a $193,753 Museums for America grant to expand its ArtReach programs in response to the needs of St. Louis students, teachers, and schools. The museum will provide arts education opportunities for middle and high school students by partnering with nearby schools through multi-week engagements with teaching artists, hosting drop-in workshops introducing contemporary art practices, and organizing field trips to the museum. The project will also include mentoring for art teachers in partner schools and a portfolio day to prepare high school students for college admissions processes. With the guidance of an evaluation consultant, the museum will measure success using formative and summative evaluation techniques, and develop tools to consistently track and analyze project activities.

In 2019, the Children's Museum of Tacoma, Washington, was awarded a $186,567 National Leadership Grant to develop and disseminate an evaluation tool that enables museums to measure the impact their programming on military families. The museum will work with a variety of partner organizations, including FRIENDS National Center for Community-Based Child Abuse Prevention, the University of Kansas Center for Public Partnerships and Research, and the Army Analytics Group, to adapt two existing frameworks for use by museums. The project partners will test iterations of the tool, which will be informed by focus groups with military families. The museum will disseminate project resources to support the evaluation of programming tailored for military families by launching a web page with explanatory information, downloadable content, and a recorded webinar. The museum and its project partners will share project results through presentations at national conferences.

In 2019, the Wing Luke Museum of the Asian Pacific American Experience in Seattle, Washington, was awarded a $136,134 Museums for America grant to draw on its collections to supplement the Asian Pacific American (APA) history curriculum in Washington state schools. Working with a committee of local educators, special education teachers, and disability advocates, the museum will research, write, and compile a new curriculum exploring the culture, immigrant and refugee history, and APA experiences in the state. The curriculum will align with state standards and address one grade at each level-elementary, middle, and high school. Each lesson will be available through an online web portal and will include multisensory lessons and components that address a variety of learning styles. Additional project activities will include teacher training opportunities, school tours at the museum based on the curriculum, and a professional evaluation.

In 2019, Imagine Children's Museum in Everett, Washington, was awarded a $154,448 Museums for America grant to work with community partners to develop the Positive Futures program to support resilience in children who have experienced trauma. The program will focus on two populations—those in kinship care and children who have an incarcerated parent or loved one. A taskforce of museum staff and community partners will incorporate the experiences learned in a previous pilot program by adding elements to specifically address social emotional and core life skills. Using playful learning formats, the museum will present monthly programs for 12–15 families per group, and take-home materials will build on the learning at the museum between sessions. Working with an evaluation consultant the project team will measure child learning and refine the programs based on feedback from caregivers. The museum will also develop a playbook for other children's museums interested in offering similar programs for their communities.

In closing, I highlight recent national public opinion polling that shows that 95 percent of voters would approve of lawmakers who acted to support museums and 96 percent want Federal funding for museums to be maintained or increased. Museums have a profound positive impact on society. If I can provide any additional information, I would be delighted to do so. Thank you again for the opportunity to submit this testimony.

[This statement was submitted Laura L. Lott, President and CEO, American Alliance of Museums.]

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION FOR DENTAL RESEARCH

On behalf of the American Association for Dental Research (AADR), I am pleased to submit testimony describing AADR's funding requests for fiscal year 2021, which include at least $44.7 billion for the National Institutes of Health and—within NIH—$512 million for the National Institute of Dental and Craniofacial Research (NIDCR).

AADR is grateful to Congress for providing critical funding increases for most federally funded research, including for NIH and NIDCR, in previous years' funding cycles. We recognize that each year Congress is faced with difficult funding decisions. Yet, lawmakers continue to support these agencies and programs, signaling that lawmakers both recognize and value the role that scientific research and public health programs provide in improving the health and well-being of the nation.

Looking ahead to fiscal year 2021, AADR recognizes the challenges that Congress will face during the appropriations process. Not only will appropriators navigate fiscal 2021 appropriations in the midst of the emergency response to COVID–19, but they will also need to consider increasing the amount of funding available to nondefense discretionary (NDD) programs in fiscal 2021. Current budget legislation provides only a $5 billion increase to divide among all NDD programs. While previous years' increases have helped make up lost purchasing power among Federal agencies, we cannot afford to slow progress by underfunding Federal agencies this coming year. We must continue to prioritize Federal research, which improves the health of Americans and supports economic growth, or we risk sending our country backward.

NIDCR-the largest institution dedicated exclusively to research to improve dental, oral and craniofacial (skull and face) health-provides more than 700 competitive research and institutional training grants to around 200 U.S. universities, hospitals, research institutions and small businesses. The Institute also cultivates a strong and diverse workforce by funding more than 300 aspiring scientists through individual research training and career development awards. NIH's reach expands even farther-with every state and almost every congressional district earning a share of NIH's investment in biomedical research.[1] In fiscal year 2017, it is estimated that NIH's extramural funding generated approximately $68.8 billion in economic output nationwide.[2]

The economic influence of NIH and NIDCR, driven by their research portfolios, reveals how vital these Federal research agencies are to our country's progress and advancement; importantly, they are having a significant impact on the health and well-being of the American people.

Among AADR's requests to the Labor-HHS, Education and Related Agencies Subcommittee for the coming fiscal year is to fund NIDCR at $512 million. NIDCR is leading to "a world where dental, oral and craniofacial health and disease are understood in the context of the whole body," [3]—an aim outlined in NIDCR's 2030 strategic visioning initiative-and AADR has appreciated the regular increases to NIDCR's budget over the past several years. While Congress' support for NIDCR has allowed the Institute to expand into research areas, including regenerative medicine, salivary diagnostics and the oral microbiome, NIDCR's funding has not kept pace with the increases provided to NIH. Indeed, NIDCR needs to expand its research portfolio in the public interest to understand how coronavirus locates in salivary and nasal secretions (craniofacial origin) to spread among people as well as how to create lasting immunity, or at least temporary resistance. The requested fiscal year 2021 amount would bring NIDCR funding into alignment with the overall NIH request and allow NIDCR to build on its myriad successes in fulfilling its mission to improve dental, oral and craniofacial health.

Oral health-too often considered in isolation-is integral to overall health. The research being conducted at, and supported by, NIDCR impacts the lives of millions of Americans. Most readily apparent in someone's day-to-day life, oral health can affect activities that may be taken for granted: the ability to eat, drink, swallow, smile, communicate or maintain proper nutrition. The oral cavity can also serve as a window into other potential health issues like COVID–19 and as a site for important scientific discovery.

Among its contributions, NIDCR-supported research helps reduce the societal costs of dental care and enhance the evidence base for the dental profession. Additionally, the Institute is supporting research that will address some of the day's most pressing public health concerns, including non-opioid treatments for pain and the oral health effects of e-cigarettes.

Beyond the broader, highly relevant public health issues, NIDCR is also improving the lives of patients across the country. NIDCR's portfolio encompasses a wide variety of basic, translational and clinical research and research training related to craniofacial disorders. For example, NIDCR research into craniofacial disorders aims to understand the underlying biology of craniofacial development, translate knowledge into treatment, and invest in well-known genetic disorders, such as cleft lip and palate, and rare diseases, such as Behcet's Disease, Fibrous Dysplasia and Cleidocranial Dysplasia. These and other diseases and conditions affecting or connected to the craniofacial tissues and organs will be addressed to improve quality of life, reduce physical debilitation, and mitigate a major financial and social burden.

The Institute's research examines the mechanisms underlying these conditions and seeks to develop new treatments and therapies for patients. Among NIDCR's

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[1] United for Medical Research report on NIH's role in sustaining the U.S. Economy. 2018 Update. http://www.unitedformedicalresearch.com/advocacy__reports/nihs-role-in-sustaining-the-u-s-economy-2018-update/.

[2] NIH's Role In Sustaining The U.S. Economy: 2018 Update Authored by Dr. Everett Ehrlich, United for Medical Research, 2018. http://www.unitedformedicalresearch.com/wp-content/uploads/2017/03/NIH-Role-in-the-Economy-fiscal year 2016.pdf.

[3] https://www.nidcr.nih.gov/research/research-priorities-nidcr-2030.

contributions in this space is the FaceBase Consortium, which began in 2009 with 11 research and technology grants that seek to compile the biological instructions to both construct parts of the human face and define the genetics underlying developmental disorders, such as cleft lip and palate. Now in its third phase, FaceBase is helping to achieve its goal of generating and disseminating datasets to facilitate research; it is a one-stop shop for researchers, clinicians and patients containing extensive data on facial development.

The possibilities for NIDCR to use dental, oral and craniofacial research to improve health and well-being is vast. We believe many of these opportunities will be highlighted in the forthcoming release of the U.S. Surgeon General's Report on Oral Health, a much-needed update to the seminal "Oral Health in America" report from 2000. NIDCR is the lead Federal agency working with the Surgeon General to produce the report, which will document the progress in oral health since 2000 and convey a vision for the future, including identifying challenges and opportunities for research. The 2000 report shifted perspectives among the public and policymakers by showing that oral health goes beyond healthy teeth and gums and that it is essential to our general health and well-being. We believe the 2020 report can have a similar impact.

As a research-centered association, AADR recognizes that public health programs and Federal research are complementary; a discovery in one area benefits another. Therefore, AADR encourages Congress, in addition to supporting NIH and NIDCR, to support all Federal research-from discovery to care delivery-in fiscal year 2021. Complementing our NIH requests, our members urge you to provide $29 million for the CDC's Division of Oral Health, $41 million for the Title VII Health Resources and Services Administration (HRSA) programs that train the dental health workforce, $471 million for the Agency for Healthcare Research and Quality (AHRQ), and $189 million for the National Center for Health Statistics (NCHS).

Finally, AADR implores Congress to use this opportunity and momentum to provide dental, oral and craniofacial research with the resources it needs to continue making a difference to all our citizens.

Thank you for the opportunity to submit this testimony. We stand ready to assist the Congress in any way we can and to answer any questions you may have.

[This statement was submitted by Mark C. Herzberg, D.D.S., Ph.D., President, Board of Directors, American Association for Dental Research.]

Prepared Statement of the American Association of Colleges of Nursing

STRENGTHENING THE CURRENT AND FUTURE NURSING WORKFORCE

On behalf of the American Association of Colleges of Nursing (AACN), we would like to thank the Subcommittee for its leadership and continued support of nursing education, the nursing profession, and nursing research. AACN is the national voice for academic nursing, proudly representing more than 840 member schools, 543,000 nursing students, and more than 45,000 faculty across the country. As we work to combat current public health challenges, such as COVID–19, ensuring a robust nursing pipeline, now and in the future, requires a strong and sustained Federal investment. For fiscal year 2021, AACN respectfully requests your continued investment in America's health by providing at least $278 million for the Nursing Workforce Development programs (Title VIII of the Public Health Service Act [42 U.S.C. 296 et seq.] administered by HRSA), at least $44.7 billion for NIH, and at least $182 million for the National Institute of Nursing Research (NINR).

The Growing Nursing Workforce Demand

Nurses make up the largest sector of the healthcare workforce, with more than four million Registered Nurses (RNs) and Advanced Practice Registered Nurses (APRNs); including Nurse Practitioners (NPs), Certified Registered Nurse Anesthetists (CRNAs), Certified Nurse-Midwives (CNMs) and Clinical Nurse Specialists (CNSs), treating patients across the entire life span and educating the next generation of healthcare providers.[1] These nurse educators, students, and practitioners are leaders within their institutions and communities and are on the frontlines as we address public health challenges, including COVID–19.

As we address COVID–19, we have witnessed the dire need for additional nurses. This demand is only expected to grow as we continue to combat this pandemic and address the healthcare needs of our communities, especially in rural and under-

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[1] National Council of State Boards of Nursing. (2020). Active RN Licenses: A profile of nursing licensure in the U.S. as of March 18, 2020. Retrieved from: https://www.ncsbn.org/6161.htm.

served areas. According to the Bureau of Labor Statistics, the projected RN Workforce demand is expected to increase 12 percent by 2028, representing a call for an additional 371,500 nurses.[2] Demand for most APRNs is expected to grow by 26 percent.[3]

While nursing schools across the country are working to meet the rising demand and educate all qualified applicants interested in the profession, they are often stymied by a shortage of nursing school faculty. Though AACN reported a 3.7 percent enrollment increase in entry-level baccalaureate nursing programs in 2018, this increase is not sufficient to meet the projected demand for nursing services, including the need for more nurse faculty, researchers, and primary care providers.[4] That is why enhancing and preserving Federal resources, such as Title VIII Nursing Workforce Development Programs and NINR, are essential to bridging this chasm between supply and demand, and ensuring we have an adequate nursing workforce ready to respond at a moment's notice and positively impact healthcare outcomes for all Americans.

Nursing Workforce Investments: Ensuring Healthcare Access

As we have seen in efforts to combat the COVID–19 pandemic, a well-educated nursing workforce is essential to ensuring the safety and health of our Nation. The Title VIII Nursing Workforce Development programs represent the largest dedicated Federal funding stream to nursing education and the workforce. These indispensable programs consistently and continually sustain the supply and distribution of highly-educated nurses by strengthening nursing education at all levels, from entry-level preparation through graduate study. Through these indispensable Federal investments, the profession's ability to serve America's patients continues in all communities, especially those most in need.

Education and Sustaining a Strong Nursing Workforce:

Each Title VIII Nursing Workforce Development Program provides a unique and crucial mission to support nursing education and the profession. Together, these programs offer opportunities to help educate nurses, address patient demand, and respond to any unforeseen challenges, such as COVID–19. For example, the Advanced Nursing Education (ANE) programs increase the number of APRNs in the primary care workforce and supported more than 9,100 students in Academic Year 2018–2019 alone.[5] The ANE programs support students studying to become APRNs, and other nurses requiring a master's or doctoral degree, by providing Federal support, as well as faculty development, to ensure a robust nursing workforce. Other examples include the Nurse Faculty Loan Program (NFLP) and Nursing Workforce Diversity (NWD) programs. In Academic Year 2018–2019, the NFLP awarded 80 grants to schools that supported 2,277 graduate nursing students, which effectively increases the number of nurse educators.[6] In the same academic year, the NWD program awarded grants supporting 11,067 nursing students from disadvantaged backgrounds, which supports the critical need of recruiting culturally and economically diverse individuals into nursing to better serve our nation's diverse patient population.[7]

To ensure the stability of our nursing workforce, we request at least $278 million for Title VIII Nursing Workforce Programs.

From Research to Reality: Nursing Science Protects Americans' Health

Scientific research and discovery are key to providing the best care possible. As one of the 27 Institutes and Centers at NIH, NINR plays a fundamental role in im-

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[2] U.S. Bureau of Labor Statistics. (2019). Occupational Outlook Handbook- Registered Nurses. Retrieved from: https://www.bls.gov/ooh/healthcare/registered-nurses.htm.

[3] U.S. Bureau of Labor Statistics. (2019). Occupational Outlook Handbook- Nurse Anesthetists, Nurse Midwives, and Nurse Practitioners. Retrieved from: https://www.bls.gov/ooh/healthcare/nurse-anesthetists-nurse-midwives-and-nurse-practitioners.htm.

[4] American Association of Colleges of Nursing. (2019). Nursing Shortage Fact Sheet as of April, 2019. Page 2. Retrieved from https://www.aacnnursing.org/Portals/42/News/Factsheets/Nursing-Shortage-Factsheet.pdf.

[5] Department of Health and Human Services fiscal year 2021 Health Resources and Services Administration Justification of Estimates for Appropriations Committees. Pages 141–143. https://www.hrsa.gov/sites/default/files/hrsa/about/budget/budget-justification-fy2021.pdf

[6] Department of Health and Human Services fiscal year 2021 Health Resources and Services Administration Justification of Estimates for Appropriations Committees. Page 154. https://www.hrsa.gov/sites/default/files/hrsa/about/budget/budget-justification-fy2021.pdf.

[7] Department of Health and Human Services fiscal year 2021 Health Resources and Services Administration Justification of Estimates for Appropriations Committees. Page 146. https://www.hrsa.gov/sites/default/files/hrsa/about/budget/budget-justification-fy2021.pdf.

proving care and is on the cutting edge of new innovations impacting how nurses are educated and how they practice.

A prime example of this groundbreaking scientific work is an NINR-funded study that has identified a protein that could be used to detect mild traumatic brain injuries through a simple blood test.[8] Annually, millions of Americans experience these mild traumatic brain injuries and this effective, fast-testing method could revolutionize diagnosis and lower costs by eliminating the need for costly and time intensive brain imaging.[9]

This is just one of countless examples showcasing the innovative and pioneering work that nurse scientists are discovering through the support of NINR. Yet, despite many research successes, NINR was only able to fund 8.9 percent of grant applications in 2017, due to insufficient funding.[10] This is the lowest research project grant (RPG) success rate among all NIH institutes and centers, and significantly lower than the overall NIH RPG success rate of 18.7 percent.[11] Despite these funding challenges, some NINR-funded projects returned between $202 and $1,206 for each dollar awarded in grants, according to a recent study in the journal Nursing Outlook.[12] To further this vital work, we are requesting a total of at least $182 million for the National Institute of Nursing Research.

Strong investments in Title VIII Nursing Workforce Development programs and NINR have a direct impact on the nursing pipeline and patient access to high-quality, evidence-based care in communities across the nation. During these challenging times, AACN respectfully requests continued support in fiscal year 2021 of at least $278 million for the Title VIII Nursing Workforce Development programs and $44.7 billion for the National Institute of Health, which includes $182 million for the National Institute of Nursing Research. Together, we can ensure that such investments promote innovation and improve healthcare in America.

[This statement was submitted by Susan Bakewell-Sachs, PhD, RN, FAAN, Board Chair, American Association of Colleges of Nursing.]

Prepared Statement of the American Association of Colleges of Osteopathic Medicine

The American Association of Colleges of Osteopathic Medicine (AACOM) leads and advocates for the full continuum of osteopathic medical education to improve the health of the public. Founded in 1898 to support and assist the nation's osteopathic medical schools, AACOM represents all 36 accredited colleges of osteopathic medicine—educating nearly 31,000 future physicians, 25 percent of all U.S. medical students—at 57 teaching locations in 33 U.S. states, as well as osteopathic graduate medical education professionals and trainees at U.S. medical centers, hospitals, clinics, and health systems.

AACOM strongly supports restoring funding for discretionary Health Resources and Services Administration (HRSA) programs to $8.8 billion; total funding of $790 million for key priorities in HRSA's Title VII and Title VIII programs under the Public Health Service Act, including adequate funding for the Centers for Excellence (COE), Health Careers Opportunity Program (HCOP), Scholarships for Disadvantaged Students (SDS) Program, Geriatrics Education Centers (GECs); $67 million for the Area Health Education Centers (AHECs) Program; $60 million for the Primary Care Training and Enhancement (PCTE) Program; $15 million for the Rural Residency Planning and Development Program; long-term sustainable funding for the Teaching Health Center Graduate Medical Education (THCGME) Program; at least $120 million in level funding for the National Health Service Corps (NHSC) and extension of the trust fund; a minimum of $44.7 billion for the National Institutes of Health (NIH); and $471 million in budget authority for the Agency for Healthcare Research and Quality (AHRQ).

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[8] National Institute of Nursing Research. (2020). Research Highlights. Retrieved from: https://www.ninr.nih.gov/researchandfunding/researchhighlights#highlight-1.

[9] National Institute of Nursing Research. (2020). Research Highlights. Retrieved from: https://www.ninr.nih.gov/researchandfunding/researchhighlights#highlight-1.

[10] Federal Funding of Nursing Research by the National Institutes of Health (NIH): 1993–2017 Kiely, Daniel P. et al. (2019) Page 9. Retrieved from: https://www.nursingoutlook.org/article/S0029–6554(19)30315–X/addons.

[11] Federal Funding of Nursing Research by the National Institutes of Health (NIH): 1993–2017 Kiely, Daniel P. et al. (2019) Page 9. Retrieved from: https://www.nursingoutlook.org/article/S0029–6554(19)30315–X/addons.

[12] Federal Funding of Nursing Research by the National Institutes of Health (NIH): 1993–2017 Kiely, Daniel P. et al. (2019) Page 2. Retrieved from: https://www.nursingoutlook.org/article/S0029–6554(19)30315–X/addons.

The Title VII health professions education programs, authorized under the Public Health Service Act and administered through HRSA, support the training and education of health practitioners to enhance the supply, diversity, and distribution of the healthcare workforce, acting as an essential part of the healthcare safety net and filling the gaps in the supply of health professionals not met by traditional market forces. Title VII programs are the only Federal programs designed to train primary care professionals in interdisciplinary settings to meet the needs of medically underserved populations, as well as increase minority representation in the healthcare workforce. AACOM supports total funding of $790 million for Title VII and Title VIII programs.

As the demand for health professionals increases in the face of impending shortages and the anticipated demand for access to care increases, these needs strain an already fragile healthcare system. AACOM appreciates the investments that have been made in these programs, and we urge the Subcommittee for inclusion and/or continued support for the following programs: the COE, the HCOP, the SDS Program, the GECs, the AHECs, the PCTE Program, and the Rural Residency Planning and Development Program.

The COE Program is integral to increasing the number of minority youth who pursue careers in the health professions.

The HCOP provides students from disadvantaged backgrounds with the opportunity to develop the skills needed to successfully compete, enter, and graduate from health professions schools.

The SDS Program provides scholarships to health professions students from disadvantaged backgrounds with financial need, many of whom are underrepresented minorities.

GECs are collaborative arrangements between health professions schools and healthcare facilities that provide training between health professions schools and healthcare facilities that provide the training of health professions students, faculty, and practitioners in the diagnosis, treatment, and prevention of disease, disability, and other health issues.

The AHEC Program provides funding for interdisciplinary, community-based, primary care training programs. Through a collaboration of medical schools and academic centers, a network of community-based leaders works to improve the distribution, diversity, supply, and quality of health personnel, particularly primary care personnel in the healthcare services delivery system, specifically in rural and underserved areas. AACOM supports a request of $67 million for the AHEC Program and strongly opposes any effort to eliminate this critical program.

The PCTE Program provides funding to support awards to primary care professionals through grants to hospitals, medical schools, and other entities. AACOM supports a request of $60 million for this important program.

The Rural Residency Planning and Development Program supports the development of new rural residency programs or Rural Training Tracks in family medicine, internal medicine, and psychiatry to help expand the physician workforce in rural areas across the country. Health professions workforce shortages are exacerbated in rural areas, where communities struggle to attract and maintain well-trained providers. AACOM supports the inclusion of $15 million for the Rural Residency Planning and Development Program.

AACOM continues to strongly support the long-term sustainment of the THCGME Program, which provides funding to support primary care medical and dental residents training in community-based settings. The majority of currently-funded medical residency programs are osteopathic or dually-accredited (DO/MD). Currently, there are more than 728 residents being trained in 56 HRSA-supported THC residencies in 23 states. According to HRSA, physicians who train in teaching health centers (THCs) are three times more likely to work in such centers and more than twice as likely to work in underserved areas. The continuation of this program is critical to addressing primary care physician workforce shortages and delivering healthcare services to underserved communities most in need. AACOM is pleased that Congress supported this highly successful bipartisan program by providing a short-term funding extension in the Coronavirus Aid, Relief, and Economic Security (CARES) Act. However, funding for this program will expire after November 30. Stable funding is necessary for the THCGME Program to continue to expand and increase the number of physicians that work in communities of need. AACOM strongly supports the continuation of and permanent funding for the THCGME Program and will continue to work with Congress to support a sustainable and viable funding mechanism for its continuation. Furthermore, we strongly support that the program's funding continues as mandatory funding.

The NHSC supports physicians and other health professionals who practice in health professional shortage areas across the U.S. The NHSC notes that a field strength of more than 13,000 primary care clinicians are providing services nationwide in health professional shortage areas in fiscal year 2020. While we were pleased to see a short-term funding extension in the Coronavirus Aid, Relief, and Economic Security (CARES) Act, stable funding is necessary for the continuation of this critically effective program. Therefore, AACOM supports the stability of the NHSC by requesting at least $120 million in level funding for the NHSC and extension of the NHSC trust fund, which expires after November 30.

Research funded by the NIH leads to important medical discoveries regarding the causes, treatments, and cures for common and rare diseases, as well as disease prevention. These efforts improve our nation's health and save lives. To maintain a robust research agenda, further investment will be needed. AACOM supports a funding level of at least $44.7 billion for the NIH.

AHRQ plays an important role in producing the evidence base research needed to improve our nation's health and healthcare. The incremental increases for AHRQ's Patient Centered Health Research Program in recent years will help AHRQ generate more of this research and expand the infrastructure needed to increase capacity to produce this evidence; however, more investment is needed. AACOM recommends $471 million in budget authority for AHRQ. This investment will preserve AHRQ's current programs while helping to restore its critical healthcare safety, quality, and efficiency initiatives. Additionally, AACOM opposes the consolidation of AHRQ into the NIH.

AACOM appreciates the opportunity to submit its views and looks forward to continuing to work with the Subcommittee on these important matters.

[This statement was submitted by Robert A. Cain, DO, FACOI, FAODME, President and Chief Executive Officer, American Association of Colleges of Osteopathic Medicine.]

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF NEUROMUSCULAR & ELECTRODIAGNOSTIC MEDICINE

FISCAL YEAR 2021 RECOMMENDATIONS

—Please continue to provide meaningful, annual funding increases for healthcare fraud and abuse programs at the Centers for Medicare and Medicaid Services (CMS) while allowing for flexibility and innovation to address emerging challenges.

—Please continue to include timely recommendations in the Committee Report accompanying the annual Labor-Health and Human Services-Education (LHHS) Appropriations Bill encouraging CMS to take substantive action to systematically address fraud, abuse, and the quality of patient care in electrodiagnostic (EDX) medicine.

Chairman Blunt, Ranking Member Murray, and distinguished members of the Subcommittee, thank you for the opportunity to present the views of the American Association of Neuromuscular & Electrodiagnostic Medicine (AANEM) during the consideration of fiscal year 2021 LHHS appropriations. The challenges and opportunities that I will review today are not unique to AANEM, but impact a variety of medical professional societies and patient communities who rely on proper EDX testing. My comments are provided in the interest of spotlighting serious issues that continue to undermine patient care and waste Federal healthcare resources, while advancing policy tools to efficiently and effectively address these issues. In this regard, please consider the AANEM a resource moving forward. Thank you again for this important opportunity.

ABOUT AANEM

AANEM is a nonprofit membership association dedicated to the advancement of neuromuscular (NM), musculoskeletal, and EDX medicine. Our members—primarily neurologists and physical medicine and rehabilitation (PMR) physicians—are joined by allied health professionals and PhD researchers working to improve the quality of medical care provided to patients with muscle and nerve disorders. Founded in 1953, AANEM currently has over 4,500 members across the country. Our mission is to improve quality of patient care and advance the science of neuromuscular diseases and EDX medicine by serving physicians and allied health professionals who care for those with muscle and nerve disorders. Our members are dedicated to diagnosing and managing a variety of nerve and muscle disorders including, but not limited to, amyotrophic lateral sclerosis, muscular dystrophies, and neuropathies, as well as more common conditions, such as pinched nerves and carpal tunnel syndrome.

ABOUT EDX MEDICINE

When functioning properly, nerves send electrical impulses to the muscles to activate them. A nerve disorder means that signals are not getting through like they should. A muscle disorder means that muscles aren't responding to the signals correctly. To determine whether your nerves and muscles are working properly, your doctor may recommend you have EDX testing, which generally includes both a nerve conduction study (NCS) and needle electromyography (EMG) testing. Other tests may include imaging, genetic testing, biopsies, biochemical tests, and strength testing. The results of these tests help your doctor diagnose your condition and determine the best treatment.

NCS.—These studies evaluate how quickly and efficiently electrical impulses move through the nervous system. While it may sound straight-forward, proper testing requires sophisticated equipment, an understanding of the patient's health history, and, most importantly, the ability to design/perform the study and interpret the results.

EMG.—This test evaluates muscles and nerves through the use of electrodes under the skin. Since the procedure is invasive and highly technical, it is considered to be the practice of medicine by the American Medical Association;requiring training, study, and experience to ensure patient safety and testing efficacy.

ABOUT EDX FRAUD AND ABUSE

In 2014, the HHS OIG published a report entitled, Questionable Billing for Medicare Electrodiagnostic Tests, which found roughly $140 million in suspicious activity annually. But experience tells us that this is just the tip of the iceberg. And the toll of patient suffering and hardship as the result of fraudulent EDX testing is incalculable. Unfortunately, since this report was released, the situation has deteriorated rather than improved. Our members have anecdotally noted an increase in fraud activity (both through solicitations and by re-testing patients that were victims of improperly performed tests), which appears to be supported by CMS utilization data. CMS revised the EDX codes in 2013 which has actually made it harder to identify systematic fraud and abuse in this area. Bad actors are aware of the gaps in the current CMS regulatory and enforcement framework that create unique blind spots for EDX testing, and this deficiency continues to be exploited with many criminal endeavors operating in the open for years as sham professional service providers (the small number that are caught and convicted annually has not served as a deterrent). To be clear, the victims continue to be the patients that are improperly tested, subjected to a battery of studies, and over-billed, with no intention of receiving an accurate diagnosis or who were never in need of testing in the first place.

COMMON FRAUD SCHEMES

Mobile Labs.—Unlike traditional healthcare mobile labs that conduct community outreach and deliver valuable clinical services, EDX "mobile labs" exist exclusively to perpetuate fraud. A provider is solicited to have a technician sent to their office to conduct EDX testing for all patients on a given day under the guise of generating additional revenue and enhancing services offered. The provider is often unaware that the testing is improper and that the fraudulent company is using the untrained provider to technically fulfill the requirement of "supervising" the tests. The testing is not guided onsite nor in real time, as is required by the AMA's CPT codebook, and as many nerves as possible are tested to increase billing. The tests are then sent to a complicit, offsite clinician that "reviews" the results after the fact and submits for reimbursement. From the perspective of the third-party payer reviewing the billing, this system of fraud is nearly impossible to identify.

Pain Fiber NCS.—Fraudulent activity in this area is increasingly associated, in part, with disreputable pain clinics. Proprietary devices claim to evaluate pain, and diagnose sensory radiculopathies (a pinched nerve in the neck or back), or even fibromyalgia. These machines are not actually capable of selectively stimulating nerve fibers or recording the nerve responses so no nerve or muscle disorders can be accurately or reliably diagnosed. CMS is aware of this and created non reimbursable codes, but bad actors simply bill for the procedure using standard NCS codes.

NCS without EMG Testing.—A complete EDX examination typically involves both NCS and EMG studies, with NCS testing exclusively required in a small number of cases. However, since needle EMG is an invasive procedure and bad actors are relying on a technician, a high rate of NCS-only studies is a hallmark of fraud and abuse.

PREPARED STATEMENT OF AANEM MEMBER DR. VINCE TRANCHITELLA

New NCS codes became effective on January 1, 2013. The new codes were developed as a direct response to fraudulent activity that resulted in the exponentially increased billing for NCSs. Unfortunately, the new NCS codes failed to have the desired effect. In the past 3 years alone, I have reviewed at least 27 EDX medicine fraud cases, involving multiple providers each, affecting hundreds of patients. Nine of these cases involved providers in the New York City region. Most of the providers I reviewed did not receive appropriate training in EDX medicine yet were still regularly conducting studies.

RECENT EXAMPLES

EDX fraud not only wastes healthcare dollars, but, more importantly, the quality of patient care suffers severely. As an example, a recent case in which I testified in Houston working for the FBI and the U.S. Attorney's Office, many patients' insurance companies were being billed more than $30,000 for a study that should cost $800 to $1200. Of note, when a detailed review was performed, more than 85 percent of the diagnoses arrived at with these fraudulent studies were incorrect and unreliable. These inappropriate and inaccurate studies did not help these patients in finding appropriate treatments or solutions to their medical problems. In fact, they often sent the patients down costly and ineffective paths of treatment. In this case alone the perpetrators were convicted of EDX fraud totaling nearly $5 million.

As is invariably the case with mobile EDX laboratories, quality of care suffers while costs skyrocket and the real losers are, unfortunately, the patients. In a case I had in California, a 47 year old man had a mobile EDX study done that cost him (and his insurance company) more than $7,500 and told him his symptoms were from a "pinched nerve in his leg". When I performed the correct study (charging about $750) I found his true diagnosis to be ALS (or Lou Gehrig's disease).

CURRENT OPPORTUNITIES

CMS, the FBI, and the HHS OIG have been doing tremendous work to root out fraud and abuse in EDX medicine, but these dedicated public servants are limited by the constraints of the current pay-and-chase model. Additional resources for ongoing CMS efforts to address healthcare fraud and abuse will facilitate incremental improvements and further protect patients, but modernization is needed as well. Over recent appropriations cycles, Congress has called on CMS to work with the EDX community on innovative solutions that could better identify bad actors conducting EDX testing or simply prevent payments for improper studies before they are made. Please continue to work with CMS through the fiscal year 2021 appropriations process to recommend greater community collaboration and to encourage meaningful and timely progress in the area of EDX fraud and abuse.

[This statement was submitted by Peter A. Grant, MD, EDX Fraud and Abuse Consultant for FBI and OIG, American Association of Neuromuscular & Electrodiagnostic Medicine.]

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF IMMUNOLOGISTS

The American Association of Immunologists (AAI), the nation's largest professional society of research scientists and physicians who are dedicated to understanding the immune system through basic, translational, and clinical research, respectfully submits this testimony regarding fiscal year 2021 appropriations for the National Institutes of Health (NIH). AAI recommends an appropriation of at least $44.7 billion for fiscal year 2021 to enable NIH to fund critically important research to prevent dangerous infectious diseases and treat debilitating chronic diseases, support meritorious scientists at all career stages, and ensure a robust biomedical research enterprise that maintains U.S. preeminence in science and innovation. Because of the current COVID–19 pandemic, NIH will require, and AAI strongly supports, the appropriation of additional emergency supplemental funding that is being considered outside of the annual appropriations process.

PUBLIC HEALTH IMPORTANCE OF UNDERSTANDING THE IMMUNE SYSTEM

While recent attention to the immune system has focused on its ability, properly harnessed, to kill malignant tumors and treat other chronic diseases (immunotherapy), the coronavirus pandemic has highlighted the immune system's critical role in protecting against infectious agents—including viruses—that cause disease. The immune system plays a significant role in preventing and fighting existing and emerging infectious diseases such as HIV/AIDS, influenza, measles, tuberculosis, and Ebola. It is also central to many chronic conditions such as Alzheimer's and cardiovascular disease. Research into many of these diseases has helped scientists take on our most recent challenge: understanding the cause, prevention, and treatment of a novel coronavirus, SARS-CoV2, and its consequent disease, COVID–19. Significant recent developments in immunology research are described below.

Vaccines for SARS-CoV2/Emerging Infectious Diseases

Vaccines are the most efficient and effective method of disease prevention. Globally, vaccination against more than two dozen viral, bacterial, and fungal diseases prevents about 2.5 million deaths and reduces the severity of illness for millions of people annually.[1] As the world's population grows and becomes more interconnected, the threat of a new emerging pathogen causing a worldwide pandemic, which has long been feared, has been realized: on March 11, 2020, the World Health Organization declared the novel coronavirus outbreak a pandemic.

Although there is currently no approved vaccine for SARS-CoV2, NIH-funded research conducted on other causative pathogens in recent epidemics, including SARS (now known as SARS-CoV1) (2002) and MERS (2012), has made possible the rapid development of vaccine candidates for SARS-CoV2.[2] While no vaccine is likely to be approved by the Food and Drug Administration (FDA) for at least another year, eight candidate vaccines are currently being tested in human subjects;[3] this includes a candidate vaccine developed in part by researchers at the National Institute of Allergy and Infectious Diseases' Vaccine Research Center that moved into a clinical trial at a rate never before observed in the history of vaccine development.[4] In addition, anti-viral therapeutics supported by NIH-funded research are already in, or are moving toward, clinical testing for efficacy against SARS-CoV2.[5] One such therapeutic, remdesivir, has already been approved by the FDA for emergency use "for the treatment of suspected or laboratory-confirmed COVID–19 in adults and children hospitalized with severe disease."[6] AAI is optimistic that previously conducted research, together with new research now being urgently pursued, will result in new vaccines and additional treatments that will prevent and/or reduce the lethality of COVID–19.

With regard to other infectious diseases, NIH-funded research has allowed scientists to make significant advances in understanding and developing vaccines against many emerging infectious agents. In 2019 alone, this research helped lead to a FDA-approved Ebola vaccine, a phase-I clinical trial for a Zika vaccine, and a multi-national phase-3 clinical trial for an HIV vaccine.[7] Researchers have also begun early-stage clinical trials of a universal vaccine for influenza, a disease that results in 9—45 million illnesses and 12,000—61,000 deaths per year in the U.S.[8] Without strong, steady support from NIH, researchers will be ill-prepared to respond to new emerging diseases threatening the safety of Americans and people around the world.

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[1] https://www.who.int/immunization/global__vaccine__action__plan/GVAP__doc__2011__2020/en/.

[2] https://www.niaid.nih.gov/diseases-conditions/coronaviruses

[3] https://www.who.int/who-documents-detail/draft-landscape-of-covid-19-candidate-vaccines; https://www.washingtonpost.com/health/2020/05/18/coronavirus-vaccine-first-results/.

[4] https://www.nih.gov/news-events/news-releases/nih-clinical-trial-investigational-vaccine-covid-19-begins.

[5] https://www.nih.gov/news-events/news-releases/nih-clinical-trial-remdesivir-treat-covid-19-begins.

[6] https://www.fda.gov/news-events/press-announcements/coronavirus-covid-19-update-fda-issues-emergency-use-authorization-potential-covid-19-treatment.

[7] https://directorsblog.nih.gov/2020/01/02/celebrating-biomedical-breakthroughs-in-2019/; https://www.nih.gov/news-events/news-releases/nih-begins-clinical-trial-live-attenuated-zika-vaccine; https://www.nih.gov/news-events/news-releases/nih-partners-launch-hiv-vaccine-efficacy-trial-americas-europe.

[8] https://www.cdc.gov/flu/about/burden/index.html; https://www.nih.gov/news-events/news-releases/nih-begins-first-human-trial-universal-influenza-vaccine-candidate.

Cancer Immunotherapy

Cancer immunotherapy harnesses the power of the immune system of the patient to fight tumors, contributing to substantial reductions in cancer mortality. These treatments include engineered tumor-specific immune cells (adoptive cell therapy), therapies that restore cellular functional capacity to exhausted immune cells (checkpoint blockade), and vaccines to generate new immune responses against the tumor. In 2019, the FDA approved immunotherapies for several types of cancer, including breast, bladder, uterine, kidney, and esophageal.[9]

—*Adoptive Cell Therapy:* The success of chimeric antigen receptor T cells (CAR–T; T cells engineered to express novel receptors targeting specific tumor-associated molecules) in the treatment of B cell lymphomas has led to current NIH-funded clinical trials testing the efficacy of CAR–T cells in solid tumors, such as for patients with glioblastoma and pancreatic cancer.[10]

—*Checkpoint Blockade Therapy:* Recent advances in this area have provided substantial benefit in clinical trials to oncology patients with solid tumors, including melanoma, non-small-cell lung carcinoma, and glioblastoma.[11] Additional research efforts aim to increase the efficacy of this treatment by identifying combinatorial therapies and biomarkers of successful treatment.[12]

—*Vaccines:* An existing therapeutic vaccine targets prostate cancer, with ongoing clinical trials testing novel vaccines designed to combat multiple myeloma and breast cancer.[13] Additionally, meta-analyses of a decade of human papilloma virus (HPV) vaccinations have provided compelling evidence of the vaccine's efficacy and safety, leading to new efforts to reduce HPV-related cervical cancer.[14]

Ongoing NIH-funded research seeks to identify new opportunities to improve the efficacy of immuno-therapies for additional cancer types as well as exploring its use as a treatment for other life-threatening or debilitating conditions, including heart disease and autoimmune conditions.[15]

Vaping

Since 2007, the U.S. has seen an exponential increase in the use of e-cigarettes. In 2018, one in 20 middle school and one in five high school students was using e-cigarettes.[16] This increased use has resulted in an outbreak of e-cigarette or vaping associated lung injuries (EVALI), with nearly 3,000 cases of hospitalization or death.[17] Pathological analyses of lung injury patterns demonstrate extensive lung inflammation in these cases.[18] While inflammation—the immune system's response to injury—is usually a sign of healing, excessive inflammation for a prolonged period of time will cause lung damage that can be fatal. As a result, NIH is currently supporting research to investigate the pathogenesis of EVALI, including studies of especially vulnerable populations, such as those with allergies or asthma.[19]

NIH'S ESSENTIAL ROLE IN THE NATION'S—AND THE WORLD'S—BIOMEDICAL RESEARCH ENTERPRISE

As the nation's major funding agency for biomedical research, NIH supports more than 300,000 researchers at ~2,500 universities, medical schools, and other research institutions across the nation and inter-nationally,[20] as well as ~6,000 additional researchers and clinicians who work at NIH facilities around the country.[21] By supporting these researchers and laboratories, NIH funding strengthens state and local economies; in 2019, NIH funding supported more than 476,000 jobs and accounted

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[9] https://www.cancerresearch.org/immunotherapy/timeline-of-progress#.

[10] https://clinicaltrials.gov/ (NCT04003649, NCT02830724).

[11] https://www.ncbi.nlm.nih.gov/pubmed/30742122; https://www.ncbi.nlm.nih.gov/pubmed/30407895.

[12] https://www.ncbi.nlm.nih.gov/pubmed/31636208; https://www.ncbi.nlm.nih.gov/pubmed/30318169.

[13] https://www.cancer.gov/about-cancer/treatment/types/immunotherapy/cancer-treatment-vaccines; https://clinicaltrials.gov/ (NCT03376477, NCT00971737).

[14] https://www.ncbi.nlm.nih.gov/pubmed/31255301; https://www.ncbi.nlm.nih.gov/pubmed/31990905.

[15] https://www.ncbi.nlm.nih.gov/pubmed/31511695; https://www.ncbi.nlm.nih.gov/pubmed/31957209.

[16] https://www.cdc.gov/tobacco/basic_information/e-cigarettes/surgeon-general-advisory/index.html.

[17] https://www.cdc.gov/tobacco/basic_information/e-cigarettes/severe-lung-disease.html.

[18] https://www.hindawi.com/journals/cripu/2020/6138083/; https://pubs.rsna.org/doi/10.1148/radiol.2020192585.

[19] https://www.niaid.nih.gov/grants-contracts/vaping-and-lung-injury.

[20] https://www.nih.gov/about-nih/what-we-do/budget; https://report.nih.gov/award/index.cfm.

[21] https://irp.nih.gov/about-us/research-campus-locations.

for $81 billion in economic activity across the U.S.[22] NIH-funded basic research is also an essential and irreplaceable part of the biomedical research pipeline, leading to lifesaving and life-changing new drugs. In 2018, NIH-funded research contributed to all 210 of the new drugs approved by the FDA from 2010–2016.[23]

NIH also serves as an indispensable scientific leader both in the U.S. and internationally. The steward of nearly $42 billion in Federal funds, NIH keeps our nation's leaders apprised of scientific advancements and research priorities and works to ensure that taxpayer dollars are prudently spent. It oversees and establishes rules governing the conduct of scientific research and the research enterprise, working most recently to combat sexual harassment in science and address concerns about foreign influence in science.

NIH also plays an essential role in responding to emerging threats; during the current novel coronavirus pandemic, NIH is providing vital scientific expertise to the President, Congress, and the American public while supporting urgently needed efforts to develop treatments and a vaccine. In April, working in collaboration with the Foundation for the NIH (FNIH), NIH announced the formation of the Accelerating COVID–19 Therapeutic Interventions and Vaccines (ACTIV) partnership. This effort will bring together leading biopharmaceutical and biotech companies and government agencies "to develop an international strategy for a coordinated research response to the COVID–19 pandemic," including developing "a collaborative framework for prioritizing vaccine and drug candidates, streamlining clinical trials, coordinating regulatory processes and/or leveraging assets among all partners to rapidly respond to the COVID–19 and future pandemics." [24]

FUNDING INCREASES CONTINUE TO REBUILD NIH CAPACITY

Congress, led by this subcommittee, has invested robustly in NIH in recent years, including a $2.6 billion budget increase for fiscal year 2020. This increase has helped restore much of the purchasing power that NIH lost after years of inadequate budgets and erosion from biomedical research inflation; once more than 22 percent below its peak funding level (2003), the gap has eased to ~5.4 percent.[25] Meaningful budget growth remains necessary to close this gap and allow NIH to make needed investments in important research priorities across all NIH Institutes and Centers. Because the current cap on fiscal year 2021 nondefense discretionary spending could preclude the subcommittee from making this investment, AAI requests a budget cap exemption for NIH.

As the baby boom generation continues to retire, it is even more urgent to ensure a dynamic research environment that will allow for the training, development, and support of our next generation of researchers, doctors, professors, and inventors. Timely, robust funding increases for NIH would instill further confidence in all researchers, including these essential early- and mid-career researchers.

CONCLUSION

AAI greatly appreciates the subcommittee's strong support for NIH and urges an appropriation of at least $44.7 billion for fiscal year 2021. This funding level will provide needed growth across NIH, including for vital immunologic research, support meritorious scientists at all career stages, and help scientists discover ways to prevent, treat, and cure diseases that afflict people in the U.S. and around the world.

[This statement was submitted by Ross M. Kedl, Ph.D., American Association of Immunologists.]

PREPARED STATEMENT OF THE AMERICAN CHEMICAL SOCIETY

Dear Chairman Blunt and Ranking Member Murray:

The American Chemical Society (ACS) urges you to support robust funding for the National Institutes of Health (NIH) when the Labor, Health and Human Services, Education and Related Agencies appropriations bill is written. The work of the Na-

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[22] https://www.unitedformedicalresearch.org/wp-content/uploads/2019/04/NIHs-Role-in-Sustaining-the-US-Economy-FY19-FINAL-2.13.2020.pdf.

[23] https://directorsblog.nih.gov/2018/02/27/basic-research-building-a-firm-foundation-for-biomedicine/.

[24] https://www.nih.gov/news-events/news-releases/nih-launch-public-private-partnership-speed-covid-19-vaccine-treatment-options; Corey et al. A Strategic Approach to COVID–19 Vaccine R&D. Science. DOI: 10.1126/science.abc5312 (2020).

[25] https://crsreports.congress.gov/product/pdf/R/R43341.

tional Institute of General Medical Sciences (NIGMS), National Center for Advancing Translational Sciences (NCATS), and the National Institute of Biomedical Imaging and Bioengineering (NIBIB) is vital to advancing medical research and promoting the health of the American people, but remains unfamiliar to many Americans compared to disease-specific centers and institutes.

Through its research grants and fellowship programs, NIH also plays an integral role in attracting and training the young scientists and engineers who will help the United States remain a leader in medical research and technology. Investing in the NIH now ensures a future of well-trained scientists and continued medical advances to combat diseases and public health crises.

As an organization of over 150,000 chemical scientists and engineers, ACS understands the benefits of sustained, predictable funding for NIH to the research community. For example:

NIGMS, which has supported more than 50 Nobel laureates, funds high-quality, non-disease-specific basic research, laying the scientific foundation for an array of advances in disease prevention, diagnosis, and treatment used by other institutes. NIGMS funds the MIDAS (Models of Infectious Disease Agent Study) Coordination Center, which coordinates and facilitates infections disease modeling research. The MIDAS collaboration brings together more than 300 scientists conduct research on computational modeling to improve the detection, control, and prevention of emerging infectious diseases. In response to the COVID–19 pandemic, the coordinating center created a central online repository for the scientific community-a clearinghouse for sharing data and data-driven discoveries about COVID–19 to enable an extraordinary international collection of data and information regarding the outbreak.

NIBIB supports basic research and training through investigator-initiated grants, contracts, program project and center grants, and career development and training awards. The Institute also specializes in the development and application of cutting-edge technologies based upon engineering, mathematics, and the physical sciences for the solution of challenges intersecting biology and medicine such as the NIH Rapid Acceleration of Diagnostics (RADx) Initiative for COVID–19, which aims to rapidly develop and scale up testing for COVID–19.

NCATS focuses on ensuring that groundbreaking research from universities reaches the people who need it by streamlining the pipeline from basic research to applied research to medicines and techniques used in medicine. Furthermore, it is a partner in the National COVID Cohort Collaborative (N3C), an effort to pool COVID–19 clinical data to answer research questions and address the pandemic. NIGMS, NIBIB, and NCATS all contribute to the vibrant health and medical research community in the United States, and to the critical mission of NIH as a whole.

As the subcommittee completes its important work, please ensure robust support for all of the institutes of the NIH, and its mission of improving the health of the citizens of the United States. While recent events have highlighted the important work of institutes focused directly on infectious illnesses, scientific advancement in all facets of biomedical research depend on steady funding.

Sincerely.

[This statement was submitted by Glenn S. Ruskin, Vice President, External Affairs & Communications.]

PREPARED STATEMENT OF THE AMERICAN COLLEGE OF CARDIOLOGY

The American College of Cardiology (ACC) commends Congress for boosting funding for the National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC), and the Health Resources and Services Administration's (HRSA) Title VII and Title VIII programs in fiscal year 2020. The College also applauds the emergency supplemental funding appropriated for these agencies in response to the COVID–19 public health emergency, including $3.5 billion for the NIH and $7.5 billion for the CDC for vaccine research, preparedness, and surveillance. Since those with underlying conditions such as cardiovascular disease may be at higher risk for developing severe COVID–19 symptoms, ensuring robust funding for both pre-COVID and post-COVID projects across these agencies is essential in the months ahead. To continue this important progress in fiscal year 2021 and beyond, ACC urges members of Congress to appropriate the following funds toward agencies doing vital work in cardiovascular disease (CVD) treatment and prevention: $3.885 billion for the National Heart Lung & Blood Institute (NHLBI) and $2.621 billion toward the National Institute of Neurological Disorders & Stroke (NINDS) to increase the NIH's purchasing power and preserve U.S. leadership in research; $160 million toward the CDC's Division for Heart Disease and Stroke Prevention to strengthen heart disease prevention efforts at state and local levels, $5 million toward CDC's Million Hearts to prevent 1 million heart attacks and strokes by 2022, $46.7 million toward CDC's WISEWOMAN to help uninsured or under-insured women prevent or control heart disease, $10 million toward CDC congenital heart research to study its effects over the patient's lifespan, and $310 million toward CDC's Office on Smoking and Health to maintain the program's cost-effective tobacco control efforts. ACC asks for the inclusion of report language promoting HRSA's Title VII and Title VIII healthcare workforce diversity programs: The committee supports programs that improve the diversity of the healthcare workforce. HRSA's diversity pipeline programs, including the Health Careers Opportunity Program, Centers for Excellence, Faculty Loan Repayment, Nursing Workforce Diversity, and Scholarships for Disadvantaged Students help advance patient care and ensure opportunity for all healthcare providers.

ACC envisions a world where innovation and knowledge optimize cardiovascular care and outcomes. As the professional home for the entire cardiovascular team, the mission of the College and its more than 52,000 members is to transform cardiovascular care and improve heart health. The ACC bestows credentials upon cardiovascular professionals who meet stringent qualifications and leads in the formation of health policy, standards and guidelines. The College also provides professional medical education, disseminates cardiovascular research through its world-renowned JACC Journals, operates national registries to measure and improve care, and offers cardiovascular accreditation to hospitals and institutions.

CVD, a class of diseases that includes diseased blood vessels, structural problems, and blood clots, continues to be the leading cause of death among men and women in the United States and is responsible for 1 in every 4 deaths.[1] More than 92 million Americans currently suffer from some form of CVD—nearly one-third of the population—but it remains one of the most underfunded deadly diseases, as the NIH only invests 4 percent of its research dollars on heart research.[2] The heart disease death rate has continued to drop since the 1970s[3] due to scientific advances and improved heart medications and procedures—but to meet the challenges of an aging population, rising obesity rates and unhealthy diets, the NIH must maintain its place at the forefront of medical innovation for years to come. The NHLBI, the third-largest institute at the NIH, conducts research related to heart, blood vessel, lung, and blood diseases, generating drugs for lowering cholesterol, controlling blood pressure, and dissolving blood clots. These biomedical advancements have contributed to a 71 percent[4] decrease in death rates due to cardiovascular disease. NHLBI's recent groundbreaking research found that more intensive management of high blood pressure in people 50 years and older reduces cardiovascular events by almost 25 percent.[5] We recommend that NHLBI be funded at $3.885 billion to maintain current activities and investment toward new research and emerging technologies related to heart disease.

NINDS conducts research on brain and nervous system disorders, including stroke prevention and treatment. Coronary heart disease and stroke share many of the same risk factors such as high cholesterol levels, high blood pressure, smoking, diabetes, physical inactivity, and being overweight or obese. The NINDS Stroke Clinical Trials Network develops high-quality, multi-site clinical trials focused on key interventions in stroke prevention, treatment and recovery. We recommend that NINDS be funded at $2.621 billion to enhance its existing initiatives and explore new priorities in stroke prevention.

The CDC plays a vital role in protecting public health through healthy lifestyle promotion and educational activities designed to curb non-infectious diseases such as obesity, diabetes, stroke, and heart disease. The CDC Division for Heart Disease and Stroke Prevention supports efforts to improve cardiovascular health by promoting healthy lifestyles and behaviors, healthy environments, and access to early detection and affordable treatment. The division engages with local and state health departments, and a variety of other partners, to provide funding and resources, conduct research, track risk factors, and evaluate current programs and policies relat-

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[1] Heart Disease Facts; Centers for Disease Control and Prevention. https://www.cdc.gov/heartdisease/facts.htm.

[2] National Coalition for Heart and Stroke Research; American Heart Association. http://www.heart.org/HEARTORG/Advocate/IssuesandCampaigns/Research/National-Coalition-for-Heart-and-Stroke-Research__UCM__428347__Article.jsp#.Wt4h-m4vypo.

[3] Decline in Cardiovascular Mortality; National Library of Medicine. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5268076/.

[4,5] HHS/NIH/NHLBI Fiscal Year 2017 Congressional Justification Report; https://www.nhlbi.nih.gov/sites/default/files/media/docs/Final%20NHLBI%202017%20CJ__R508__v1__0.pdf.

ing to heart disease. We recommend that the CDC Division for Heart Disease and Stroke Prevention be funded at $160 million to continue its prevention activities among the most vulnerable communities.

Launched in 2012 and co-led by the CDC and the Centers for Medicare and Medicaid Services, the Million Hearts program coordinates and enhances CVD prevention activities with the objective of preventing 1 million heart attacks and strokes by the year 2022. The initiative aims to achieve this goal by encouraging the public to lead a healthy and active lifestyle, as well as improving medication adherence for aspirin and other medications to manage blood pressure, cholesterol, and smoking cessation. We recommend that Million Hearts be funded at $5 million to enhance efforts preventing heart attacks and strokes.

CDC's WISEWOMAN initiative provides more than 165,000 under-insured, low-income women ages 40–64 with services to help reduce heart disease and stroke risk factors. Heart disease ranks as the leading cause of death for women. Only 1 in 5 women[6] believes heart disease is her greatest health threat, and 11 percent[7] of women remain uninsured. We recommend that $46.7 million be allocated for WISEWOMAN to provide preventive health services, referrals to local healthcare providers, lifestyle programs, and counseling in all 50 states.

Congenital heart disease (CHD), a life-long consequence of a structural abnormality of the heart present at birth, is the number one birth defect in the U.S. While the diagnosis and treatment of CHD has greatly improved over the years, most patients with complex heart defects need special care throughout their lives, and only by expanding research opportunities can we fully understand the effects of CHD across the lifespan. As authorized by the Congenital Heart Futures Reauthorization Act of 2017, we recommend that the CDC National Center for Birth Defects and Developmental Disabilities be funded at $10 million for enhanced CHD surveillance and public health research.

Programs within CDC's Office on Smoking and Health (OSH) work to prevent smoking among young adults and eliminate tobacco-related health disparities in different population groups. In 2012, OSH launched the national tobacco education campaign, Tips from Former Smokers, which has motivated more than 5 million[8] people to quit smoking, with at least 400,000 quitting permanently.[9] While these programs have proven effective in tobacco cessation and prevention, more than 480,000 people still die every year from causes attributable to smoking, and 33 percent of those deaths stem from heart disease.[10] We recommend that OSH be funded at $310 million to continue leading the nation's efforts in preventing chronic diseases caused by tobacco use.

Treating and preventing chronic disease is dependent on robust healthcare workforce programs, which are vital given projections of severe physician shortages.[11] The HRSA Title VII and Title VIII training and enhancement grants help expand the primary care and nursing workforce to treat patients in rural and other underserved areas. We encourage HRSA to enhance its diversity workforce programs to address current and emerging healthcare quality and access challenges.

On behalf of our members who work to prevent and treat CVD, ACC would like to thank members of Congress for supporting medical innovation as we continue the fight against heart disease. Stable funding for medical research and healthy lifestyle promotion, as well as advancing our healthcare workforce will not only save lives, but save healthcare costs in the long term. Medical research nurtures economic growth by creating jobs and new technologies, which will produce billions of dollars in Medicare and Medicaid savings over the next decade. Please help us secure robust funding for NIH and CDC funding to protect the health of future generations.

[This statement was submitted by Athena Poppas, MD, FACC, President, American College of Cardiology.]

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[6] WISEWOMAN; Centers for Disease Control and Prevention. https://www.cdc.gov/wisewoman/.

[7] Women's Health Insurance Coverage; The Henry J. Kaiser Family Foundation. http://kff.org/womens-health-policy/fact-sheet/womens-health-insurance-coverage-fact-sheet.

[8,9] Office on Smoking and Health; Centers for Disease Control and Prevention. https://www.cdc.gov/tobacco/about/osh/.

[10] Smoking and Tobacco Use, Fast Facts; Centers for Disease Control and Prevention. https://www.cdc.gov/tobacco/data__statistics/fact__sheets/fast__facts/index.htm..

[11] New Findings Confirm Predictions on Physician Shortage, AAMC. https://www.aamc.org/news-insights/press-releases/new-findings-confirm-predictions-physician-shortage.

PREPARED STATEMENT OF THE AMERICAN COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS

The American College of Obstetricians and Gynecologists (ACOG), representing more than 60,000 physicians and partners dedicated to advancing women's health, is pleased to offer this statement to the Senate Committee on Appropriations, Subcommittee on Labor, Health and Human Services, Education, and Related Agencies. We thank Chairman Blunt, Ranking Member Murray, and the entire Subcommittee for this opportunity to provide comments on some of the most important programs to support and advance women's health.

ACOG commends Congress for making great strides to support research and data collection that advance the health of women and families. Looking ahead, we urge you to make funding of the following programs and agencies a priority in fiscal year 2021:

Safe Motherhood, Maternity and Perinatal Quality Collaboratives at Centers for Disease Control and Prevention (CDC):

The United States has the highest rate of maternal mortality and severe morbidity of any developed country. The Safe Motherhood Initiative at CDC works with state health departments to collect information on pregnancy-related deaths, gives technical assistance to maternal mortality review committees, tracks preterm births, and improves maternal outcomes through perinatal quality collaboratives. These data and initiatives are imperative to addressing the nation's maternal mortality and morbidity crisis. Important strides have been made as nearly every state currently has, is in the process of implementing, or is making plans to develop a state maternal mortality review committee. We must continue to build on this progress and improve maternal health outcomes. ACOG requests funding for the Safe Motherhood Initiative at $76 million, including $30 million to help states expand or establish maternal mortality review committees, and $2 million for state-based perinatal quality collaboratives.

Women's Health Research at the National Institutes of Health (NIH):

Women represent half of the U.S. population. As such, conditions and diseases that are specific to women's health, or those that present differently in women than men, must be a priority for federally funded research. Women's health research is a central part of the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)'s research mission and portfolio, and the Institute has achieved great success in advancing research on women's health throughout the life cycle; maternal, child, and family health; fetal development; reproductive biology; population health; and medical rehabilitation. With sufficient resources, NICHD can build upon its existing initiatives to produce new insights and solutions to benefit women and families. ACOG supports an appropriation of $44.7 billion for the National Institutes of Health (NIH) in fiscal year 2021, including $1.6 billion for NICHD. This amount would maintain a steady trajectory of a $3 billion annual increase for the NIH.

ACOG also supports the convening of a consensus conference at NIH to evaluate research currently underway related to women's health and identify priority areas for additional study to advance women's health research, including reproductive sciences.

ACOG also urges that additional funds appropriated to NIH pursuant to the COVID–19 response be directed to NICHD for research specific to COVID–19 and pregnancy. To date, no COVID–19 response funds have been directed to NICHD, limiting the Institute's ability to support critical and groundbreaking research on the impact of COVID–19 on pregnancy and pregnancy outcomes.

Advancing Maternal Therapeutics at the NIH:

Each year, more than 4 million women give birth in the United States and more than 3 million breastfeed. However, little is known about the effects of most drugs on the woman and her child. In 2015 as part of the 21st Century Cures Act (Sec. 2041 of Public Law 114–255), Congress created the Task Force on Research in Pregnant Women and Lactating Women (PRGLAC) to advise the Secretary of HHS on gaps in knowledge and research on safe and effective therapies for pregnant and breastfeeding women. In September 2018, PRGLAC produced a report to the Secretary outlining 15 recommendations to facilitate the inclusion of this population in clinical research. ACOG supports the implementation of these recommendations under the oversight of NICHD, working with other relevant NIH Institutes, the CDC, and the Food and Drug Administration, and urges Congress to express its continued support.

ACOG also urges the Committee to ensure that additional funds appropriated to support vaccine development pursuant to the COVID–19 response encourage the inclusion of pregnant and breastfeeding women, including women of color. Pregnant and breastfeeding women are currently excluded from these trials, placing them at risk of exclusion from eventual immunization or treatment recommendations.

Title X Family Planning Program at Health Resources and Services Administration (HRSA):

Family planning and pre-pregnancy care are imperative to ensuring healthy women and healthy pregnancies. The Title X Family Planning Program provides essential services to over 4 million low income men and women who may not otherwise have access to these services. For many individuals, particularly those who are low-income, uninsured, or adolescents, Title X is essential to their ability to affordably and confidentially obtain birth control, cancer screenings, STI tests and other basic care. From 2010–2016, Title X funding was cut by $31 million, despite an increase of 1.5 million women in need of publicly funded family planning services over the same period. ACOG requests $400 million for Title X in fiscal year 2021 to ensure individuals in need have access to evidence-based care.

ACOG is also deeply concerned about the impact of the Title X program rule, which has caused more than 1.5 million patients to lose access to medically accurate, comprehensive Title X-funded services, and urges Congress to show its strong support for women's health by not only funding this critical program but ensuring that no funds are used to implement the harmful final rule.

Title V Maternal and Child Health Block Grant at HRSA:

The Title V Maternal and Child Health (MCH) Block Grant at HRSA is a critical Federal program exclusively focused on improving the health of mothers and children. The Block Grant is a cost-effective, accountable, and flexible funding source used to address critical, pressing, and unique needs of maternal and child health populations in each state, territory and jurisdiction. Notably, through the Special Projects of Regional and National Significance (SPRANS) discretionary grant, the Block Grant supports the Alliance for Innovation on Maternal Health (AIM)—a program that works with states and hospital systems to implement evidence-based toolkits, or bundles, to improve maternal outcomes and reduce rates of maternal mortality and severe morbidity. ACOG requests at least $715 million for fiscal year 2021 to respond to the increased demands placed on the Block Grant, including $15 million within SPRANS to support continued implementation of AIM.

Investing in Data and Quality at the Agency for Healthcare Research and Quality (AHRQ):

AHRQ is the Federal agency with the sole purpose of improving healthcare quality. AHRQ produces data with the mission of making healthcare safer, higher quality, more accessible, equitable, and affordable. AHRQ works with HHS and other partners to ensure that the evidence improves patient safety. ACOG supports $471 million for AHRQ in fiscal year 2021, which is consistent with the fiscal year 2010 funding level for the agency adjusted for inflation.

Public Health Surveillance at CDC:

Uniform, accurate, and comprehensive data is essential for addressing the rising rates of maternal mortality and severe maternal morbidity in the United States. Unfortunately, the nation's public health data systems are antiquated, lack interoperability and data and reporting standards, and are in dire need of security updates. The COVID–19 pandemic has demonstrated the shortcomings of these systems and the need for a robust public health infrastructure. ACOG urges Congress to demonstrate its commitment to public health surveillance and requests funding be used to modernize these systems to improve America's health. ACOG requests $100 million in fiscal year 2021 to implement advanced technologies and train the next generation of data scientists.

Firearm Morbidity and Mortality Prevention (CDC and NIH):

In 2017, there were more than 39,000 U.S. firearm-related fatalities. federally funded public health research has a proven track record of reducing public health-related deaths, whether from motor vehicle crashes, smoking, or Sudden Infant Death Syndrome. This same approach should be applied to increasing gun safety and reducing firearm-related injuries and deaths, and CDC research will be as critical to that effort as it was to these previous public health achievements. The foundation of a public health approach is rigorous research that can accurately quantify and describe the facets of an issue and identify opportunities for reducing its related morbidity and mortality. For fiscal year 2021, ACOG requests $50 million, shared evenly between CDC and NIH, to conduct public health research into firearm morbidity and mortality prevention.

Diagnosing and Treating Maternal Depression (HRSA):

About 1 in 5 women experience maternal depression, and ACOG recommends that all patients be screened, yet women face barriers to accessing treatment. ACOG commends Congress for fully funding Sec. 10005 of Public Law 114–255 to support the establishment of a program at HRSA to expand depression screening and treatment for pregnant and postpartum women. ACOG urges you to again fully fund the program at $5 million for fiscal year 2021.

Advancing Women's Health During the COVID–19 Pandemic:

ACOG commends Congress for its swift response to the COVID–19 pandemic through appropriations to support the nation's public health response. This response, however, must not harm ongoing efforts to advance women's health. ACOG urges Congress to provide additional emergency funding to address the public health emergency or adjust the fiscal year 2021 budget caps to allow for continued response to the public health and medical needs of women, including pregnant and postpartum women. Without these adjustments, Congress risks compounding the harm of the pandemic by abandoning successful initiatives that advance women's health.

Thank you again for the opportunity to submit our recommendations to the Subcommittee, and for your commitment to improving women's health.

[This statement was submitted by Rachel Tetlow, Federal Affairs Director.]

PREPARED STATEMENT OF THE AMERICAN COLLEGE OF PHYSICIANS

The American College of Physicians (ACP) is pleased to submit the following statement for the record on its priorities, as funded under the U.S. Department of Health & Human Services, for fiscal year 2021. ACP is the largest medical specialty organization and the second-largest physician group in the United States. ACP members include 159,000 internal medicine physicians (internists), related subspecialists, and medical students. Internal medicine physicians are specialists who apply scientific knowledge and clinical expertise to the diagnosis, treatment, and compassionate care of adults across the spectrum from health to complex illness. As the Subcommittee begins deliberations on appropriations for fiscal year 2021, ACP is urging funding for the following proven programs to receive appropriations from the Subcommittee:

—Health Resources Services Administration (HRSA), $8.8 billion;

—Title VII, Section 747, Primary Care Training and Enhancement (PCTE), Health Resources and Services Administration (HRSA), $71 million;

—National Health Service Corps (NHSC), $860 million in total program funding;

—Agency for Healthcare Research and Quality (AHRQ), $471 million;

—Centers for Medicare and Medicaid Services (CMS), Program Operations for Federal Exchanges, $268.9 million;

—Centers for Disease Control and Prevention (CDC), $8.3 billion, Injury Prevention and Control, Research on Prevention of Firearms-related Injuries and Deaths, $50 million;

—Public Health and Social Services Emergency Fund (PHSSEF); highest possible funding level over the fiscal year 2020 $2.7 billon enacted level;

—National Institutes of Health (NIH), $44.7 billion.

The United States is facing a shortage of physicians in key specialties, notably in general internal medicine and family medicine-the specialties that provide primary care to most adult and adolescent patients. Current projections indicate there will be a shortage of 21,100 to 55,200 primary care physicians by 2032. Without critical funding for vital workforce programs, this physician shortage will only grow worse. HRSA is responsible for improving access to health-care services for people who are uninsured, isolated or medically vulnerable. Without critical funding for vital workforce programs, this physician shortage will only grow worse. A strong primary care infrastructure is an essential part of any high-functioning healthcare system, with over 100 studies showing primary care is associated with better outcomes and lower costs of care. Therefore we urge the Subcommittee to provide $8.8 billion for HRSA programs for fiscal year 2021 to improve the care of medically underserved Americans by strengthening the health workforce.

The health professions' education programs, authorized under Title VII of the Public Health Service Act and administered through HRSA, support the training and education of healthcare providers to enhance the supply, diversity, and distribution of the healthcare workforce. Within the Title VII program, we urge the Subcommittee to fund the Section 747 PCTE program at $71 million, in order to maintain and expand the pipeline for individuals training in primary care. While the College appreciates the $10 million increase to the program in fiscal year 2018, ACP urges more funding because the Section 747 PCTE program is the only source of Federal training dollars available for general internal medicine, general pediatrics, and family medicine. For example, general internists, who have long been at the frontline of patient care, have benefitted from PCTE training models emphasizing interdisciplinary training that have helped prepare them to work with other health professionals.

The College urges at least $860 million in total program funding for the NHSC. For fiscal year 2021, the NHSC's funding situation is particularly dire and faces a funding cliff because its mandatory funding is set to expire. In fiscal year 2020, the NHSC received $120 million in discretionary funding to expand and improve access to quality opioid and substance use disorder treatment in underserved areas, in addition to $310 million in mandatory funds. The NHSC awards scholarships and loan repayment to healthcare professionals to help expand the country's primary care workforce and meet the healthcare needs of underserved communities across the country. In fiscal year 2019, with a field strength of over 13,000 primary care clinicians, NHSC members are providing culturally competent care to over 13 million patients at over 17,000 NHSC-approved healthcare sites in urban, rural, and frontier areas. These funds would help maintain NHSC's field strength helping to address the health professionals' workforce shortage and growing maldistribution. There is overwhelming interest and demand for NHSC programs, and with more funding, the NHSC could fill more primary care clinician needs. In fiscal year 2016, there were 2,275 applications for the scholarship program, yet only 205 new awards were made. There were 7,203 applications for loan repayment and only 3,079 new awards. Accordingly, ACP urges the subcommittee to double the NHSC's overall program funding to $860 million to meet this need.

AHRQ is the leading public health service agency focused on healthcare quality. AHRQ's research provides the evidence-based information needed by consumers, clinicians, health plans, purchasers, and policymakers to make informed healthcare decisions. The College is dedicated to ensuring AHRQ's vital role in improving the quality of our nation's health and recommends a budget of $471 million, restoring the agency to its fiscal year 2010 enacted level adjusted for inflation. This amount will allow AHRQ to help providers help patients by making evidence-informed decisions, to fund research that serves as the evidence engine for much of the private sector's work to keep patients safe, to make the healthcare marketplace more efficient by providing quality measures to health professionals, and, ultimately, to help transform health and healthcare.

ACP supports at least $268.9 million in discretionary funding for Federal exchanges within CMS' Program Operations, which has been funded at $2.8 billion in fiscal year 2020. This funding would allow the Federal Government to continue administering the insurance marketplaces, as authorized by the Affordable Care Act, if a state has declined to establish an exchange that meets Federal requirements. CMS now manages and operates some or all marketplace activities in over 30 states. Without these funds it will be much more difficult for the Federal Government to operate and manage a federally-facilitated exchange in those states, raising questions about where and how their residents would obtain and maintain coverage.

The Center for Disease Control and Prevention's mission is to collaborate to create the expertise, information, and tools needed to protect their health-through health promotion, prevention of disease, injury, and disability, and preparedness for new health threats. ACP supports $8.3 billion overall for this mission, especially in light of the COVID–19 national emergency. The College also supports $50 million for the CDC's Injury and Prevention Control to fund research on prevention of firearms-related injuries and deaths and support 10 to 20 multi-year studies to continue to rebuild lost research capacity in this area.

As the Federal Government responds to COVID–19, ACP supports the highest possible funding level for the PHSSEF in fiscal year 2021 over the $2.7 billion enacted in fiscal year 2020 for the Assistant Secretary for Preparedness and Response to continue efforts to research, prevent, control, and treat of illnesses associated with the SARS-CoV–2 virus through the National Disaster Medical System, the Strategic National Stockpile, the Hospital Preparedness Program, Biomedical Advanced Research and Development Authority, and Medical Reserve Corps. PHSSEF funding is crucial in providing personal protective equipment (PPE) to the physicians and other clinicians on the frontlines of the COVID–19 outbreak. The PHSSEF must be funded adequately enough to maintain a robust pandemic response, especially when emergency supplemental funds are no longer available.

Lastly, the College strongly supports $44.7 billion for NIH in fiscal year 2021 so the nation's medical research agency continues making important discoveries that treat and cure disease to improve health and save lives and that maintain the United States' standing as the world leader in medical and biomedical research.

The College greatly appreciates the support of the Subcommittee on these issues and looks forward to working with Congress on the fiscal year 2021 appropriations process.

[This statement was submitted by Jared Frost, Senior Associate, Legislative Affairs, American College of Physicians.]

PREPARED STATEMENT OF THE AMERICAN COLLEGE OF PREVENTIVE MEDICINE

The American College of Preventive Medicine (ACPM) urges the Senate Labor, Health and Human Services, Education, and Related Agencies Appropriations Subcommittee to support training for preventive medicine physicians and other public health professionals by providing $23.359 million in fiscal year 2020 to the Heath Resources and Services Administration (HRSA) for the Public Health and Preventive Medicine line item in Title VII of the Public Health Service Act.

In today's healthcare environment, especially during the COVID–19 pandemic, the tools and expertise provided by preventive medicine physicians play an integral role in ensuring the effective functioning of our nation's public health system. These tools and skills include the ability to deliver evidence-based clinical preventive services, expertise in population-based health sciences, and knowledge of the social and behavioral determinants of health and disease. These are the tools employed by preventive medicine physicians who practice at the health system level where improving the health of populations, enhancing access to quality care, and reducing the costs of medical care are paramount. As the body of evidence supporting the effectiveness of clinical and population-based interventions continues to expand, so does the need for specialists trained in preventive medicine.

Organizations across the spectrum have recognized the growing demand for preventive medicine professionals. The Institute of Medicine released a report in 2007 calling for an expansion of preventive medicine training programs by an "additional 400 residents per year," and the Accreditation Council on Graduate Medical Education (ACGME) recommends increased funding for preventive medicine residency training programs.

Preventive medicine is the only one of the 24 medical specialties recognized by the American Board of Medical Specialties that requires and provides training in both clinical and population-based medicine. Preventive medicine residency training programs provide a blueprint on how to train our future physician workforce; physicians trained to provide individual patient care needs as well as practice at the community and population level to identify and treat the social determinants of health. Preventive medicine physicians have the training and expertise to advance the population health outcomes that public and private payers are increasingly promoting to their providers. These physicians have a strong focus on quality care improvement and are at the forefront of efforts to integrate primary care and public health.

According to HRSA, and health workforce experts, there are personnel shortages in many public health occupations, including epidemiologists, biostatisticians, and environmental health workers among others. According to the 2018 Physician Specialty Data Book released by the Association of American Medical Colleges, preventive medicine is one of only six specialties that saw a decrease in the number of active physicians between 2012 and 2017. This represents a worsening trend in the number of preventive medicine physicians in the field that is not due to a lack of interest or need, but is due to a lack of funding. Nearly 70 percent of preventive medicine physicians are over age 55, and the funding gaps mean that there are not enough entering the field to make up for the current and expected future shortage. ACPM is deeply concerned about the shortage of preventive medicine-trained physicians and the ominous trend of even fewer training opportunities. This deficiency in physicians trained to carry out core public health activities will lead to major gaps in the expertise needed to deliver clinical prevention and community public health services. The impact on the health of those populations served by HRSA is likely to be profound.

Despite being recognized as an underdeveloped national resource and in shortage for many years, physicians training in the specialty of Preventive Medicine are the only medical residents whose graduate medical education (GME) costs are not supported by Medicare, Medicaid or other third party insurers. Training occurs outside hospital-based settings and therefore is not financed by GME payments to hospitals. Both training programs and residency graduates are rapidly declining at a time of unprecedented national, state, and community need for properly trained physicians in public health, disaster preparedness, prevention-oriented practices, quality improvement, and patient safety.

Currently, residency programs scramble to patch together funding packages for their residents. Support for faculty and tuition has been almost non-existent. Directors of residency programs note that they receive many inquiries about and applications for training in preventive medicine; however, training slots often are not available for those highly qualified physicians who are not directly sponsored by an outside agency or who do not have specific interests in areas for which limited stipends are available (such as research in cancer prevention). HRSA—as authorized in Title VII of the Public Health Service Act—is a critical funding source for several preventive medicine residency programs, as it represents the largest Federal funding source for these programs.

Of note, the preventive medicine residency programs directly support the mission of the HRSA health professions programs by facilitating practice in underserved communities and promoting training opportunities for underrepresented minorities:

—Seventy-seven percent of HRSA-supported preventive medicine graduates practice in medically underserved communities.

—Nearly half of preventive medicine training sites funded through HRSA programs were are located in medically underserved communities.

In addition to training under-represented minorities and physicians who work in medically underserved areas, preventive medicine residency programs equip our society with health professionals and public health leaders who possess the tools and skills needed in the fight against the chronic disease epidemic that is threatening the future of our nation's health and prosperity. Chronic diseases currently cost the U.S. billions of dollars per year, including heart disease and stroke ($315.4 billion per year), diabetes ($245 billion per year), and obesity-related diseases ($145 billion per year). Correcting the root causes of this critical problem of chronic diseases will require a multidisciplinary approach that addresses issues of access to healthcare; social and environmental influences; and behavioral choices. Any efforts to strengthen the public health infrastructure and transform our communities into places that encourage healthy choices must include measures to strengthen the existing training programs that help produce public health leaders.

Further, expanding the preventive medicine workforce strengthens the disaster preparedness capabilities we must have to ensure our nation's health security. Vulnerable populations, including those in poor health, with disabilities, and chronic diseases are at an increased risk of adverse health outcomes resulting from natural disasters. New threats are always on the horizon and some, like the Zika virus, require preventive medicine specialists working to find ways to stop the spread before it becomes an epidemic.

Many of the leaders of our nation's local and state health departments are trained in preventive medicine. Their unique combination of expertise in both medical knowledge and public health makes them ideal choices to head the fight against chronic disease as well as other threats to our nation's health, such as the opioid epidemic. Their contributions are invaluable. Investing in the residency programs that provide physicians with the training and skills to take on these leadership positions is an essential part of keeping Americans healthy and productive. As such, the American College of Preventive Medicine urges the Labor, Health and Human Services, Education, and Related Agencies Appropriations Subcommittee to reaffirm its support for training preventive medicine physicians and other public health professionals by providing $23.359 million in fiscal year 2021 to HRSA for the Public Health and Preventive Medicine line item in Title VII of the Public Health Service Act.

[This statement was submitted by Kate McFadyen, Director, Government Affairs.]

PREPARED STATEMENT OF THE AMERICAN COLLEGE OF SURGEONS

Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee, on behalf of the more than 82,000 members of the American College of Surgeons (ACS), thank you for the opportunity to submit written testimony addressing fiscal year 2021 appropriations. The ACS is a scientific and educational organization of surgeons that was founded in 1913 to raise the standards of surgical practice and improve the quality of care for all surgical patients. The College is dedicated to the ethical and competent practice of surgery. Its achievements have significantly influenced the course of scientific surgery in America and have established it as an important advocate for all surgical patients.

The ACS respectfully requests your consideration of the following priorities as the Subcommittee works through the annual appropriations process for fiscal year 2021:

MISSION ZERO Military and Civilian Partnership for the Trauma Readiness Grant Program

Trauma, including car crashes, falls, head injuries, burns, and firearm injuries, is the leading cause of death in America for those ages 44 and younger and accounts for more years of life lost and disability than any other disease, including cancer and heart disease. Unfortunately, nearly 45 million Americans live in areas more than an hour away from either a Level I or II trauma center. Ensuring access to trauma care requires many crucial components including trauma centers and appropriately trained physicians and nurses, all of which must dedicate extensive resources around the clock so that seriously injured patients have the best possible chance for survival.

In 2016, the National Academies of Science, Engineering, and Medicine (NASEM) released a report titled, "A National Trauma Care System: Integrating Military and Civilian Trauma Systems to Achieve Zero Preventable Deaths After Injury." This report suggests one of four military trauma deaths and one of five civilian trauma deaths could be prevented if advances in trauma care reach all injured patients. The report concludes that military and civilian integration is critical to saving these lives both on the battlefield and at home, preserving the hard-won lessons of war, and maintaining the nation's readiness and homeland security.

The MISSION ZERO Act was signed into law on June 24th, 2019 as part of S. 1279, the Pandemic and All Hazards Preparedness and Advancing Innovation (PAHPAI) Act (Public Law No: 116–22). MISSION ZERO takes the recommendations of the NASEM report to create a U.S. Department of Health and Human Services (HHS) grant program to cover the administrative costs of embedding military trauma professionals in civilian trauma centers. These military-civilian trauma care partnerships will allow military trauma care teams and providers to gain exposure to treating critically injured patients and increase readiness for when these units are deployed. Similarly, best practices from the battlefield are brought home to further advance trauma care and provide greater civilian access.

By facilitating the implementation of military-civilian trauma partnerships, this program will preserve lessons learned from the battlefield, translate those lessons to civilian care, and ensure service members maintain their readiness to deploy in the future. The ACS strongly supports the funding of MISSION ZERO at the authorized amount of $11.5 million for fiscal year 2021.

Funding for Cancer Research and Prevention

The ACS and the Commission on Cancer (CoC) are dedicated to improving survival and quality of life for cancer patients through advocacy of issues pertaining to prevention and research. To continue the progress that has led to medical breakthroughs for treatment therapies for millions of cancer patients, the ACS and CoC support the following funding increases for fiscal year 2021.

The budget of the National Institutes of Health (NIH) should be increased to at least $44.7 billion (a $3 billion increase), including $6.9 billion for the National Cancer Institute (NCI). The ACS also urges the inclusion of $555 million for cancer control and prevention programs and $70 million for the National Program of Cancer Registries (NPCR) through the Centers for Disease Control and Prevention (CDC).

Additionally, the ACS asks you to consider the inclusion of the following report language recognizing the importance of the American College of Surgeons Cancer Programs, which benefit an array of healthcare professionals, patients, and facilities through standard-setting, accreditation, and educational activities.

Quality Care for Cancer.—The Committee recognizes the importance of voluntary accreditation by the American College of Surgeons Cancer Programs, which provide tools, resources, and data to enable cancer programs to deliver comprehensive, high-quality, multidisciplinary, evidence-based, patient-centered care to patients with cancer and diseases of the breast. This voluntary accreditation program includes several key modules, including those focused generally on cancer, breast cancer and diseases of the breast, rectal cancer, and data sharing and performance accountability. The Committee applauds the work of the American College of Surgeons Cancer Programs and encourages facilities to seek its accreditation to support performance evaluation and inform quality care improvements.

Firearm Morbidity and Mortality Prevention Research

The ACS supports an appropriations request of $50 million specifically for public health research into firearm morbidity and mortality prevention through the CDC for fiscal year 2021.

Federally funded research from the perspective of public health has contributed to reductions in motor vehicle crashes, smoking, and Sudden Infant Death Syndrome (SIDS). ACS believes a similar approach could reduce firearm-related injuries and deaths in our communities.

Repeal the Ban on UPI

A Unique Patient Identifier (UPI) would help to ensure that surgeons have a more accurate and consistent means of linking patients to their health information across the continuum of care. Repealing the twenty-year prohibition on the use of Federal funds to establish a national UPI would provide HHS with the ability to evaluate a range of patient identification solutions, enabling the agency to explore potential challenges and identify cost-effective, scalable, and secure solutions that protect patient privacy. The ACS supports removal of the ban in Section 510 that prohibits HHS from spending any Federal dollars to promulgate or adopt a unique patient identifier (UPI).

Thank you for your consideration of our requests. Please contact Amelia Suermann, ACS Congressional Lobbyist, at asuermann@facs.org if you have any questions or would like additional information.

PREPARED STATEMENT OF THE AMERICAN DENTAL ASSOCIATION

On behalf of the American Dental Association (ADA) and our more than 163,000 members, thank you, Chairman Blunt, Ranking Member Murray and members of the Subcommittee for the opportunity to submit testimony in support of Federal agencies and programs that work to expand access to oral healthcare. Within the Department of Health and Human Services, the American Dental Association is requesting for fiscal year 2021 (fiscal year 2021), $29 million for the Centers for Disease Control and Prevention (CDC) Division of Oral Health; $40 million for the Health Resources and Services Administration (HRSA) Oral Health Workforce Development, including $24 million for Pediatric and General Dental Residency programs; and $512 million for the National Institute of Dental and Craniofacial Research (NIDCR) in the National Institutes of Health (NIH). COVID–19 has highlighted the need for a strong public health infrastructure. The following programs and efforts are important to the foundation and future of oral health and dental care.

ACTION FOR DENTAL HEALTH ACT

The ADA applauds Congress for the passage of the Action for Dental Health (ADH) Act to help ensure greater access to dental care for all Americans. As you weigh ADA's funding requests for CDC and HRSA, please consider ADH (Public Law 115–302, section 3) among the programs that additional funding would support. The new law allows the CDC Division of Oral Health and HRSA Oral Health Workforce Development program to expand their roles in dental prevention, education, and continuity of care in underserved communities. These efforts would include initiatives such as the Community Dental Health Coordinator (CDHC) and Emergency Department (ED) Referral programs. CDHCs are community health workers who are members of the dental team. CDHCs provide oral health prevention and education, care coordination, and patient navigation services to people in underserved urban, rural, and Native American communities. CDHCs serve in numerous community settings including, health centers, private practices, schools and Head Start programs. In a post-pandemic future, the role of CDHCs is even more critical to help families reconnect with their dentists and re-establish their dental treatment routines. CDHCs also play an important role in keeping patients out of the ED by connecting them to other sources of care. In 2017, there were 2.1 million visits to EDs for dental-related reasons, at a cost of $2.7 billion.[1] There are seven different ED referral program models where the EDs form alliances with graduate dental education programs, non-profit agencies, community health centers, and/or private dental practices. By referring patients to an ongoing and comprehensive source of dental treatment, these programs are reducing costs and helping to decrease opioid abuse.

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[1] American Dental Association Health Policy Institute. Emergency Department Visits for Dental Conditions-A Snapshot. https://www.ada.org/en/science-research/health-policy-institute/publications/infographics?utm__source=adaorg&utm__medium=hpifeaturedbox&utm__content=infographics.

CDC DIVISION OF ORAL HEALTH ($29 MILLION)

The CDC Division of Oral Health is a much needed and highly valued source of support for state health departments to help reduce oral health disparities through evidence-based community preventive interventions and access to clinical preventive services. The Division's investment in programs like oral health surveillance, community water fluoridation, school-based dental sealant programs, and oral health literacy has helped to significantly reduce the incidence of oral disease among children and adults. In order to expand the Division's capacity and outreach, more funding is needed to support additional states with the infrastructure to develop and implement policies and programs to prevent or minimize oral disease. Currently 20 states, including Alabama and New Mexico, which have some of the highest poverty rates, have never received funding from the Division of Oral Health. Additional funding would provide these states with the capacity and infrastructure needed to translate health promotion and disease prevention approaches into effective policies and healthcare practices where all Americans benefit. Also, the Division's contributions in the CDC response to COVID–19 has guided the dental community through the uncertainty of the nation's public health emergency. The dental community continues to look to the CDC and the Division of Oral Health for further guidance as states begin to reopen.

HRSA—TITLE VII, GENERAL AND PEDIATRIC DENTAL RESIDENCY PROGRAMS ($24 MILLION)

Within the amount requested for HRSA's Oral Health Workforce Development Program, the ADA requests $24 million for Title VII—General and Pediatric Dental Residencies. This amount includes funding for the Dental Faculty Loan Repayment Program. Title VII is the only Federal program focused on improving the supply, distribution, and diversity of the dental profession workforce. By providing advanced training opportunities to oral health professionals, the program plays a critical role in helping the workforce adapt to meet the nation's changing healthcare needs. We are pleased that Congress understands the importance of this program and the impact that it has on medically underserved communities.

HRSA—CHIEF DENTAL OFFICER

The ADA believes that HRSA needs a leading voice on oral health to oversee and lead all oral health programs and initiatives across the agency. In 2012, the Chief Dental Officer (CDO) position was downgraded to a senior dental advisor and moved several layers below HRSA leadership without appropriate staff or resources. This occurred despite the Administration's commitment in 2010 to establish the Oral Health Initiative, which highlighted several HRSA programs to improve access to oral healthcare, especially for underserved populations. We thank the Subcommittee for its strong support directing HRSA to reinstate the CDO with executive level authority. However, while the title was restored in 2017, the function of the position remains unchanged. We urge the Subcommittee to direct HRSA to fully restore this position with the appropriate duties of a chief dental officer.

NIH—NIDCR ($512 MILLION)

We extend our gratitude to Congress for supporting NIDCR research over the years. Because of your efforts, NIDCR continues to conduct and support research on some of our nation's most pressing public health issues contributing to better oral and overall health for all Americans. Those efforts include contributing to the knowledge base on pain biology and management, including non-opioid treatments for pain; salivary diagnostics; and the social, behavioral, and genetic underpinnings of oral health disparities. The COVID–19 pandemic has been a stark reminder of the crucial role that biomedical and public health research play in our society. The research enterprise is essential to safeguarding public health, national security, economic growth and competitiveness in global scientific leadership. While research institutions are understandably concentrating on coronavirus-related research, most other research has been scaled back or stopped entirely due to pandemic-induced closures of university campuses and laboratories. The longer this pandemic continues, the more harm and strain it will cause to our nation's research workforce and capabilities; sustaining its strength will be vital if the United States is to remain a leader in global research and in its ability to respond to future public health crises. This funding request—in addition to our emergency supplemental request of $170 million and $90 million—would help restore NIDCR research to pre-pandemic levels and help align the agency's research agenda to reflect the new reality of

COVID–19 and the impact it will have on the practice of dentistry and oral health. We respectfully request your continued support for NIDCR.

Chairman Blunt and Ranking Member Murray, thank you for the opportunity to share with you and the Subcommittee the importance of access to dental care and the programs needed to help meet the nation's changing oral healthcare needs. We understand the difficult task you face as you put together the fiscal year 2021 Labor-HHS-Education-Appropriations bill in the current environment of tight budget constraints while dealing with a public health crisis. The ADA looks forward to working with the Subcommittee in maintaining oral health as a priority in healthcare.

PREPARED STATEMENT OF THE AMERICAN DENTAL EDUCATION ASSOCIATION

The American Dental Education Association (ADEA) represents all 68 U.S. dental schools, more than 1,000 allied and advanced dental education programs, over 60 corporate partners and more than 20,000 individuals. ADEA submits this testimony on the Departments of Health and Human Services, Education and Related Agencies budget for the record and for your consideration as you begin prioritizing fiscal year 2021 appropriation requests.

According to the Health Resources and Services Administration (HRSA), 59 million Americans live in one of the nearly 6,319 dental care Health Professional Shortage Areas (HPSAs). To close this gap, HRSA estimates that over 10,495 new practitioners are needed.

Dental schools have suffered the same challenges that other health profession education institutions have faced related to the coronavirus pandemic. ADEA is grateful for the support from the Committee on Appropriations and the Congress in establishing the Providers Relief Fund and look forward to working with you further to address the infrastructure and modernization needs that will be required as we move toward reopening our facilities and dental clinics.

Before these schools and programs can fully reopen for patient care, most will require some modification to clinic spaces and protocols. For dental students, patient care experience is obtained in dental clinics, which are in all dental schools. These clinics must include most of the major service areas of a hospital and adhere to the rigorous guidelines that protect the health and safety of the public, much like hospitals do. Dental schools operate full clinical facilities with all the necessary treatment rooms and surgical suites, including areas for sterilization, diagnostic services such as radiology and pathology, and business operations. In contrast, medical schools conduct the majority of their clinical teaching and training in separate hospitals or affiliated academic health centers and do not require the stringent protective guidelines in their education buildings that are in place at dental school clinics.

Many dental schools are part of the same campus as the medical schools which are often in underserved communities. Dental schools also exist within Minority Serving Institutions.

During this crisis, some dental school clinics have been retrofitted to accommodate hospital beds to assist the academic medical centers, which are operating above capacity. Also, dental faculty and residents who remain on campus to treat dental emergencies have volunteered in many medical centers or hospitals to evaluate patients coming to the ER and perform other duties within their scope of practice (administering COVID–19 tests, for instance).

Dental schools are part of their local communities' healthcare safety net and are a valuable untapped healthcare resource that could be used at this time, and in future pandemics. Dental school clinics serve the same geographic patient populations as their medical colleagues, providing care at reduced rates. A large number of the individuals who receive dental care in these clinics are members of underserved populations and do not have private insurance or the ability to pay private practice fees.

As you deliberate funding for fiscal year 2021, ADEA respectfully urges your support for the following funding requests.

$40.7 million: Title VII, Section 748, Public Health Service Act

The dental programs in Title VII provide critical education for pre-doctoral dental and dental hygiene students and training for post-doctoral residents in general, pediatric and public health dentistry. Support for these programs will help ensure an adequately prepared and culturally competent dental workforce. The funding supports the investment made by Title VII in educating dentists, dental therapists, dental hygienists, dental assistants and dental laboratory technicians. The program also expands access to care for underserved areas in community-based settings located in HPSAs.

HRSA programs address the dental school faculty shortage with Dental Faculty Development and Dental Faculty Loan Repayment Program grants to those who teach pediatric, general or public health dentistry, and dental hygiene. Currently, more than 250 open, budgeted faculty positions exist in dental schools. These programs assist schools with recruiting and retaining faculty. Additionally, ADEA is increasingly concerned that the dental research community will not be able to attract and grow the pipeline of new researchers into academic dental institutions without this support and recognition of its importance.

Title VII Diversity and Student Aid programs play a critical role in ensuring the future health profession workforce reflects the nation's changing demographics. For the last several years, these programs have not received adequate funding to sustain the progress necessary to meet the challenges of an increasingly diverse U.S. population.

The Health Careers Opportunity Program (HCOP) provides a vital source of support for dental professionals serving underserved and disadvantaged patients by providing a pipeline for individuals from these populations. This unique workforce program encourages young people from diverse and disadvantaged backgrounds to explore careers in healthcare generally, and dentistry specifically. ADEA and the Association of American Medical Colleges, through the funding of the Robert Wood Johnson Foundation, operate the Summer Health Professions Education Program (SHPEP), a six-week academic enrichment program for rising college sophomores and juniors from historically underrepresented (HUR) populations who are interested in the health professions. A study of participants from 2006 to 2015 found that 65 percent applied to dental school and, as of 2015, 589 have graduated from dental school. These pipeline programs are effective in attracting HUR individuals. ADEA requests that funding for HCOP be continued.

The Area Health Education Centers (AHEC) program enhances high-quality, culturally competent care in community-based interprofessional clinical training settings. The infrastructure development grants and point-of-service maintenance and expansion grants ensure that patients from underserved populations receive quality care and health professionals receive experience working with diverse populations. ADEA strongly encourages the Committee to continue funding the vitally important AHEC program.

$512 million: National Institute of Dental and Craniofacial Research

Dental research serves as the foundation of the dental professions. Discoveries stemming from dental research have reduced the burden of oral diseases, led to better dental health for millions of Americans, and uncovered important links between oral and systemic health. ADEA and dental school researchers are grateful for the increase NIDCR received in fiscal year 2020; however, we note that NIDCR continues to have the smallest budget of all the Institutes.

The requested increase for fiscal year 2021 will not bring us to parity, but it will bring us closer and provide the stable and consistent growth that Dr. Collins seeks for research. Through NIDCR grants, dental researchers in academic dental institutions have enhanced the quality of the nation's dental and overall health. Dental researchers are poised to make dramatic breakthroughs, such as restoring natural form and function to the mouth and face as a result of disease, accident, or injury, and diagnosing systemic disease (such as HIV and certain types of cancer) from saliva instead of blood and urine samples. These breakthroughs, and countless others that bolster America's role as a global scientific leader, require adequate funding.

$29 million: Centers for Disease Control and Prevention (CDC) Division of Oral Health

The CDC Division of Oral Health expands the coverage of effective prevention programs. The Division increases the basic capacity of state oral health programs to accurately assess the needs of the state, organize and evaluate prevention programs, develop coalitions, address oral health in state health plans, and effectively allocate resources to the programs. This strong public health response is needed to meet the challenges of dental disease affecting children and vulnerable populations. The current path of decreased funding will have a significant negative effect on the overall health and preparedness of the nation's states and communities.

$18 million: Ryan White HIV/AIDS Treatment and Modernization Act, Part F: Dental Reimbursement Program (DRP) and Community-Based Dental Partnerships Program

Patients with compromised immune systems are more prone to oral infections, such as periodontal disease and caries (tooth decay). The DRP is a cost-effective

Federal/institutional partnership that provides partial reimbursement to academic dental institutions for costs incurred from providing dental care to people living with HIV/AIDS. Simultaneously, the program provides educational and training opportunities to dental students, residents and allied dental students. However, DRP reimbursement only averages 26 percent of the dental schools' unreimbursed costs. The current reimbursement rate is unsustainable long-term. Adequate funding of the Ryan White Part F programs will help ensure that people living with HIV/AIDS receive necessary dental care.

ADEA thanks you for your consideration of these funding requests and looks forward to working with you to ensure the continuation of these critical programs and improve the oral and systemic health and well-being of the nation. Please consider ADEA a resource on any matter pertaining to academic dentistry and education of the dental workforce under your purview. For additional information, please contact B. Timothy Leeth, ADEA Chief Advocacy Officer, at leetht@adea.org.

Prepared Statement of the American Diabetes Association

For fiscal year 2021, the American Diabetes Association (ADA) urges the Subcommittee to increase its investment in diabetes research and prioritize funding for diabetes prevention to help stop the diabetes epidemic in our country. This is best accomplished by the Subcommittee providing funding levels of $2.25 billion for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH), $185 million for the Division of Diabetes Translation (DDT) at Centers for Disease Control and Prevention (CDC), and $35 million for the National Diabetes Prevention Program (National DPP) at CDC.

Over 34 million Americans live with diabetes and an additional 88 million Americans have prediabetes. Diabetes is personal to me as I have had type 1 diabetes almost my entire life (since age 5) and have two sons who were diagnosed with type 1 diabetes in their early teenage years. Additionally, I have spent over 40 years as a physician scientist at the University of Colorado School of Medicine and have focused on advancing the science and medicine of diabetes. Research is so important as it drives the unknown and allows researchers, like me, to keep learning and gaining new knowledge. Thanks to medical discoveries and advancements at the NIH and translation research from the CDC, diabetes care has advanced tremendously in recent years and has improved the quality of life and life expectancy for the millions of individuals with diabetes.

Although insulin was discovered nearly a century ago, we are still at the beginning of diabetes care. Newer insulins are available, providing more options than we had in 1922, but we still see the impact of the disease both in complications directly attributable to the disease—blindness, kidney disease, amputations, cardiovascular diseases—and in problems stemming from the stressors caused by the disease, including increased depression among people with diabetes. The only way to reverse the troubling consequences of the disease is better research into understanding and treating diabetes.

NIH is the single most important funding source for diabetes research. As a researcher, NIDDK funding has allowed me to study two major unanswered questions regarding diabetes and impact of diabetes on lipid and lipoprotein metabolism. Major unanswered questions among many include why some children and adults with genetic predisposition to type 1 diabetes develop diabetes, i.e. what are the environmental influences for the etiology of type 1 diabetes? A major task also relates to the etiology of type 2 diabetes, i.e. why beta cells do not respond to the insulin resistance that occurs in people who are obese and do not develop type 2 diabetes? We need the continuation of robust funding for NIDDK in support of dedicated research to provide the best hope both for those who have been living with diabetes for decades, fortunately like me, and for those who are newly diagnosed.

The human cost of diabetes is significant. The lifetime risk for developing diagnosed diabetes among U.S. adults is 40 percent. Today alone, 4,110 Americans will be diagnosed with diabetes, diabetes will cause 295 to undergo an amputation, and 137 will enter end-stage kidney disease treatment due to diabetes. Every 80 seconds an adult with diabetes is hospitalized in the U.S. for heart disease and every 2 minutes an adult with diabetes is hospitalized with stroke. People living with diabetes are twice as likely to develop and die from cardiovascular disease. In addition to the physical toll, diabetes is economically devasting in our country and for individuals impacted by the disease. Released in March 2018, "Economic Costs of Diabetes in the U.S. in 2017," found the total annual cost of diagnosed diabetes in our country has skyrocketed by an astonishing 26 percent over 5 years, to $327 billion. This is unsustainable for our nation, especially when 1 in 3 Medicare dollars is already spent caring for people with diabetes and people with diagnosed diabetes have healthcare costs 2.3 times higher than those without diabetes. Despite the escalating physical and economic cost of diabetes to our nation and families, the Federal investment in diabetes research and prevention programs at the NIH and CDC still falls short of the need. The state of our nation's diabetes epidemic justifies increased Federal funding in fiscal year 2021.

BACKGROUND

Diabetes is a chronic disease that impairs the body's ability to utilize food. The hormone insulin, which is made in the pancreas, is needed for the body to convert food into energy. In people with diabetes, the pancreas fails to produce insulin (type 1 diabetes), or it does not create enough insulin to overcome cells that are resistant to insulin (type 2 diabetes). Diabetes results in too much glucose in the blood stream. Additionally, up to 9.2 percent of pregnancies are affected by gestational diabetes, a form of glucose intolerance diagnosed during pregnancy that places both mother and baby at risk for complications and for type 2 diabetes later in life.

Diabetes does not have a cure, and management is necessary every single day. People with diabetes make over 300 decisions about their disease in a single day. They must carefully balance what they eat, when they eat, when and how much they exercise, and manage insulin injections constantly, knowing that one decision impacts all the others. In my experience, individuals with diabetes can in part overcome these challenges due to the advances with technology and are able to carefully balance out the decisions they make daily.

NATIONAL INSTITUTE OF DIABETES, DIGESTIVE, AND KIDNEY DISEASES AT NIH

ADA requests funding of $2.25 billion for NIDDK in fiscal year 2021 because NIDDK is responsible for major research breakthroughs that have revolutionized how diabetes is treated and managed. People with diabetes, including myself and my sons, can now use a variety of insulin formulations, insulin infusion pumps, continuous glucose monitoring (CGM) sensors, and regimens far superior to those used in the past, which has significantly reduced the risk for serious complications of diabetes

Although NIDDK research has led to the development of CGMs and insulin pumps, which are life-changing managements tools for patients, there is even more promising research that Congress needs to fund. Diabetes researchers across the country are working on fruitful proposals that can lead to the goal—a cure for this devasting disease. NIDDK would be able to fund additional investigator-initiated research grants to meet critical needs in areas with increased funding. This includes: research biomarkers that can improve the treatment of diabetic foot ulcers and ultimately reduce lower-limb amputations; better understand gestational diabetes; the continued progress on the artificial pancreas; understanding the relationship between diabetes and neuro-cognitive conditions like dementia and Alzheimer's disease; and study important emerging areas such as the incidence of type 2 diabetes in youth and artificial pancreas systems, particularly in underrepresented populations. Mechanisms that relate to how diabetes increases the risk of eye/kidney/nervous system complications, and importantly cardiovascular disease is also under the purview of NIDDK.

THE DIVISION OF DIABETES AND TRANSLATION AT CDC

The Federal Government's efforts to prevent diabetes and its serious complications through the DDT and its evidenced-based, outcome-focused diabetes programs are essential to help stop the diabetes epidemic. DDT's mission is to eliminate the preventable burden of diabetes through research, education, and by translating science into clinical practice. DDT has a proven record of success in primary prevention efforts, as well as programs to help those with diabetes manage their disease and complications.

The ADA urges Congress to provide DDT with $185 million in fiscal year 2021. The increased funding will allow DDT to continue diabetes prevention activities at the state and local levels. Additionally, increased funding will support these efforts through the State and Local Public Health Actions to Prevent Obesity, Diabetes, and Heart Disease grants, which focus on improving prevention at the community and health systems levels in populations with the highest risk for diabetes; diabetes prevention efforts under the State Public Health Actions grant program for cross-cutting approaches to prevent and control diabetes, heart disease, and stroke; and allow for DDT to translate research into more effective ways to prevent and treat diabetes in communities and continue its valuable diabetes surveillance work. DDT's surveillance work includes integrating and modernizing the data collection

CDC receives regarding prediabetes determining best practices and addressing social determinates of health.

THE NATIONAL DIABETES PREVENTION PROGRAM AT CDC

It is alarming that 88 million Americans have prediabetes and are on the cusp of developing type 2 diabetes. Nine out of ten individuals with prediabetes do not know they have it, and within 5 years 15–30 percent of individuals with prediabetes will develop type 2 diabetes. The National DPP managed by the CDC, can make progress in lowering the incidence of diabetes in high-risk populations. The National DPP is made up of a combination of public-private partnership of community organizations, private insurers, employers, healthcare organizations, faith-based organizations, and government agencies. This national network of local sites provides trained staff, who work with individuals who have a high risk of developing type 2 diabetes, with cost-effective, group-based lifestyle intervention programs.

The National DPP grew out of a successful NIDDK clinical study showing weight loss of 5–7 percent of body weight, achieved by reducing calories and increasing physical activity to at least 150 minutes, reduced the risk of developing type 2 diabetes by 58 percent in people with prediabetes, and by 71 percent for those over 60 years old. Also, the DPP conducted additional translational research, which showed the National DPP works in the community setting, at a lower cost of about $425 per participant.

The ADA urges Congress to provide $35 million for the National DPP in fiscal year 2021 to continue its nationwide expansion. It is imperative that Congress increase funding for National DPP to allow CDC to increase the number of sites that offer this effective program, specifically in the hardest-hit communities, continue to manage National DPP programs, ensure sites follow the evidence-based curriculum to achieve the same high level of results, and support programs as they become Medicare suppliers.

CONCLUSION

Congress must continue to make progress and invest in diabetes research, education, and prevention: the 32 million Americans with diabetes cannot wait. I urge the Subcommittee to make decisions for fiscal year 2021 appropriations that reflect the necessity of reversing the human and economic burden of this staggering disease. I look forward to working with you and the ADA to stop diabetes.

[This statement was submitted by Robert H. Eckel, MD, President, Medicine & Science, American Diabetes Association.]

PREPARED STATEMENT OF THE AMERICAN EDUCATIONAL RESEARCH ASSOCIATION

Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee; thank you for the opportunity to submit written testimony on behalf of the American Educational Research Association. As Congress continues to address the current public health and economic needs related to COVID–19, there are ongoing education research programs and statistical infrastructure needs that would be appropriately addressed through the regular appropriations process. AERA recommends that the Institute of Education Sciences (IES) within the Department of Education receive $670 million in fiscal year 2021. This recommendation is also consistent with the request from the Friends of IES coalition, for which we are a leading member. In addition, AERA recommends $44.7 billion for the National Institutes of Health (NIH) in fiscal year 2021, in support of important research in the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) and the Office of Behavioral and Social Science Research (OBSSR).

AERA is the major national scientific association of 25,000 faculty, researchers, graduate students, and other distinguished professionals dedicated to advancing knowledge about education, encouraging scholarly inquiry related to education, and promoting the use of research to improve education and serve the public good. Our members, as well as state and Federal policymakers and practitioners, rely on IES to provide and support reliable education statistics, data, research, and evaluations.

IES is the independent and nonpartisan statistics, research, and evaluation arm of the U.S. Department of Education charged with supporting and disseminating rigorous scientific evidence on which to ground education policy and practice. While located within the Department of Education, the mission of IES as a science agency is more closely aligned with other Federal agencies such as the National Science Foundation and the National Institutes of Health.

This is a critical time to invest in education research, data, and statistics to produce essential knowledge about teaching and learning across all levels of education due to the unprecedent impact of the COVID–19 pandemic on educational institutions and the students, parents, teachers, and school leaders they serve. No institution is more vital than education to developing essential capacities and skills, to the economic wherewithal of our country, and to building a sense of community and citizenship. Yet, without monitoring the conditions of education and generating the knowledge we need and in real time, we will diminish our effectiveness in adapting to changing conditions that we inevitably will face. IES is already working proactively to provide data and evidence-based resources, including, for example, the addition of questions on longitudinal surveys undertaken by National Center for Education Statistics (NCES) to gauge the impact of COVID–19, conducting a meta-analysis study to highlight effective distance learning practices, and webinars and guidance from the Regional Educational Laboratories (RELs). But additional resources seem both wise and prudent.

Outside of the response to the current crisis, we see numerous examples of bipartisan support for scientific research and evidence-based decisionmaking.

—The Department of Education is implementing the provisions of the Foundations of Evidence-Based Policymaking Act, which directs Federal agencies to leverage data and evaluations to inform policy decisions. NCES as the statistical agency within the Department has special responsibilities with respect to data integrity, linkages, and analysis that simply cannot be assumed elsewhere with the same degree of confidentiality and trust, as mandated by this bi-partisan act.

—School districts are implementing school improvement plans for their lowest performing schools under the framework provided under the Every Student Succeeds Act (ESSA), and research and evidence-based resources from IES are important tools for supporting student needs and fostering school improvement.

—IES is increasing investment in research on career and technical education, which also includes involvement in research and evaluation activities specified in the Strengthening Career and Technical Education for the 21st Century Act.

In short, the data and research infrastructure to build evidence for improving educational outcomes require additional funding necessitating action by your committee.

Since IES was created in 2002, it has made visible scientifically-based contributions to the progress of education. Take, for example, IES-supported research at the Community College Research Center (CCRC) that led to significant changes in the remedial education program in the North Carolina Community College System. In a partnership between the system and CCRC, there was a shift from remedial education toward an accelerated structure of developmental education that increased student retention and degree completion. At the same time, the money saved from restructuring remedial education was reinvested into STEM and high-demand technical education. Despite the potential of research to inform key policy decisions, we have much left to do to provide high-quality education to all of our students.

As states are moving forward implementing their Every Student Succeeds Act (ESSA) state plans, they are increasingly depending on their Statewide Longitudinal Data Systems (SLDS). Initially developed to help states measure accountability, these administrative data have transformed from a hammer to a flashlight, increasing understanding about student performance and teacher effectiveness without needing major and sustained investments in research. To date, IES has unfortunately been unable to meet the state demand for SLDS grants. In 2015, only 16 of 43 states that submitted applications received grants. Those states that have benefitted from SLDS grants have clear success to show from the Federal investment, but others are without this information source to use. State leaders in Georgia and Mississippi have testified in front of Congress about their use of SLDS to improve student outcomes in their states.

I also want to bring to your attention the numerous ways that Congress has signaled support for the use of education data in decisionmaking. The most recent bipartisan, bicameral draft of the IES reauthorization includes the continuation of SLDS, and we appreciate Congress continuing to invest in this program despite proposals to eliminate funding in recent budget requests. Eliminating this program would act in direct contrast to the broad bipartisan support to increase the use of data to inform policy decisions. Furthermore, cuts to SLDS hurt states working to build data capacity at the same time that ESSA is requiring states to make evidence-based decisions. Rather than eliminating the SLDS program, AERA encourages this committee to expand upon this very successful program. In addition, AERA opposes the proposal to eliminate the Regional Educational Laboratories in the fiscal year 2021 budget.

AERA also is concerned with the reduced staff capacity at IES, and I would like to draw particular attention to the decades-long staff attrition at NCES. As the second-oldest principal Federal statistical agency in the U.S., NCES provides objective, nonbiased data on a wide range of education indicators, including information on teacher salaries, the amount of loans taken out by undergraduate students, and the participation of students in English language learner programs. NCES staff are also responsible for the development and administration of the National Assessment of Educational Progress, detailing longitudinal trends in student achievement. In recognizing the need for NCES to produce accurate and reliable data and report in it objectively, we encourage the subcommittee to ensure that NCES and IES have the appropriate level of staff in order to effectively carry out their missions in the Program Management line. Essential work is being stymied and delayed in ways that are not cost effective from a public policy perspective.

We also have concerns about the inclusion of proposals to reauthorize the Education Sciences Reform Act (ESRA) in the fiscal year 2021 IES Congressional Justification to support the administration's request for IES. Of particular concern is the proposal to create a new assessment center within IES. In light of the May 12 blog post from IES Director Mark Schneider detailing his argument for this center, we wish to emphasize a fundamental problem in separating statistics, data, and assessment. Every statistical agency worthy of that role needs to examine outcomes with rigorous, reliable measures and statistics. Thus, the very ambition that Director Schneider has for high-quality assessments could be undermined by less, rather than more, connectivity.

At a time of fiscal constraint when more expert staff are sorely needed rather than an expanded administrative apparatus, the creation of a separate assessment center seems ill-timed. It also seems hasty to skip thoughtful consideration of a significant change to the structure of IES that is in the jurisdiction of authorizing committees. We strongly urge against the inclusion of appropriations language that would establish an assessment center in absence of ESRA reauthorization.

In addition to IES, AERA recommends $44.7 billion for the National Institutes of Health (NIH) in fiscal year 2021 with proportional increases for the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) and the Office of Behavioral and Social Science Research (OBSSR). NICHD supports research at the intersection of health and education, including the genetic and behavioral risks for child obesity, the use of opioids by mothers and potential impact on infant and child brain development, and interventions for students with learning disabilities who struggle with reading. Investment in NICHD will allow the institute to continue research both to increase understanding of the impact of opioid use across the educational lifespan and to reduce risk for addiction, and to bolster the professional development of early career researchers. OBSSR plays an important role in coordinating and co-funding behavioral and social science research across NIH that contribute to the understanding of influences on health and interventions to improve health outcomes.

Thank you for the opportunity to submit written testimony in support of $670 million for IES and $44.7 billion for NIH in fiscal year 2021. AERA welcomes working with you and your subcommittee on strengthening investments in essential research, data, and statistics related to education and learning.

[This statement was submitted by Felice J. Levine, PhD, Executive Director, American Educational Research Association.]

PREPARED STATEMENT OF THE AMERICAN FOUNDATION FOR SUICIDE PREVENTION

My name is John H. Madigan, Jr. and I am the Senior Vice President and Chief Public Policy Officer for the American Foundation for Suicide Prevention (AFSP). I am pleased to submit this written testimony today on behalf of our over 28,000 Field Advocates nationwide, and the thousands of individuals who participate in our Out of the Darkness Walks each year. AFSP has Chapters in all 50 states and sponsors a variety of events and programs across the country each year. In addition to raising to raising funds for research, education, and advocacy, our Chapters also disseminate resources and programs in their communities. This written testimony includes information that outlines the suicide crisis in the United States and information about each of AFSP's recommendations to the Subcommittee for fiscal year 2021.

Suicide is a major public health crisis in the United States. Suicide is the second leading cause of death for ages 10–34, the fourth leading cause of death for ages 35–54, and the tenth leading cause of death overall in the United States. I lost my sister Nancy to suicide, 23 years ago. Every year over 10 million people seriously consider suicide, over 1 million attempt suicide, and in 2018 we lost 48,344 Americans to suicide. Each of these individuals lost to these preventable deaths are survived by tens of thousands of family, friends, and community members. Despite such a high rate of incidence and despite nearly 1-in-5 Americans living with a mental health condition, more than half of those individuals won't seek treatment due to poor public access to suicide prevention and treatment resources, sparse and inadequate mental health services, and deeply entrenched stigma. The most recent data from the Centers for Disease Control and Prevention (CDC) confirmed that suicide rates are rising in the United States. Suicide deaths across the country increased over 30 percent since the turn of the century and continue to do so every year.

AFSP believes Congress must prioritize suicide prevention research, programs, and education at funding levels commensurate with other leading causes of death in the United States. We thank the Subcommittee, Chairwoman Blunt and Ranking Member Murray for this opportunity. Please find below AFSP's recommendations on funding and report language for the Subcommittee to consider for fiscal year 2021.

Suicide Prevention Programs at the Substance Abuse and Mental Health Administration (SAMHSA) need a greater investment towards crisis and support services for suicide prevention activities throughout the country. The National Suicide Prevention Lifeline (Lifeline) (1-800-273-8255), one of SAMHSA's most effective and far reaching suicide prevention initiatives, which provides free 24/7 confidential support and resources for individuals experiencing distress, as well as prevention, education, and best practices for professionals. The Lifeline was funded at $19 million in fiscal year 2020 and the President's fiscal year 2021 budget proposes keeping the Lifeline at that same funding level. AFSP proposes an increase of $31 million, for a total of $50 million for the National Suicide Prevention Lifeline program to ensure more dedicated funding can be directed to the states with the lowest answer rates and with the highest need, and for national initiatives to better improve Lifeline quality and services.

Given the current COVID–19 pandemic in the United States, these funds are urgently needed. During moments of acute public stress, the Lifeline has seen surges in distressed individuals in need of crisis services. In the current situation, calls to the National Suicide Prevention Lifeline have increased depending on many factors, and the majority of those reaching out are doing so related to anxiety, feeling isolated, or related to loss. Mental health organizations are already responding to unique challenges[1] that the nearly 1-in-5 individuals living with mental health conditions will face during this national emergency. Following high profile suicides, the Lifeline has seen nearly an eightfold increase in crisis calls[2] and call volumes can double after natural disasters.[3] It is crucial that the Lifeline be adequately resourced to respond to public demand for crisis services.

—fiscal year 2020 actual: $19 million

—fiscal year 2021: $50 million—proposed

Suicide prevention research conducted at the National Institute of Mental Health (NIMH) will allow for better understanding, treatment and prevention of suicidality. NIMH has awarded grants totaling roughly $65 million over the last year on direct suicide prevention research, and while this is a step in the right direction, we believe that more can be done given the increasing rate of suicide across our country. AFSP is the largest funder for suicide prevention research outside of the Federal Government and much of what is known about suicide comes from studies that AFSP has helped sponsor. Our studies open up new areas of inquiry, and our council of scientific advisors helps set the national research agenda.

There is no single cause to suicide. It most often occurs when stressors exceed current coping abilities of someone suffering from a mental health condition. Suicide prevention research is a vital tool in identifying prevention, intervention, and postvention strategies that save lives and inform best practices and future approaches and areas of inquiry. Through encouraging increased synergy between the National Institute for Mental Health (NIMH), the National Institute on Drug Abuse (NIDA), and National Institute on Alcohol Abuse and Alcoholism (NIAAA) a multifaceted approach to suicide prevention research beyond the current work that the NIH is conducting can be applied. It is important that we can evaluate suicide as the complex condition that it is and find treatments and interventions for comorbid conditions that will save lives. Therefore, the American Foundation for Suicide Pre-

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[1] https://www.nami.org/getattachment/Press-Media/Press-Releases/2020/COVID-19-and-Mental-Illness-NAMI-Releases-Importan/COVID-19-Updated-Guide-1.pdf?lang=en-US.

[2] https://www.usatoday.com/story/news/nation/2014/08/14/suicide-hotline-calls-surge/14053415/.

[3] https://www.sprc.org/news/puerto-rico-%E2%80%98i-sit-cry-all-day%E2%80%99-suicide-hotline-calls-double-puerto-rico-six-months-after.

vention encourages the House and Senate Appropriations Committee to adopt report language that will increase suicide prevention research at the NIMH.

—*Proposed Report Language: Suicide Prevention*.—The Committee continues to be alarmed by the growing rates of suicide across the country, with the CDC reporting a 30 percent increase since 1999. Suicide is currently the 10th leading cause of death for all ages and the 2nd leading cause of death for young people aged 10–34. The Committee commends NIMH for consistently increasing the resources dedicated to suicide screening and prevention research over the last three fiscal years and encourages the Institute to provide an additional increase for this purpose in fiscal year 2021, with special emphasis on producing models that are interpretable, scalable, and practical for clinical implementation, including mental and behavioral healthcare interventions. The Committee also encourages NIMH to consider the recommendations included in the Action Alliance for Suicide Prevention's A Prioritized Research Agenda for Suicide Prevention when allocating resources for this purpose. In addition, the Committee believes increased collaboration between NIMH and other NIH Institutes holds immense value. The Committee strongly encourages NIMH to partner with NIDA and NIAAA to examine the multifaceted relationship between suicide and substance use disorder (SUD), including opioid abuse. Enhanced research into these relationships will provide critical knowledge surrounding suicide warning signs. The Committee directs NIMH to provide an update on these efforts in the fiscal year 2022 justification materials.

The Centers for Disease Control and Prevention (CDC) is the nation's leading health protection agency, and so it is a natural fit that the CDC expand their suicide prevention efforts.

Through investing further in the CDC's new Suicide Prevention line which began fiscal year 2020 at the National Center for Injury and Prevention, there is a more holistic approach to suicide prevention programming beyond the work that SAMHSA and the NIH are implementing, evaluating, and researching. CDC data show that while depression and other mental health conditions are a significant risk factor for suicide, less than half of the individuals who die by suicide have a known mental health condition. Further, the latest data show that there is no single determining cause. Instead, suicide occurs in response to multiple biological, psychological, interpersonal, environmental, and social influences that interact with one another, often over time. This evidence demonstrates a need for a comprehensive public health approach to address suicide from all vantage points.

Currently, there is no complete set of suicide attempt data in the United States, and through pilot programs to enhance the completeness of data, researchers may be able to identify further connections between suicide attempt behavior, and its connection to suicide, thus allowing for improved prevention strategies. In order to prevent suicide, programs implemented within communities must be scalable and allow for sustainable efforts. Therefore, as the suicide rate continues to grow each year, there is a need to make strategic investments that will help save lives and reduce the suicide rate, such as the work that the CDC is implementing through the Suicide Prevention line.

—fiscal year 2020: $10 million
—fiscal year 2021: $15 million—proposed

—*Proposed Report Language: Suicide*.—The Committee recognizes that suicide is devastating communities across the U.S., as evidenced by more than 48,344 deaths in 2018, and is the tenth leading cause of death in America. While depression and other mental health conditions are a significant risk factor for suicide, less than half of the people who die by suicide have a known mental health condition. The Committee includes $15,000,000, an increase of $5,000,000 to build on the initial appropriation in fiscal year 2020, for CDC to expand research on the leading mechanisms of suicide deaths and identify prevention strategies to reduce the deaths by suicide through pilot projects to enhance the completeness of data to capture mechanisms of death; expand syndromic surveillance; and support research and evaluation projects to understand the pathways and mechanisms that contribute to suicide attempts, and identify prevention strategies that can be scaled at the community level.

The Core State Violence and Injury Prevention Program (Core SVIPP) in the National Center for Injury Prevention and Control (NCIPC) at the CDC. Injuries and violence are the leading causes of death during the first four decades of life, regardless of gender, race or socioeconomic status. The inclusion of this dedicated funding through the National Center for Injury Prevention and Control, housed under the Injury Prevention Activities line would contribute in a meaningful way to suicide prevention by empowering states to implement, evaluate, and disseminate effective violence and injury prevention programs and policies of their choice in addition to the core four areas identified by the CDC: child abuse and neglect, traumatic brain injury, motor vehicle crash injury and death, and intimate partner/sexual violence. Currently, the Core SVIPP is only funded in 23 states, and serves the purpose of reducing violence related morbidity and mortality, and increases the sustainability of injury prevention programs.

—fiscal year 2020: $6.7 million

—fiscal year 2021: $20 million—proposed

We thank you for your consideration and hope that Congress is willing to make greater investments in suicide prevention and crisis services. The American Foundation for Suicide Prevention is dedicated to saving lives and bringing hope to those affected by suicide. AFSP creates a culture that's smart about mental health through education and community programs, develops suicide prevention through research and advocacy, and provides support for those affected by suicide.

Please let me know if you or any of your staff have any additional questions.

[This statement was submitted by John H. Madigan, Jr. Senior Vice President and Chief Public Policy Officer, American Foundation for Suicide Prevention.]

PREPARED STATEMENT OF THE AMERICAN GASTROENTEROLOGICAL ASSOCIATION

NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES

Chairman Blunt, Ranking Member Murray, and members of the Subcommittee, I would like to start by thanking you for the opportunity to submit testimony on the U.S. Department of Health and Human Services (HHS) fiscal year 2021 appropriations bill. I am Dr. Colleen Kelly, and I am an associate professor of medicine at the Alpert Medical School of Brown University. I am submitting testimony on behalf of the American Gastroenterological Association (AGA) and its Fecal Microbiota Transplant National Registry, whose principal investigators include myself, Dr. Loren Laine from Yale School of Medicine, and Dr. Gary Wu from the University of Pennsylvania School of Medicine. The AGA was founded in 1897, and today, it has expanded its membership to include more than 16,000 professionals who are dedicated to the advancement of science, practice, and research in the field of gastroenterology. We respectfully request the subcommittee to provide robust funding for the National Institutes of Health (NIH). Additionally, we request report language to support the Fecal Microbiota Transplant (FMT) National Registry, a national data registry funded by the National Institute of Allergy and Infectious Diseases (NIAID) that assesses short and long-term safety and effectiveness of FMT as it relates to recurrent Clostridioides difficile infection (CDI) and other clinical indications.

Antimicrobial Resistant Infections

CDI is associated with the use of antibiotics and is the most frequently transmitted infection in healthcare settings. CDI affects more than 500,000 Americans each year, leading to hospitalizations, which in turn, provide increased opportunity for the infection to spread. Today, approximately 30,000 annual deaths can be attributed to the condition. In recent years, there has been a concerning rise in community acquired CDI and cases which are more severe or resistant to standard therapies.

The human gastrointestinal system contains trillions of bacteria, viruses and other microorganisms that collectively are known as the gut microbiota. These microorganisms play an essential role in the body's immune and digestive systems. However, the health of this microbial community is adversely affected when antibiotics are used to treat an underlying bacterial infection. The resultant loss of beneficial organisms increases the risk for pathogens, such as C. difficile to overgrow and cause disease. Like other resistant infections, the annual incidence of CDI continues to rise with the widespread use of antibiotics.

According to the Centers for Disease Control and Prevention (CDC), patients who receive antibiotics are 7–10 times more likely to contract CDI, with the risk increasing significantly for the elderly, immunocompromised, and those with an extended stay in a hospital or assisted living facility. Recent studies have confirmed elevated risk of infection for certain demographics and hospital-related exposure. For example, a 2011 study showed that 57 percent of CDI cases occurred in patients older than 65 and 56 percent of cases occurred in females. Remarkably, the same study also showed that 65 percent of cases were contracted in a healthcare setting.

When CDI does not self-resolve after the cessation of antibiotic treatments, many seek medical attention due to the severity of their symptoms. At this point, additional antibiotics are used to treat the infection, but approximately 25 percent of patients will experience a recurrence. In cases where CDI persists after multiple rounds of antibiotics, FMT may be used to treat the patient.

Fecal Microbiota Transplantation

FMT involves the delivery of a stool sample, containing the entire community of microorganisms, from a healthy donor to a recipient in order to restore the health of the gut microbiome. This process is highly effective in treating recurrent CDI; nearly 90 percent of patients do not experience a recurrence of symptoms after FMT. However, this therapy presents a number of safety concerns, including risk of infection transmission, and more research is necessary to understand the short and long-term effects of FMT in the treatment of CDI.

Currently, the Food and Drug Administration (FDA) has not approved the use of FMT, as it has designed the therapy as a drug and biological product that requires an investigational new drug (IND) application; yet, the agency has recognized the benefits of FMT treatment in patients with CDI who have not responded to other therapies. To that end, the FDA issued guidance in 2013 whereby it exercised enforcement discretion to accommodate the needs of patients with recurrent CDI that did not respond to standard therapies. While the enforcement discretion policy ensures patient access to FMT, it has consequently left a void in the surveillance of safety and effectiveness that must be addressed as the practice of FMT continues to expand. Physicians and scientists have learned the importance of vigilance in collecting information on the outcomes of medical interventions after a generation of patients was infected with HIV and hepatitis C from blood transfusions.

Real-world surveillance of FMT is more important than ever due to the emergence of the novel coronavirus SARS-CoV–2 and the associated coronavirus disease 2019 (COVID–19). As reported by the Centers for Disease Control and Prevention, COVID–19 has led to over 78,000 deaths in the U.S. as of May 10, 2020. FMT procedures have largely stopped across the U.S. as many clinics perform FMT using endoscopic techniques, and these “elective” procedures have been discouraged during the COVID–19 pandemic. In addition, the novel coronavirus has been detected in the stool of patients hospitalized for COVID–19 and it remains unknown whether SARS-CoV–2 can be transmitted from person to person through feces. When COVID–19 subsides, it will be critical to monitor how clinics performing FMT are screening stool donors and testing donated stool for the presence of SARS-CoV–2. It will also be important to track the outcomes of patients receiving FMT, including the incidence of COVID–19.

FMT National Registry

In August of 2016, the FMT National Registry was developed and received 5 years of funding from the National Institute of Allergy and Infectious Diseases (NIAID) to study patients receiving FMT or other gut-related microbiota products. The AGA collaborated with the Crohn’s and Colitis Foundation, Infectious Diseases Society of America and North American Society for Pediatric Gastroenterology, Hepatology and Nutrition to create the registry and our steering committee includes physician liaisons from each of these partners. The registry aims to collect data from 75 clinical sites across the country to monitor patients 30 days, 6 months, 1 year, and 2 years after they receive FMT. The registry will also collect patient-reported outcomes directly from participants annually, starting at 1 year and up to 10 years after their FMT.

To date, more than 250 patients have been observed through the first benchmark of 30 days and have seen an initial success rate of 90 percent. Of these patients, more than 150 have been observed through the second benchmark of 6 months and 96 percent of those with an initial success remained cured. From the perspective of safety, no new infections were reported in 95 percent of patients and no deaths were reported at the first benchmark of 30 days. At the second benchmark of 6 months, 90 percent of patients remained without any life-threatening infections. Though four deaths were reported at the second benchmark, none were for reasons determined to be related to the FMT procedure.

In June 2019, the FDA announced the death of a patient receiving FMT caused by a contaminated donor sample. Consequently, sites performing FMT under an IND permit have additional donor screening criteria and testing requirements to detect the presence of antibiotic resistant bacteria in donor samples. The FMT National Registry fills the information gap for sites performing FMT under the FDA’s enforcement discretion policy, for whom these requirements are non-binding. In addition to patient safety and effectiveness outcomes, the registry collects procedural information such as donor screening criteria and method of FMT delivery. This data is especially important given the emergence of the novel coronavirus, and the unknowns regarding potential transmission of the virus through stool. Therefore, the registry will serve as a central hub to gather information on donor screening and stool testing procedures related to COVID–19.

Beyond CDI, FMT is being studied for many other clinical applications with known associations to the gut microbiome. These include gastrointestinal disorders such as inflammatory bowel disease (i.e., Crohn's disease, ulcerative colitis), irritable bowel syndrome and hepatic encephalopathy; central nervous system diseases such as autism, Parkinson disease and multiple sclerosis; obesity and metabolic syndrome; and cancers, particularly colorectal cancer, as well as the effectiveness of cancer immunotherapies and the treatment of graft-versus-host disease in patients who have received stem cell transplantation. As such, the FMT National Registry has been built with the flexibility to collect data on these other indications.

The NIH funding received thus far has been instrumental in the development of future treatments for millions of patients. The FMT National Registry has provided us with valuable insights regarding the safety and effectiveness of FMT in the treatment of CDI. The AGA recognizes the continued need to collect systemic data on the short and long-term outcomes of FMT. Therefore, the AGA urges the subcommittee to include the following report language that would allow NIH to continue its support of the FMT registry.

FMT National Registry.—The Committee recognizes that the FDA has allowed for enforcement discretion to promote continued patient access to fecal microbiota transplantation (FMT) for recurrent C. difficile infections. To help inform clinicians and patients, Congress encourages NIH to continue to support the FMT National Registry and related research efforts to better understand the short- and long-term safety and effectiveness of FMT.

In addition to the AGA, the requested report language is supported by the following organizations: American College of Gastroenterology, American Neurogastroenterology and Motility Society, American Society for Gastrointestinal Endoscopy, Association of Gastrointestinal Motility Disorders, Crohn's & Colitis Foundation, Digestive Disease National Coalition, Global Liver Institute, Infectious Diseases Society of America, Massachusetts Gastroenterology Association, The National Chronic Pancreatitis Support Network, No Stomach For Cancer, North American Society for Pediatric Gastroenterology, Hepatology and Nutrition, North Carolina Society of Gastroenterology, The Oley Foundation, Peggy Lillis Foundation, Society of Gastroenterology Nurses and Associates, and United Ostomy Associations of America.

On behalf of AGA, its members, and the FMT National Registry, I would like to thank you for your consideration of this request. If you have any questions, please contact Kathleen Teixeira, Vice President of Government Affairs, at kteixeira@gastro.org.

[This statement was submitted by Dr. Colleen Kelly, MD, FACG, Associate Professor of Medicine, Brown Alpert Medical School, American Gastroenterological Association.]

PREPARED STATEMENT OF THE AMERICAN GEOPHYSICAL UNION

The American Geophysical Union (AGU), a non-profit, non-partisan scientific society, appreciates the opportunity to submit testimony regarding the fiscal year 2021 appropriation for the National Institute of Environmental Health Sciences (NIEHS). AGU, on behalf of its community of 110,000 Earth and space scientists, respectfully requests that the 116th Congress appropriate $860.3 million for the NIEHS. AGU's appropriations request takes into consideration previous budget cuts and accounts for both inflation and a necessary real four-percent year-over-year growth, to ensure that the U.S. remains at the forefront of research and innovation.[1]

Under the umbrella of the National Institutes of Health (NIH), the NIEHS conducts essential, innovative research that advances our understanding of the effects of environmental changes or exposures on human health and disease in the U.S. and across the globe. Through NIEHS research, policymakers have access to vital, unbiased science that is necessary for making informed decisions when addressing public health issues. A few examples of the NIEHS's invaluable work are provided below.

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[1] This amount of growth is recommended by the Innovation: An American Imperative statement, which was authored by nine large U.S. corporations and endorsed by over 500 leading industry, higher education, science, and engineering organizations from across the 50 states. https://innovation-imperative.herokuapp.com/index.html.

Improving Disaster Response, Reducing Health Impacts, & Preventing Future Harm

The NIH Disaster Research Response program, launched by the NIEHS and the National Library of Medicine, helps to address the ongoing need for time-sensitive research in the aftermath of disasters, such as hurricanes, wildfires, oil spills, and public health crises. Such research helps scientists, government agencies, and communities better understand immediate environmental exposures and injury risks, potential short-term and long-term health impacts, the effectiveness of health response efforts and environmental cleanup efforts, as well as factors affecting post-disaster recovery and resiliency to future events. To support timely gathering of the environmental and toxicology data needed, the program has readily available research protocols, data collections tools, and training resources.[2]

Increasing Knowledge of Health Effects Related to PFAS Exposure

The NIEHS continues to be at the forefront of research on perfluoroalkyl and polyfluoroalkyl substances (PFAS). A year ago, at least 610 locations in 43 states were known to be affected by PFAS contamination, which included drinking water systems serving an estimated 19 million people.[3] Research into the possible health impacts of PFAS chemicals exposure has already unmasked many links to adverse health outcomes. For example, research has revealed that PFAS exposure may increase a woman's risk of pregnancy complications.[4] However, there is still much to understand regarding the effects of PFAS exposure, which is why the NIEHS continues to conduct research and award grants to external organizations across the nation.

Growing the Environmental Health Science Workforce

To further expand the world's understanding of environmental impacts on human health and disease and support interdisciplinary scientific research, the NIEHS provides training and educational opportunities for students of all ages-from the high school and undergraduate levels to graduate students and faculty. For example, the NIEHS Medical Student Research Fellowship program provides medical students an opportunity to train in environmental health-related research for a year at the NIEHS.[5] The NIEHS also awards NIH Summer Research Experience Program (R25) grants that give high school and college students and science teachers an opportunity to gain valuable research experience at a higher education institution during the summer.[6]

CONCLUSION

AGU recognizes that difficult decisions must be made within the constraints of the current budget environment and believes that the future of the U.S. is best served by a strong and sustained investment in the full scope of our research enterprise-including new, innovative research regarding the impact of environmental factors on human health generated by the NIEHS. Thank you for your thoughtful consideration of this request and for the opportunity to submit this testimony.

[This statement was submitted by Michael Villafranca, Senior Specialist, Public Affairs.]

Prepared Statement of the American Geriatrics Society

The American Geriatrics Society (AGS) greatly appreciates the opportunity to submit this testimony. The AGS is a national non-profit organization of nearly 6,000 geriatrics healthcare professionals and basic and clinical researchers dedicated to improving the health, independence, and quality of life of all older Americans. As the Subcommittee works on its fiscal year 2021 Labor, Health and Human Services, and Related Agencies Appropriations Bill, we ask that you prioritize funding for the geriatrics education and training programs under the Title VII of the Public Health

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[2] See, NIH Disaster Research Response Program (DR2), https://dr2.nlm.nih.gov/.

[3] Based on data analysis by the Environmental Working Group and Northeastern University. Walker, B., (6 May 2019). Mapping the PFAS contamination crisis: New data show 610 sites in 43 states, EWG News and Analysis, https://www.ewg.org/news-and-analysis/2019/04/mapping-pfas-contamination-crisis-new-data-show-610-sites-43-states.

[4] Broadfoot, M., (February 2020). Replacement chemicals may put pregnancies at risk. Environmental Factor, NIEHS Newsletter, https://factor.niehs.nih.gov/2020/2/science-highlights/replacement/index.htm.

[5] See, NIEHS Medical Student Research Fellowships, https://www.niehs.nih.gov/careers/research/med-students/index.cfm.

[6] See, the NIH Summer Research Experience Programs (R25), https://www.niehs.nih.gov/research/supported/irt/summer__research/index.cfm.

Service (PHS) Act, and for aging research within the National Institutes of Health (NIH) and National Institute on Aging (NIA).

We are appreciative of your ongoing support of the Title VII and VIII Geriatrics Health Professions Programs at the Health Resources and Services Agency (HRSA), which includes the Geriatrics Workforce Enhancement Programs (GWEPs) and Geriatrics Academic Career Awards (GACAs). However, the AGS believes it is urgent that we increase the educational and training opportunities in geriatrics and gerontology and ensure that HRSA receives the funding expansion necessary for these critically important programs for the care and health of older adults.

We ask that the Subcommittee consider the following funding levels for these programs in fiscal year 2021:

—At least $51 million to support the Geriatrics Workforce Enhancement Program and the Geriatrics Academic Career Award Program (PHS Act Title VII, Sections 750 and 753(a))

—An increase of $3 billion over the enacted fiscal year 2020 level in the fiscal year 2021 budget for total spending at NIH and a minimum increase of $354 million to invest in biomedical, behavioral, and social sciences aging research efforts across NIH and research on Alzheimer's disease and related dementias over the enacted fiscal year 2020 level

Sustained and enhanced Federal investment in these initiatives is essential to delivering high-quality, better coordinated, efficient, and cost-effective care to our older Americans whose numbers are projected to increase dramatically in the coming years. According to the U.S. Census Bureau, the number of people age 65 and older is projected to more than double from 49 million today to more than 94 million by 2060,[1] while those 85 and older is projected to more than triple from 6 million today to 19 million by 2060.[2] As our aging population increases, so too will the prevalence of diseases disproportionately affecting older people-most notably Alzheimer's disease and related dementias (including vascular, Lewy body, and frontotemporal dementia)—and the economic burden associated with these diseases.

To ensure that our nation is prepared to meet the unique healthcare needs of this rapidly growing population, we request that Congress provide additional investments necessary to expand and enhance the geriatrics workforce, which is an integral component of the primary care workforce, and to foster groundbreaking medical research.

PROGRAMS TO TRAIN GERIATRICS HEALTHCARE PROFESSIONALS

Geriatrics Workforce Enhancement Program and Geriatrics Academic Career Awards (at least $51 million)

Our healthcare workforce receives little, if any, training in geriatric principles,[3] which leaves us ill-prepared to care for older Americans as health needs evolve, especially during the current crisis. With our nation continuing to face a severe shortage of geriatrics healthcare providers and academics with the expertise to train these providers, the AGS believes it is urgent that we increase the number of educational and training opportunities in geriatrics and gerontology. The requested increase in funding over fiscal year 2020 levels would help ensure that HRSA receives the funding necessary to expand these critically important programs commensurate with the increasing need.

The GWEP is currently the only Federal program designed to increase the number of providers, in a variety of disciplines, with the skills and training to care for older adults. The GWEPs educate and engage the broader frontline workforce, including family caregivers, and focus on opportunities to improve the quality of care delivered to older adults, particularly in underserved and rural areas. The GWEP was launched in 2015 by HRSA with 44 three-year grants provided to awardees in 29 states. In 2019, HRSA funded a second cohort of 48 GWEPs across 35 states and two territories (Guam and Puerto Rico) and provided extension grants to 15 former GWEP awardees. Due to GWEPs' partnerships with primary care and community-

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[1] U.S. Census Bureau. (2018). An Aging Nation: Projected Number of Children and Older Adults. Retrieved from https://www.census.gov/library/visualizations/2018/comm/historic-first.html.

[2] Ibid.

[3] Only 3 percent of medical students take even one class in geriatric medicine and fewer than 1 percent of RNs, pharmacists, physician assistances and physical therapists are certified in geriatrics or gerontology. Yet estimates are that by 2030, 3.5 million additional healthcare professionals and direct-care workers will be needed to care for older adults. 2018 Issue Brief, Eldercare Workforce Alliance, available at: https://eldercareworkforce.org/wp-content/uploads/2018/03/GWEP__OnePager__v2.pdf.

based organizations, GWEPs are uniquely positioned to rapidly address the needs of older adults and their caregivers.

The GACA program is an essential complement to the GWEP. GACAs ensure we can equip early-career clinician educators to become leaders in geriatrics education and research. It is the only Federal program designed to increase the number of faculty with geriatrics expertise in a variety of disciplines. The program was eliminated in 2015 through a consolidation of several training programs. However, the program was reestablished in November 2018 when HRSA released a funding opportunity indicating their intention to fund 26 GACAs for 4 years starting September 1, 2019. Since 1998, original GACA recipients have trained as many as 65,000 colleagues in geriatrics expertise and have contributed to geriatrics education, research, and leadership across the U.S.

Our nation currently faces an unprecedented public health emergency, the novel coronavirus, significantly impacting our older loved ones. Access to a well-trained workforce and appropriate care for medically complex older adults is imperative to maintaining the health and quality of life for this growing segment of the nation's population. As our nation works toward recovery and resilience from the pandemic, our population will continue to age, and the need for training in geriatrics and gerontology will continue to increase.

To address this issue, we ask the Subcommittee to provide a fiscal year 2021 appropriation of at least $51 million for the GWEPs and GACAs. This small increase in funding over fiscal year 2020 levels would help ensure that HRSA receives the funding necessary to carry these critically important programs forward. Additional funding will also allow HRSA to expand the number of GWEPs and GACAs and move towards closing the current geographic and demographic gaps in geriatrics workforce training.

RESEARCH FUNDING INITIATIVES

National Institutes of Health/National Institute on Aging (additional $500 million for aging research efforts and a minimum increase of $354 million for Alzheimer's disease and related dementias research)

The institutes that make up the NIH and specifically the NIA lead the national scientific effort to understand the nature of aging and to extend the healthy, active years of life. As a member of the Friends of the NIA (FoNIA), a broad-based coalition of aging, disease, research, and patient groups committed to the advancement of medical research that affects millions of older Americans-the AGS urges you to include an increase of at least $500 million in the fiscal year 2021 budget for biomedical, behavioral, and social sciences aging research efforts across NIH and a minimum increase of $354 million for research on Alzheimer's disease and related dementias over the enacted fiscal year 2020 level.

The Federal Government spends a significant and increasing amount of funds on healthcare costs associated with age-related diseases. By 2060, for example, the number of people affected by dementia is estimated to reach 14.9 million cases-nearly triple the number in 2020.[4] Further, chronic diseases related to aging, such as diabetes, heart disease, and cancer continue to afflict 80 percent of people age 65 and older[5] and account for more than 75 percent of Medicare and other Federal health expenditures.[6] Continued and increased Federal investments in scientific research will ensure that the NIH and NIA have the resources to conduct groundbreaking research related to the aging process, foster the development of research and clinical scientists in aging, provide research resources, and communicate information about aging and advances in research on aging.

Additionally, the AGS supports a $3 billion increase over the enacted fiscal year 2020 level in the fiscal year 2021 budget for total spending at NIH. We believe that a meaningful increase in NIH-wide funding, in combination with aging and prevalence of diseases increases, will be essential to sustain the research needed to make progress in addressing chronic disease, Alzheimer's disease, and related dementias that disproportionately affect older people.

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[4] Matthews, K. A., Xu, W., Gaglioti, A. H., Holt, J. B., Croft, J. B., Mack, D., & McGuire, L. C. (2019). Racial and ethnic estimates of Alzheimer's disease and related dementias in the United States (2015–2060) in adults aged≥ 65 years. Alzheimer's & Dementia, 15(1), 17–24.

[5] National Prevention Council. (2016). Health Aging in Action: Advancing the National Prevention Strategy. Retrieved from https://www.cdc.gov/aging/pdf/healthy-aging-in-action508.pdf.

[6] Erdem, E., Prada, S.I., Haffer, S.C. (2013). Medicare Payments: How Much Do Chronic Conditions Matter? Medicare & Medicaid Research Review, 3(2). Retrieved from http://dx.doi.org/10.5600/mmrr.003.02.b02.

Strong support such as yours will help ensure that every older American is able to receive high-quality care. We greatly appreciate the Subcommittee for the opportunity to submit this testimony.

PREPARED STATEMENT OF THE AMERICAN HEART ASSOCIATION

On behalf of our 40 million volunteers and supporters, the American Heart Association (AHA) thanks Congress for its ongoing commitment to the National Institutes of Health (NIH) and Centers for Disease Control and Prevention (CDC). We also commend Congress for its bipartisan response to the COVID–19 pandemic, which places heart disease and stroke patients at heightened risk. According to emerging data, 40 percent of hospitalized coronavirus patients have some form of cardiovascular disease, and experience 2 to 3 times higher death rates. Doctors are reporting that hospitalized coronavirus patients are experiencing cardiovascular complications such as heart-rhythm disorders, blood clots, inflammation of the heart, and myocarditis, which can lead to heart failure. Research from several countries has also found cardiac damage in as many as 1 in 5 patients, even among those with no signs of respiratory distress or previous heart disease. Furthermore, new studies indicate that children with multisystem inflammatory syndrome caused by COVID–19 may experience heart failure.

Although advances in research and prevention have produced large reductions in mortality over many decades, cardiovascular disease (CVD) stubbornly remains the leading cause of death and disability in the United States, affecting 121.5 million Americans and accounting for 1 in every 6 healthcare dollars spent. Recent data shows that nearly half (48 percent) of U.S. adults have some form of cardiovascular disease. Even more troubling, the overall decline in population mortality rates for CVD is slowing with actual increases for some groups, especially for those living in rural counties in the United States. Data from the 2017 Centers for Disease Control and Prevention (CDC) National Health Interview Survey showed a 40 percent higher prevalence of heart disease among rural residents compared with their counterparts in small metropolitan and urban areas, a gap that has grown over the past decade. Among leading causes, rural areas have significantly higher rates of uncontrolled cardiovascular risk factors including tobacco use, physical inactivity, diabetes, high cholesterol, obesity, and substance abuse.

Placing the highest burden on our nation's health and economy, heart disease, stroke and other forms of cardiovascular disease remain our nation's top killer and most expensive disease, costing nearly $1 billion a day. This cost is projected to reach over $1 trillion a year by 2035. The American Heart Association calls on Congress to respond to the challenges presented by cardiovascular disease by supporting the NIH and CDC heart disease and stroke programs.

National Institutes of Health (NIH)—Propelling Scientific and Economic Growth

Robust NIH-funded research helps prevent and cure disease, transforms patient care, propels economic growth, drives innovation, and preserves U.S. leadership in pharmaceuticals and biotechnology. NIH continues to be the world's leader of basic research-the basis for all medical progress and a basic Federal Government role the private sector cannot emulate. Unfortunately, our country's competitive edge in research has been eroded recently by inadequate resources. Specifically, the U.S. has fallen out of the top 10 in innovation and China is on the path to surpass our Nation in spending on science research and development.

In addition to enriching health, NIH generates a strong return on investment. In 2019, NIH supported more than 476,000 U.S. jobs and more than $81 billion in economic activity in every state and in nearly all congressional districts. Between 2010–2016 NIH research investments led to 210 new medicines winning FDA approval and for every dollar increase in public basic research an additional $8.38 of industry research and development is stimulated. Yet, due to insufficient funding, NIH lost over 20 percent of its purchasing power since 2003, as other countries have boosted scientific investments, some by double digits. Moreover, NHLBI extramural heart research dropped 22 percent in constant dollars since 2003. This threatens to stall scientific progress and could deter young scientists from pursuing careers in research unless Congress acts now.

American Heart Association Advocates: We urge Congress to appropriate $44.7 billion to the NIH to build on recent investments and to improve health, spur economic growth, and preserve U.S. leadership in biomedical research. We ask Congress to prioritize funding for heart disease and stroke research to reflect the devastating burden they inflict on Americans and to restore progress that has been stalled in the battle against cardiovascular disease.

Cardiovascular Disease Research: National Heart, Lung, and Blood Institute (NHLBI)

People with underlying health conditions, such as cardiovascular disease, hypertension, and diabetes have a higher risk for severe COVID–19 complications and death. In severe cases, the SARS-CoV2 triggers an inflammatory response that can damage many organs in the body including the heart, lung, and vascular systems. With initial supplemental funding provided in the CARES Act, the National Heart, Lung, and Blood Institute (NHLBI) is supporting research that will improve our understanding of how COVID–19 attacks the body. This newly acquired knowledge will in turn catalyze safe and effective treatments against the virus. Recognizing the disparate impact the coronavirus is having on segments of the American population, NHLBI is also leveraging existing clinical trials and community-based studies to uncover the different manifestations of the virus and its biomarkers.

To expand its investment in vital basic, clinical, and translational research that addresses COVID–19 while also sustaining current activities and investment in promising and critically needed scientific research, AHA supports $3.924 billion for NHLBI. This funding will allow the institute to tandemly address the COVID–19 pandemic while aggressively advancing the fight against heart disease, stroke, heart failure, congenital heart disease, and vascular dementia identified in NHLBI's Strategic Vision. Funding will also target reducing heart disease deaths for women including mothers. The U.S. maternal mortality rate is the worst among industrialized nations and heart disease is the number one reason for maternal mortality. Furthermore, many women who experience conditions like preeclampsia or gestational diabetes are at greater risk for heart disease later in life.

Stroke Research: National Institute of Neurological Disorders and Stroke (NINDS)

Stroke continues to inflict a massive burden on our nation's long-term health and economic stability. An estimated 795,000 Americans will suffer a stroke this year, and more than 146,000 will die. Many of the 7 million survivors face grave physical, mental, and emotional distress. Stroke costs an estimated $45.5 billion in medical expenses and lost productivity annually. Projections also show that stroke's medical direct costs will more than double by 2035. Since the onset of the coronavirus pandemic, hospitals are reporting unusually high numbers of stroke victims infected with COVID–19. These strokes are believed to be caused by blood clots that form as the virus damages blood vessel linings throughout the body. Experts say that this can happen in any patients regardless of age, and even in those with few or no symptoms.

AHA recommends $2.621 billion for NINDS. This funding level will enhance existing initiatives and proactively advance the top priorities in stroke prevention, treatment, and recovery research. This includes supporting basic research and large population-based studies exploring genetic, lifestyle, and other risk factors related to stroke in diverse populations, including in rural communities that are found in the stroke belt. Additional support will also fund ongoing stroke research conducted under the BRAIN Initiative; research exploring how the accumulation of white matter lesions in the brain can lead to stroke and dementia; and ongoing clinical trials that are developing new treatments and improved approaches to stroke recovery and rehabilitation.

Preventing Cardiovascular Disease: Centers for Disease Control and Prevention (CDC)

Cardiovascular disease is largely preventable -yet, risk factors such as the increasing prevalence of diabetes mellitus, childhood obesity, and hypertension rates are rising. Additionally, the use of e-cigarettes has reached an epidemic level and threatens to erase decades of progress to reduce tobacco use, especially among youth. We join the CDC Coalition in asking for $8.3 billion for the Centers for Disease Control and Prevention. In addition, we request $1.73 billion for the National Center for Chronic Disease and Health Promotion to support chronic disease prevention and public health initiatives. Chronic diseases are responsible for 7 in 10 deaths each year and account for most of our nation's healthcare costs.

The association requests $192 million for the Division for Heart Disease and Stroke Prevention (DHDSP) as part of the national effort to reduce COVID–19 related health complications and mortality. This $50 million in additional funding will expand and enhance the division's ongoing activities to improve the nation's overall cardiovascular health through risk factor screening and promoting behavioral health interventions. These funds and resources should be focused on communities with the highest burden of heart disease and stroke; especially among populations where cardiovascular disease mortality rates have recently increased.

As part of an overall strategy to prevent the development of cardiovascular disease, AHA requests $125 million for the Division for Nutrition, Physical Activity, and Obesity (DNPAO) to invest in effective strategies that support healthy eating and active living. Currently, DNPAO funds a limited number of states and communities to support these evidence-based strategies. An increase in funding will allow the CDC to fund all 50 states and the District of Columbia.

Cardiovascular disease is the leading cause of death for women. To help combat this largely preventable disease, AHA proposes $46.7 million for WISEWOMAN to expand access to this state-based initiative to the entire nation. WISEWOMAN helps uninsured and under-insured low-income women ages 40 to 64 understand and reduce their risk for heart disease and stroke by providing risk factor screenings and connecting them with lifestyle programs, health counseling, and other community resources.

We further recommend $5 million for Million Hearts to advance its goal of preventing 1 million heart attacks and strokes by 2022. Additional support will help to identify best practices to reduce heart disease and stroke, conduct surveillance and data analysis to improve interventions in high burden populations, and to administer recognition programs for hospitals and health systems that are committed to working systematically to improve the cardiovascular health of the communities they serve.

AHA also supports a $310 million appropriation for the Office on Smoking and Health (OSH). Additional resources will allow OSH to address the new threat to public health posed by skyrocketing rates of youth e-cigarette use while continuing to prevent and reduce other forms of tobacco use.

Bridge Funding to Protect Nonprofit Research Pipeline

Supporting the biomedical research enterprise is more important than ever for learning from this pandemic, creating evidence-based clinical guidelines and robust systems of care, understanding the epidemiology of infectious and chronic disease, and assuring population health and well-being. The AHA is deeply concerned about the economic consequences that the COVID–19 pandemic will have on America's research ecosystem including the nonprofit and voluntary health community, which is a critical pillar of America's drug research and development pipeline as the fourth largest contributor for U.S. medical and health research and development expenditures, and funder of thousands of early and mid-career scientists and researchers each year. The decreases in revenue that the sector is experiencing as a direct result of the COVID–19 pandemic will significantly impact its ability to fund new basic or clinical research and halt completion of ongoing clinical trials, effectively bringing innovation to a stand-still. The AHA urges Congress to provide at least $2 billion in emergency funding to support organizations by offsetting the costs associated with stalled research, costs for restarting research once researchers can return to their labs, and unanticipated delays resulting from the COVID–19 pandemic that will cause funding overages.

[This statement was submitted by Robert A. Harrington, M.D., FAHA, President, American Heart Association.]

PREPARED STATEMENT OF THE AMERICAN INDIAN HIGHER EDUCATION CONSORTIUM

On behalf of the nation's 37 Tribal Colleges and Universities (TCUs), which collectively are the American Indian Higher Education Consortium (AIHEC), we thank you for the opportunity to share our fiscal year 2021 funding requests. The following is a list of recommendations including Department, program, and funding requests.

Department of Education

Office of Postsecondary Education

—Strengthening Institutions HEA Title III—Part A (Sec. 316): $45,000,000 (discretionary)

—Perkins Career and Technical Education Programs (Sec. 117): $12,000,000

Department of Education

Office of Indian Education

—Indian Education Professional Development Program: $20,000,000

Department of Health and Human Services

—Administration for Children and Families/Office of Head Start
    —TCU-Head Start Partnership Program: $8,000,000 in existing funds

Tribal Colleges and Universities: Serving Students Across Indian Country and Rural America

Currently, 37 TCUs operate more than 75 campuses and sites in 16 states. TCU geographic boundaries encompass 80 percent of American Indian reservations and Federal Indian trust lands. American Indian and Alaska Native (AI/AN) TCU students represent more than 230 federally recognized tribes and hail from more than 30 states. Nearly 80 percent of these students receive Federal financial aid, and more than half are first generation students. In total, TCUs serve over 165,000 American Indians, Alaska Natives, and other rural residents each year through a wide variety of academic and community-based programs. Funding cuts of any amount to even one TCU program would force TCUs to scale back vital programs and services that students rely on to complete degree and certificate programs needed to succeed in their chosen career paths. Any reduction in funding will threaten TCU accreditation status and will further stretch overtaxed faculty and staff or result in cuts to faculty and staff. The following are justifications for TCU fiscal year 2021 funding requests.

U.S. DEPARTMENT OF EDUCATION

Strengthening Tribal Colleges (HEA Title III—Part A—Section 316): TCUs urge the Subcommittee to provide $45,000,0000 for the Strengthening Tribal Colleges program (HEA Title III—Part A).

The Strengthening Institutions HEA Title III program for TCUs (Section 316) is specifically designed to address the critical, unmet needs of AI/AN students and their communities. Through this program, TCUs are able to provide student support services, native language preservation, basic upkeep of campus buildings and infrastructure, critical campus expansion, enterprise management systems, faculty for core courses, and other necessary elements for a quality educational experience. The Strengthening Institutions program provides formula-based aid to 35 TCUs through two funding sources: Part A discretionary funding (fiscal year 2020, $36.6 million) and Part F mandatory funding (fiscal year 2020, $28.2 million). Last year, TCUs feared losing nearly half of Title III funding with the anticipated expiration of Part F funding. Fortunately, the "Fostering Undergraduate Talent by Unlocking Resources to Education Act (Public Law 116–91) was signed in to law on December 20, 2019, permanently authorizing Part F mandatory funding at $30 million for TCUs. Part A and Part F of the Title III program are essential in supporting institutional development and student services. We strongly urge the Subcommittee to fund the Strengthening Institutions HEA III Part A—TCU Program (Section 316) at $45,000,000 million.

Carl D. Perkins Career and Technical Education Programs

Tribally Controlled Postsecondary Career and Technical Institutions: AIHEC requests $12,000,000 to fund grants under Sec. 117 of the Perkins Act.

Carl D. Perkins Career and Technical Education Act provides a competitively awarded grant opportunity for tribally chartered career and technical institutions (Sec.117), which provide critical workforce development and job creation education and training programs to AI/ANs from tribes and communities with some of the highest unemployment rates in the nation.

Native American Career and Technical Education Program (NACTEP): NACTEP (Sec. 116) reserves 1.25 percent of appropriated funding to support AI/AN career and technical programs. The TCUs strongly urge the Subcommittee to continue to support NACTEP, which is vital to the continuation of career and technical education programs offered at TCUs that provide job training and certifications to remote reservation communities.

Office of Indian Education

Indian Education Professional Development Program: AIHEC requests $20,000,000 for grants to TCUs and other institutions of higher education.

The Indian Education Professional Development Program, administered by the Office of Indian Education at the U.S. Department of Education, provides grants to institutions of higher education to prepare and train AI/ANs to serve as teachers and school administrators at elementary and secondary schools. There is a growing teacher shortage across the country, especially in urban and rural communities with high AI/AN populations, where teacher recruitment and retention pose unique challenges. In communities with teacher shortages, existing obstacles to student success such as inadequate facilities and limited broadband are further compounded by overcrowded classrooms. Targeted resources like the Indian Education Professional

Development Program help address this shortage and ensure that AI/AN students receive high quality elementary and secondary education.

Report Language Needed: Funding for two distinct activities is provided under the "Special Programs for Indian Children" account: the Indian Education Professional Develop Program and Native Youth Community Projects. Despite increased funding in 2016 to the overall account, increases were only provided to Native Youth Community Projects; the Indian Education Professional Development Program did not receive increased funding. In fiscal year 2019, the Special Programs for Indian Children account received $67,993,000, of which $9,564,000 was provided to the Indian Education Professional Development Program. AIHEC requests specific report language in order to increase funding for the Indian Education Professional Development Program, at a minimum of $20,000,000 in fiscal year 2021.

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES PROGRAMS

Administration for Children and Families—Office of Head Start: Tribal Colleges and Universities Head Start Partnership Program: AIHEC requests $8,000,000 for the TCU-Head Start Partnership program.

The TCU Head Start Partnership program was re-established with the designation of $4,000,000 within the fiscal year 2020 LHHS appropriations bill. TCUs have had marked success in training early childhood educators and Head Start teachers that are urgently needed across Indian Country. In 2017, 74.5 percent of Head Start teachers nationwide held a bachelor's degree as required by Federal law; but less than 42 percent of Head Start teachers met the requirement in Indian Country (Head Start Region 11); only 70 percent of workers in Region 11 met the associate-level requirements or were enrolled in associate's programs, compared to 90 percent nationally. TCUs are the most cost-effective way for filling this gap. From 2000 to 2007, the U.S. Department of Health and Human Services provided modest funding for the TCU-Head Start Program (42 U.S.C. 9843g), which helped TCUs build capacity in early childhood education by providing scholarships and stipends for Indian Head Start teachers and teacher aides to enroll in TCU early childhood/elementary education programs. Before the program ended in 2007 (ironically, the same year that Congress specifically authorized the program in the reauthorization of the Head Start Act), TCUs had trained more than 400 Head Start workers and teachers, many of whom have since left for higher paying jobs in elementary schools. Today, TCUs such as Salish Kootenai College (Pablo, MT) are providing culturally based early childhood education free of charge to local Head Start professionals. In Michigan, Bay Mills Community College provides online education programming for $50/credit to Head Start staff nationwide. However, many Head Start programs in Indian Country are paying far more for other sources to provide training. With the restoration and continuation of this modestly funded program, TCUs can aid in building an early childhood education workforce to better serve the education needs of our AI/AN children.

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

NEW Tribal College and University Centers for Excellence in Behavioral Health/Substance Abuse Prevention: AIHEC requests $10,000,000 to establish this program.

The goal of the TCU Centers of Excellence program, similar to an existing SAMHSA (Substance Abuse and Mental Health Services Administration) program for HBCUs, is to grow a well-skilled and culturally competent AI/AN behavioral health workforce by developing an apprenticeship-based network of TCUs and partners from the health industry and local, tribal, state, and regional providers. The TCU Centers of Excellence would share best practices in curriculum development, program implementation, and apprenticeships; recruit students to careers in behavioral health fields to address mental and substance use disorders; provide job training in behavioral health fields; and prepare students for achieving credentials in behavioral health fields. The TCU Centers of Excellence would emphasize education, awareness, workforce training, and preparation for careers in mental and substance use treatment, prevention, and research, including addressing opioid abuse prevention, opioid use disorder treatment, serious mental illness, and suicide prevention.

Conclusion

Tribal Colleges and Universities provide thousands of AI/AN students with access to high quality, culturally appropriate, postsecondary education opportunities, including critical early childhood education and behavioral health programs. The modest Federal investment in TCUs has paid great dividends in terms of employment, education, and economic development. We ask you to renew your commitment to help move our students and communities toward self-sufficiency and request your full consideration of our fiscal year 2021 appropriations requests. Thank you.

PREPARED STATEMENT OF THE AMERICAN LIBRARY ASSOCIATION

The American Library Association (ALA) urges the Subcommittee to include in its regular fiscal year 2021 appropriations bill at least the authorized level of $232 million for programs for the Library Services and Technology Act (LSTA), $24.5 million for the Laura Bush 21st Century Librarian Program administered by the Institute of Museum and Library Services (IMLS), and at least $30 million for the Innovative Approaches to Literacy (IAL) program under the Department of Education (DOE).

Libraries, like other public and private institutions, are struggling to keep up with community needs for information resources, particularly during the national emergency. As the crisis continues, reduced tax revenue from state and local governments are already impacting library budgets and forcing furloughs for library staffs. At the same time, community demand for library services for economic recovery will increase markedly (as we saw during the Great Recession).

Libraries offer streaming support for business advancement, career development, and online resume building for those who have been recently unemployed, and access to telehealth resources and trusted sources for public health information. Many libraries also have hotspot lending programs to help underserved families and students who do not have access to the Internet at home. Libraries are thinking creatively to provide services to patrons, such as streaming “story times” and author discussions to encourage young children and adult learners to keep reading in their homes. Libraries are leading the way in supporting student distance learning needs through 24-hour WiFi access in parking lots, homework help, mobile hotspots and other services.

ALA is the foremost national organization providing resources to inspire library and information professionals to transform their communities through essential programs and services. For more than 140 years, the ALA has been the trusted voice for academic, public, school, government and special libraries, advocating for the profession and the library’s role in advancing learning and ensuring access to information for all.

LSTA funding of at least $232 million for Grants to States and $24.5 million for the Laura Bush 21st Century Librarian Program will support your local library. If Senators haven’t been to a library recently, we urge Senators to visit their local library and see the range of services they provide constituents.

The bulk of LSTA funds are distributed to each state through the Institute of Museum and Library Services (IMLS) according to a population-based grant formula. Each state must provide a 33 percent match and determines at the state level how to meet local needs and best allocate its LSTA grant awards. Libraries have used LSTA funding for a broad range of diverse and innovative programs that profoundly touch and better the lives of tens of millions of Americans in every state in the nation, including particularly service to people with disabilities, veterans, and job seekers. LSTA is truly a local decisionmaking success story and a shining example of how a small Federal investment can be efficiently and reliably leveraged into dramatic state and local social and economic results. Here are just a few current examples among many thousands made possible by LSTA over time:

- —Libraries across Missouri have used LSTA Grants to participate in the annual Beanstalk Reading Challenge. The Challenge provides customized reading support, books, tracking, and incentives for young readers at numerous libraries in the state, including Carthage Public Library, Little Dixie Regional Libraries, Rolla Public Library, and University City Public Library.
- —LSTA Grants have supported the activities of the Washington Digital Heritage in carrying out a variety of digital initiatives focuses on archival and special collections of cultural and/or historical significance. These grants help preserve the stories of local communities and celebrate a common heritage.
- —The Alabama Regional Library for the Blind and Physically Handicapped has provided digital recordings and equipment, braille material, and services to more than 4,500 active patrons since 1978. LSTA Grants help make these services possible.
- —Caswell (NC) County Public Library used its grant to create a Learning Lab and Workforce Development Lab assisting local businesses access to tailored employment assistance, equipment, and access to a business and career center. A state-wide priority includes meeting needs of local business for workforce support.

—Dr. Soohyung Joo, assistant professor at the University of Kentucky School of Information Science, was awarded a Laura Bush 21st Century Librarian Program Planning Grant for her work towards helping UK libraries examine research needs of patrons, librarians, administrators, and scholars. This research helped refocus the services and curricular provided at UK libraries.

Patrons described above were the direct beneficiaries of the LSTA "Grants to States" program administered by IMLS. Grants support veterans, entrepreneurs, job seekers, taxpayers, children, and many others throughout our nation. The President's proposal to eliminate LSTA funding, in fact any cut to LSTA, will jeopardize vital and highly cost-effective programs that benefit millions of Americans in every state, and help build our economy one job and one community at a time. These community resources are needed now more than ever.

Thanks to LSTA and other IMLS funds, many state libraries can support Libraries for the Blind and Physically Handicapped or Talking Book services, which provide access to reading materials in alternate formats. There is no dedicated Federal funding stream for these individuals at the local and state level. LSTA Grants to States funding often fills this need.

Native American tribes are eligible to apply for LSTA grants through the Native American Library Services program which currently accounts for more than 8 percent of LSTA funding. These grants support existing library operations for tribal communities, enhancing digital connections, supporting professional development, and promote lifelong learning for tribes. Recent recipients of these grants include the Native Village of Port Graham (AK), Aroostook Micmac Council (ME), Little Travers Bay Bands of Odawa Indians (MI), and Kat Nation (OK).

Accordingly, ALA asks that the Subcommittee provide at least $232 million for LSTA and $24.5 million for the Laura Bush 21st Century Librarian Program in fiscal year 2021 to ensure that Americans of all ages continue to have access to important resources at their local library. ALA respectfully submits that there can be few, if any, more democratic, cost-effective and impactful uses of Federal dollars than LSTA in the entirety of the Federal budget.

In addition to supporting LSTA, ALA also asks that you maintain the modest, but critical, Federal investment of $30 million in the Innovative Approaches to Literacy (IAL) program, which was authorized under Every Student Succeeds Act. IAL provides competitive awards to school libraries and national not-for-profit organizations (including partnerships that reach families outside of local educational agencies) to put books into the hands of children and their families in high-need communities.

Providing books and childhood literacy for such children is crucial to their learning to read, which is crucial to their—and the nation's—economic futures. Studies have shown that developing early childhood reading proficiency is directly correlated to success in K–12 and college education and in careers. IAL also supports parental engagement in their children's reading life and focuses on promoting student literacy from birth through high school. IAL grants have been awarded during the life of the program to almost every state in the nation. Schools and non-profits across the country have received grants, including the Bering Strait (AK) School District, The Children's Reading Foundation (Kennewick, WA), Kansas City (MO) School District, Cuero (TX) School District, and as well as many others.

For families living in poverty, access to reading materials is severely limited. Children in such households have fewer books in their homes than their peers, which hinders their ability to prepare for school and to stay on track. IAL helps bridge that gap. Accordingly, we urge the Subcommittee to foster this work by continuing to invest at least $30 million in IAL.

ALA understands the tight fiscal constraints on the Subcommittee, and we appreciate its continued dedicated support of LSTA and IAL. Thank you for your commitment to sustaining and strengthening our communities and our nation by supporting America's libraries.

[This statement was submitted by Kathi Kromer, Associate Executive Director, American Library Association.]

PREPARED STATEMENT OF THE AMERICAN LIVER FOUNDATION

SUMMARY OF FISCAL YEAR 2021 APPROPRIATIONS RECOMMENDATIONS

—Please provide the National Institutes of Health (NIH) with a funding increase of at least $3 billion for to bring total agency funding up to a minimum of $44.7 billion annually.

  - —Please provide proportional increases for NIH Institutes and Centers, including the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Institute of Allergy and Infectious Diseases (NIAID).
- —Please provide the Centers for Disease Control and Prevention (CDC) with a funding increase of at least $500 million in discretionary resources to bring total agency funding up to a minimum of $8.3 billion annually.
  - —Please provide $5 million in line-item funding for a CDC "Chronic Disease Education and Awareness Program" as outlined in the fiscal year 2020 House L–HHS Appropriations Bill.
  - —Please provide at least $58 million for the CDC's new Elimination Initiative focused on the nexus of the opioid epidemic and the spike in infectious diseases.
  - —Please provide a meaningful fiscal year 2021 funding increase of $95 million for the Division of Viral Hepatitis (DVH) at the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, which was level-funded at $39 million for fiscal year 2020.
- —Please provide the Health Resources and Services Administration (HRSA) with a funding increase to at least $8.8 billion for fiscal year 2021.
  - —Please continue to support and encourage efforts to improve organ donation and otherwise enhance the ability of donor livers for individuals waiting on the transplant list for a donated liver.

Thank you for the opportunity to submit testimony on behalf of the American Liver Foundation (ALF) and the liver disease community. Chairman Blunt, Ranking Member Murray, and distinguished members of the subcommittee, we extend our thanks for the significant investments in HHS, particularly NIH, provided for fiscal year 2020. Please maintain this commitment and further enhances this support for medical research and public health programs during the fiscal year 2021 appropriations process. Thank you again.

ABOUT THE FOUNDATION

Founded in 1976, the American Liver Foundation (ALF) is the nation's largest patient advocacy organization for people with liver disease. ALF reaches more than?2?million individuals each year with health information, education and support services via its national office,?16?U.S. divisions and an active online presence. Recognized as a trusted voice for liver disease patients, ALF also operates a national toll-free helpline (800–GO–LIVER), educates patients, policymakers and the public, and provides grants to early-career researchers to help find a cure for all liver diseases. ALF is celebrating more than 40 years of turning patients into survivors. For more information about ALF, please visit liverfoundation.org.

LIVER FACTS

The liver is one of the body's largest organs, performing hundreds of functions daily including, removal of harmful substances from the blood, digestion of fat, and storing of energy. Non-alcoholic fatty liver disease (NAFLD), hepatitis C, and heavy alcohol consumption are the most common causes of chronic liver disease or cirrhosis (severe liver damage) in the U.S. Approximately 30 percent of adults and 3–10 percent of children have excessive fat in the liver or NAFLD which can lead to a severe liver disease called non-alcoholic steatohepatitis (NASH). Approximately 4.4 million Americans are living with Hepatitis B or C but most do not know they are infected. More than 2 million Americans are living with alcohol related liver disease. Approximately 5.5 million Americans are living with chronic liver disease or cirrhosis. Vaccinations for hepatitis A and B and treatments for hepatitis C are helping to change the course of this chronic life altering disease for the patient community.

LIVER CANCER PUBLIC HEALTH AT CDC

CDC hosts many important programs for cancer as well as chronic disease, but none focused on addressing liver cancer. While liver cancer is a leading killer, it is also preventable and more easily managed if diagnosed early. The reality though is that risk factors are not well known and there is an overall lack of public and professional awareness about preventative practices and properly managing the condition. CDC should have dedicated resources and congressional encouragement to conduct liver cancer activities so this patient community can enjoy the same benefits and public health improvements as similar communities with ongoing CDC programs. Rather than having Congress constantly adding and removing funding for timely activities, public health experts at CDC should have a dedicated pot of resources to administer grants and partnerships in meritorious and impactful areas.

ORGAN DONATION

Consistently, the number of organs available for transplantation on an annual basis amounts to only a fraction of the number of patients on the transplant list. Compounding this situation is the fact that fatty liver disease affects a large and growing number of individuals and makes livers unavailable for transplantation. Another complicating factor is the fact that the rationing of cures for hepatitis ensures that many patients who could otherwise be healthy end up on the transplant list too and arbitrarily deny available organs to other patients facing a variety of life-threatening illnesses. Please promote organ donation and otherwise work to ensure Medicaid and other patients impacted by hepatitis receive curative therapy when medically appropriate.

THE OPIOID EPIDEMIC

CDC has dubbed opioids and the infectious diseases that arrive in the wake of the opioid crisis a “dual epidemic”. Due to the rise in rates of injection drug use, CDC has identified a 400 percent increase in rates of hepatitis C among 20—29 year olds an 300 percent increase among 30—39 year olds. Last year, the elimination initiative was established at CDC, and the current budget request recommends greatly enhancing support from $5 million to $58 million. Significantly enhanced investment in this area is certainly warranted given the ongoing need.

PATIENT PERSPECTIVES

Alison.—Alison is now a healthy 25-year-old from Trumbull, Connecticut, only 5 years ago she was near death. Alison had been suffering for most of her life with primary sclerosing cholangitis (PSC), a condition that left her in need of a live-saving liver transplant. On October 19th, 2009, Alison began her new life when her transplant was successfully performed at Yale-New Haven Hospital. Further complications ensued. Alison needed three additional surgeries to ensure her health and that of her new liver. Today, she is healthy.

Kevin.—In May 2007, a medical team at New York Columbia Presbyterian Hospital conducted its first living donor liver transplant surgery on a bile duct cancer patient. The patient was Kevin, my younger brother. I was the living donor. The transplant worked, but Kevin had to endure multiple follow-up surgeries to address a bile leakage that would not stop. But now, over 10 years later, he has long since healed and doing great. We were lucky. And we know it.

Despite advances in medical and surgical science, the demand for organs continues to vastly exceed the number of donors. Here, in New York, only 27 percent of people age 18 and over have enrolled in the New York State Donate Life Registry. But every ten minutes another person is added to the national transplant waiting list. We need to encourage more people to sign up to donate organs.

David.—In October 2014 my mother Geraldine passed away after a very brief and completely unexpected battle with late-stage NASH. They call NASH the “silent killer” and in Mom’s case it was certainly true; she was never diagnosed with any form of liver disease at all before NASH. We had noticed some yellowing of her eyes and convinced her to go to the doctor about a month earlier, but it took time to get an appointment with a specialist, who checked her into a hospital upon the visit. I founded NASHAWARE.com to help raise awareness and educate others. If I can help even a few people it will all be worth it. But I still want to do much more.

[This statement was submitted by Lynn Seim, Executive Vice President and COO, American Liver Foundation.]

Prepared Statement of the American Lung Association

The American Lung Association is pleased to submit its recommendations for fiscal year 2021 to the Labor, Health and Human Services, and Education Appropriations Subcommittee.

The American Lung Association was founded in 1904 to fight tuberculosis and is one of the oldest voluntary health organizations in the United States. Since the beginning, the Lung Association has been on the front lines advocating for laws that protect the air we breathe and our lungs. Accordingly, the Lung Association is the leading organization working to save lives by improving lung health and preventing lung disease through education, advocacy and research. As the result of funding from this Committee, public health and research programs will help to prevent lung disease, improve health and, by extension, save the lives of millions of Americans.

STRENGTHENING AND REBUILDING PUBLIC HEALTH INFRASTRUCTURE

The COVID–19 pandemic has unscored the need for more robust investments in our nation's public health infrastructure and supporting programs that respond to public health emergencies. Several ideas have been discussed, including a revision of the fiscal year 2021 discretionary budget caps in general, an exemption of certain public health programs from the caps, and the creation of a health defense program designed to address emerging crises that would not be confined to the caps. The American Lung Association urges the committee to consider these and other approaches to build and strengthen the capacity of our national public health system.

The COVID–19 pandemic has also highlighted the importance of preventing and managing chronic lung conditions. Individuals living with lung disease are among the most at risk of serious health complications as a result of COVID–19. The Lung Association recognizes the tremendous challenge the Committee faces in responding to COVID–19 and urges the Committee to continue to invest in CDC programs that help smokers quit, promote asthma control and support prevention and treatment of other lung diseases, including COPD and lung cancer.

IMPROVING PUBLIC HEALTH AND MAINTAINING OUR INVESTMENT IN MEDICAL RESEARCH

The American Lung Association strongly supports an increase in funding to $44.7 billion for the National Institute of Health (NIH). We need sustained investments in NIH so that the promise of biomedical research can be achieved. The Lung Association supports robust funding increases for the individual institutes within NIH, recognizing the need for research funding increases to ensure the pace of research is maintained across NIH.

LUNG DISEASE

Lung disease is the third highest killer in America, taking the lives of almost 414,000 Americans each year. It has been estimated that more than 36 million Americans suffer from a chronic lung disease and lung disease costs the economy $129 billion each year.

THE PREVENTION AND PUBLIC HEALTH FUND

The Lung Association strongly supports the Prevention and Public Health Fund that was established in the Affordable Care Act. We ask the Committee to oppose any attempts to divert or use the Fund for any purposes other than what it was originally intended. The Prevention Fund provides funding to the Centers for Disease Control and Prevention (CDC) and its critical public health initiatives. The Prevention Fund also supports CDC's media campaign "Tips from Former Smokers."

LUNG CANCER

Lung cancer is the number one cancer killer of both women and men. It is estimated that 228,820 new cases of lung cancer will be diagnosed in 2020, and more than 135,000 Americans will die from the disease in 2020. Survival rates for lung cancer tend to be lower than those of other leading cancers due to the lack of early detection and diagnosis. African Americans are more likely to die from lung cancer than persons of any other racial group. We ask the Committee to increase funding for the National Institutes of Health to $44.7 billion in fiscal year 2021 and to include increased funding for lung cancer research as well as support for the Cancer Moonshoot and the All of Us Program.

TOBACCO USE

The use of tobacco is the number one preventable cause of death in the United States. More than 37 million American adults smoke and approximately half a million people die of tobacco-related disease each year. Annual healthcare and lost productivity cost more than $300 billion in the U.S. each year. Each day, about 1,600 kids under 18 years of age try their first cigarette and close to 200 kids become new, regular daily smokers. Additionally, e-cigarette use continues to increase among our nation's youth, and now 1 in 3 high school students use at least one tobacco product.

The CDC Office on Smoking and Health (OSH) must continue to receive robust funding to help combat the tobacco-caused diseases that are burdening the nation. Public health interventions have been scientifically proven to reduce tobacco use, the leading cause of preventable death in the United States. The American Lung Association urges that $310 million be appropriated to OSH for fiscal year 2021.

The American Lung Association respectfully requests the Committee's support for the Office of Smoking and Health and the "Tips from Former Smokers" Campaign. Over the past 5 years, 500,000 Americans have successfully quit smoking because of "Tips" and millions more have made quit attempts. The "Tips" campaign has been an incredible return on investment that continues to generate positive outcomes. An accepted threshold for cost-effective public health interventions is approximately $50,000. The 2012 Tips campaign spent $480 per smoker who quit and $393 per year of life saved.

ASTHMA

Over 24 million Americans have asthma, including 5.5 million children. It is a highly prevalent and costly disease. The nation is making progress to combat asthma, but this advancement can only continue with sustained investment. Asthma costs the U.S. an estimated $82 billion in healthcare costs, lost productivity and mortality. Almost half of children in the U.S. miss one or more days of school due to asthma symptoms.

The American Lung Association asks that you appropriate $34 million to CDC's National Asthma Control Program (NACP) in fiscal year 2021. The NACP tracks asthma prevalence, promotes asthma control and prevention and builds capacity in state programs. This program has been highly effective: the rate of asthma has increased, yet asthma mortality and morbidity rates have decreased. Currently, only 24 states and Puerto Rico receive funding—leaving a nationwide public health void that can lead to unnecessary asthma-related attacks and healthcare costs. Increased funding could help develop asthma programs in the remaining 26 states and the District of Columbia as well as allow for better surveillance, management and treatment of asthma. Currently, the CDC does not have comprehensive surveillance data for asthma nationwide, which makes it difficult to compare statistics across states, cities and territories. An increase in funding would provide CDC with resources to conduct better monitoring of asthma and identify states, regions and communities with the greatest burden of disease.

Additionally, we recognize the importance of robust and sustained increases for the National Heart, Lung and Blood Institute, the National Institute of Allergy and Infectious Diseases and the National Institute for Environmental Health Sciences. With increased support, these agencies will be able to continue their investments in asthma research in pursuit of treatments and cures.

CHRONIC DISEASE EDUCATION AND AWARENESS

COPD is the fourth leading cause of death in the U.S. More than 18 million U.S. adults had evidence of impaired lung function, indicating an under diagnosis of COPD. In 2016, 151,078 people in the U.S. died of COPD, representing one COPD death every 3.5 minutes. The American Lung Association also asks the Committee to continue its support of the National Heart, Lung and Blood Institute working with CDC and other appropriate agencies to act on its national action plan to address COPD, which should include public awareness and surveillance activities. The American Lung Association requests sustained and robust funding for the National Heart, Lung and Blood Institute as well as funding for CDC to implement the National COPD Action Plan.

In fiscal year 2020, the House created a new line for chronic disease education and awareness within CDC's National Center for Chronic Disease Prevention and Health Promotion. This additional line will allow CDC to respond to chronic diseases—including COPD—that do not have stand-alone programs. The American Lung Association is requesting an initial investment of $5 million in funding for this program.

IMPACT OF CLIMATE CHANGE ON LUNG HEALTH

CDC's Climate and Health Program is the only HHS program devoted to identifying the risks and developing effective responses to the health impacts of climate change, including worsening air pollution; diseases that emerge in new areas; stronger and longer heat waves; and more frequent and severe droughts, and provides guidance to states in adaptation. Pilot projects in 16 states and two city health departments use CDC's Building Resilience Against Climate Effects (BRACE) framework to develop and implement health adaptation plans and address gaps in critical public health functions and services. As climate-related challenges intensify, CDC must have increased resources to support states and cities in meeting the challenge. The Lung Association supports $15 million for the Centers for Disease Control and Prevention's Climate and Health Program.

TUBERCULOSIS

TB, an airborne infectious disease, is a leading global infectious killer, causing 1.3 million deaths annually. In the U.S., every state reports cases of TB (Tuberculosis) annually, with California, Texas, Hawaii and Alaska having the highest burdens. TB outbreaks continue to occur across the country in schools, workplaces and prisons, costing the U.S. over $460 million annually. Drug-resistant TB poses a particular challenge to TB control due to the high costs of treatment and intensive healthcare resources required. Treatment costs for multidrug-resistant (MDR) TB range from $100,000 to $300,000 per case and can be over $1 million for treatment of extensively drug resistant (XDR) TB, which can outstrip state and local public health department budgets. We request that Congress increase funding for tuberculosis programs at CDC to $243 million for fiscal year 2021.

CONCLUSION

Lung disease remains a growing problem in the United States and is leading the nation as the third highest killer. The COVID–19 pandemic demonstrates the critical need to invest in public health programs so that they can respond to new and emerging diseases while continuing to direct resources towards chronic lung disease. The level of support this Committee approves for lung disease programs should be reflective of the urgency and magnitude of impact that lung disease has had on Americans.

The American Lung Association respectively requests that the Committee supports funding requests and strongly encourages you to oppose all policy riders on appropriations bills. Policy riders can weaken key lung health protections, including those in the Affordable Care Act, the Clean Air Act and the Tobacco Control Act. The Lung Association is appreciative of your support, and we thank you for your consideration of our recommendations.

[This statement was submitted by Harold P. Wimmer, National President and CEO, American Lung Association.]

PREPARED STATEMENT OF THE AMERICAN MASSAGE THERAPY ASSOCIATION

The American Massage Therapy Association (AMTA) appreciates the opportunity to submit a statement to the Senate Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies in support of continued robust funding in fiscal year 2021 for the National Center for Complementary and Integrative Health (NCCIH) within the National Institutes of Health (NIH).

Established in 1943 and numbering over 94,000 members, AMTA works to advance the massage therapy profession through the promotion of fair and consistent licensing of massage therapists in all states, public education on the benefits of massage therapy, and support of research to advance knowledge about massage therapy. Massage therapists are currently licensed in 45 states and the District of Columbia.

We would like to note at the outset some examples of the growing support and recognition of the health benefits of massage therapy that have occurred as a direct result of an ever-growing body of research, after which we will note some examples of areas where continued Federal support is crucial to help us continue to move forward.

Research has served to increase support for massage therapy by policymakers at both the Federal and state level, as we learn more about the health benefits of massage therapy as part of an integrative approach to patient care. NCCIH notes the value of massage therapy for a wide variety of health conditions involving both acute and chronic pain, including low back pain, neck and shoulder pain, symptoms and side effects associated with certain cancers, fibromyalgia, HIV/AIDS, among others.

In addition to NIH, massage therapy is supported by the American College of Physicians and The Joint Commission. Massage is currently utilized in many nationally renowned hospitals and other institutions, such as the Mayo Clinic, M.D. Anderson Cancer Center, Duke Integrative Medicine, the Cleveland Clinic, and Memorial Sloan Kettering Cancer Center. Finally, CMS includes massage therapy provided by a state licensed massage therapist as a supplemental benefit for pain management in Medicare Advantage plans, and massage is also a covered benefit for our nation's veterans and active duty military personnel

In recent years, policymakers have also recognized the benefits of massage therapy as a non- pharmacologic alternative to opioid use to manage pain. Massage therapy is specifically supported in the May 2019 final report of the "HHS Best Practices Pain Management Task Force (PMTF)" and is included in the PMTF "Pain Management Toolbox" as an example of a treatment modality that should be considered as part of an overall integrative and collaborative care model to ensure optimal patient outcomes. https://www.hhs.gov/sites/default/files/pmtf-final-report-2019-05-23.pdf.

As well, massage has been specifically noted in guidelines for non pharmacologic opioid alternatives issued by the Attorney General of West Virginia; and, it is among a list of four non-pharmacologic approaches to pain in a September 18, 2017 letter to American's Health Insurance Plans, signed by 37 Attorneys General, which urges health insurance companies to encourage healthcare providers to prioritize non-opioid pain management options for chronic pain, as follows:

"When patients seek treatment for any of the myriad conditions that cause chronic pain, doctors should be encouraged to explore and prescribe effective non-opioid alternatives, ranging from non-opioid medications (such as NSAIDs) to physical therapy, acupuncture, massage, and chiropractic care."

Despite the demonstrated value and efficacy of massage therapy through research, we know that more needs to be done. Long standing CMS policy notes the critical importance of research in driving Medicare coverage and reimbursement for medical procedures, therapies, and interventions. As such, additional research is needed to help assess any potential risks and the optimal benefits of massage for particular demographic groups, including patients as young as infants up to Medicare beneficiaries, as well as the scope and length of time needed for massage therapy for specific conditions in order to determine the optimal amount of therapy needed to achieve both short and long term results. Last, we need to better understand the underlying mechanisms of pain, and how and why pain manifests differently for different patients.

For the last 30 years, the Massage Therapy Foundation (MTF) a 501(c) (3) organization, working with AMTA, has provided over $1 million in research grants studying the science behind therapeutic massage. This seed money has funded needed research on a wide range of topics including: the effectiveness of massage therapy in decreasing muscle atrophy to help individuals recover from muscle disuse, the benefits of massage for patients with severe heart failure, and the effect of massage therapy on opioid use in hospital pediatric populations. Many of these efforts have been specifically designed to include racially diverse and underserved populations.

While the MTF seed money has helped refine our collective understanding about massage in many important areas, it is critical that NCCIH continue to drive forward the most promising science surrounding massage and other integrative therapies to address both acute and chronic pain conditions. In these most challenging times, the need to advance and support evidence-based non-opioid alternatives for pain management has likely never been more important.

Many experts believe that COVID–19 and opioid misuse will unfortunately impact and worsen each other, because of the volume of deferred medical treatments over these last months, combined with overall rising levels of anxiety and stress throughout our society. More research is needed to determine the impact of the COVID–19 pandemic on patients currently experiencing chronic pain: early anecdotal evidence appears to indicate that patients with chronic pain during the COVID pandemic are beginning to exhibit symptoms similar to those who are have PTSD.

We know that massage therapy can improve health outcomes and is also among the most cost-effective therapies that can save healthcare expenditures in the long run. Massage therapy demonstrably reduces or mitigates reliance on opioids to address pain. Massage therapy can serve as a 'portal' to increase patient involvement in other important health activities, e.g. research shows that patients who obtain massage are more likely to be able to move better, and thus engage in other physician-prescribed activities such as corrective exercise programs.

We recognize the challenges that Congress faces in these difficult times. We encourage the Subcommittee to include a sustained and meaningful funding level for NIH and NCCIH that supports the role of integrative therapies to help mitigate opioid abuse and misuse, and which will enable continued advancements in the use of non pharmacologic therapies such as massage.

Sincerely.

[This statement was submitted by James Specker, Director, Industry and Government Relations, American Massage Therapy Association.]

PREPARED STATEMENT OF THE AMERICAN NATIONAL RED CROSS AND THE UNITED NATIONS FOUNDATION

Chairman Roy Blunt, Ranking Member Patty Murray, and Members of the Subcommittee, the American Red Cross and the United Nations Foundation appreciate the opportunity to submit testimony. We are writing today in support of measles and rubella control activities of the U.S. Centers for Disease Control and Prevention (CDC).

We request that Congress invest $50 million for CDC's global measles and rubella elimination efforts for fiscal year 2021. The American Red Cross and United Nations Foundation recognize the leadership that Congress has shown in funding CDC in prior years and urge Congress to protect the CDC's funding necessary for their global measles control activities for fiscal year 2021 at $50 million, which is part of the $226 million for the overall Global Immunization Programs line.

COVID–19 ENVIRONMENT

The outbreak and eventual pandemic status of the COVID–19 disease has ushered in a new global reality, particularly related to infectious disease. Immediate supplemental funding for the emergency response is critical to turn the tide against the COVID–19 both domestically and abroad. However, investments in global health programs through the regular appropriations process are equally vital to ensure that gains made in reducing maternal and child mortality and morbidity are not lost, and that the global health infrastructure established through these investments is preserved and strengthened.

Global estimates indicate that more than 117 million children in 37 countries may miss out on life-saving measles vaccines. Measles immunization campaigns are delayed in more than 24 countries increasing the risk of future outbreaks. Among other benefits, this global health architecture is vital to protecting global health security by detecting emerging infectious diseases like COVID–19, establishing networks of laboratories capable of processing diagnostics, and bolstering the global public health workforce of trained professionals and volunteers who are often the first responders during health crises.

ELIMINATING MEASLES AND RUBELLA: AMERICAN LEADERSHIP THROUGH CDC

The United States is the leader in the drive to eliminate measles and rubella globally. Congressional support has enabled CDC to detect, prevent, detect, respond to vaccine preventable threats including measles and rubella. With this context in mind, we respectfully provide the following justification for robust investment in CDC's global measles and rubella elimination efforts. The global immunization infrastructure is built off investments initially made by polio eradication and strengthened by continuing under measles and rubella elimination. In 2019, there were major outbreaks of measles in every major region of the world. CDC supported 8 measles outbreak countries and immunization activities in 6 non-outbreak countries leading to more than 26 million people vaccinated globally in 2019. In February 2020, CDC's Center for Global Health activated the Measles Incident Management System (MIMS) to help accelerate the response to global measles outbreaks. The Measles & Rubella Initiative, of which CDC is a core partner, is fully committed to supporting countries to maintain and restart measles immunization campaigns when it is safe to do so.

CDC's core strength is disease surveillance and data analysis, which allows countries to better design, plan, and implement measles elimination activities and outbreak response immunization campaigns. CDC played a key role in assuring the quality of supplemental campaigns in Samoa's measles outbreak and helped re-establish case-based, lab-supported measles surveillance in Samoa as the outbreak ended. In D.R. Congo, CDC's data analysis helped the country strengthen its measles program and conduct outbreak response activities. The result has been a marked decrease in measles cases after vaccination, while the country also fought outbreaks of Ebola and circulating vaccine-derived poliovirus. Finally, the CDC Global Measles and Rubella laboratory provides the backbone of support for training laboratorians, providing reagents needed for measles testing, and serving as a global reference lab for measles and rubella.

WHY MEASLES AND RUBELLA?

U.S. leadership has saved the lives of 21.1 million children between 2000 and 2018 the Measles & Rubella Initiative drove measles deaths down by 73 percent.

Measles is a highly contagious disease that can cause blindness, swelling of the brain, and death. Nine out of ten people who are not immune to measles will contract the disease if they come into contact with a contagious person, and there are long-term damages to the immune system for those who contract the virus. The rubella virus is a leading infectious cause of birth defects in the world despite availability of an affordable, effective vaccine since 1969. Every day, roughly 384 children still die of measles-related complications. When rubella occurs early in a pregnancy, it can cause miscarriages, stillbirths, or a constellation of severe birth defects that can impact vision, hearing, heart health, overall development.

Since 2000, measles vaccines have been the single greatest contribution in reducing preventable child deaths globally. We've had safe and effective vaccines for both rubella and measles for over 50 years, but unfortunately vaccination rates globally have stagnated for almost a decade.

DOMESTIC IMPLICATIONS

In 2019 the U.S. reported 1,282 cases of measles in 32 states, the largest number of cases since 1992. Major outbreaks in New York and Washington state have been linked to importation of the disease from Israel and Ukraine by unvaccinated travelers. Controlling measles and rubella cases in other countries also protects adults and children in the U.S. In the United States, measles control measures have been strengthened, and endemic transmission of measles cases has been eliminated since 2000 and rubella in 2002. However, importations of measles cases into this country continue to occur each year.

Measles spreads much more quickly than the flu or the Ebola virus. A single person infected with measles can infect up to 18 other unvaccinated people, compared with three for Ebola. The 2014–2015 Ebola outbreak in Guinea, Sierra Leone and Liberia killed a total of 11,310 people. By comparison 2014, measles killed nearly 115,000 people worldwide, more than 10 times the number of deaths from Ebola. Measles can also cause severe complications such as pneumonia and encephalitis. In addition, each year more than 100,000 children are born with congenital rubella syndrome (CRS). CRS is the leading vaccine preventable cause of severe birth defects worldwide. These birth defects can include blindness, deafness, heart defects and mental retardation. CRS is very costly to treat, yet very inexpensive to prevent. Working closely with host governments, the Measles & Rubella Initiative has been the main international supporter of mass measles immunization campaigns since 2001.

Responding to a measles outbreak can cost state and local health departments $100,000 per case to halt disease spread. One in four cases of measles requires hospitalization, costing up to $15,000 per patient. For people experiencing complications such as encephalitis, occurring in one in 1,000 cases, the diagnosis and treatments can cost patients more than $100,000. In the U.S., caring for a person with congenital rubella syndrome can cost close to $1 million over the patient's lifetime.

Eliminating measles and rubella is the right thing to do for children to meet their full potential. The $58 to $1 return on investment, coupled with the benefit of protecting American children against importation of measles into the U.S., demonstrates that investments in CDC's measles and rubella elimination program is an excellent use of taxpayer dollars.

THE MEASLES & RUBELLA INITIATIVE

The Measles & Rubella Initiative (M&RI)—which includes the American Red Cross, CDC, UNICEF, the United Nations Foundation and WHO, as well as Gavi, the Vaccine Alliance, helps countries respond to measles outbreaks, through key interventions like supplementary vaccination campaigns and emergency response.

M&RI has achieved outstanding results by supporting the vaccination of nearly three billion individuals in over 90 countries since 2001 and saving the lives of more than 21.1 million children. In part due to M&RI, global measles mortality has dropped 73 percent, from an estimated 545,000 deaths in 2000 to an approximately 114,000 in 2018 (the latest year for which data is available), mostly children under the age of five. During this same period, measles deaths in Africa fell by 86 percent.

Despite these gains, we continue to see unfortunate and preventable deaths and complications due to both measles and rubella. In 2018, the last year for which data is available, every day approximately 384 children died of measles-related complications. These deaths could have been prevented with a safe, effective and inexpensive vaccine—generally, less than $2 USD in lower income countries. Measles is among the most contagious diseases ever known, and a top killer of children in low-income countries where children have little or no access to medical treatment and are often malnourished. The rubella virus is a leading infectious cause of birth defects in the world despite availability of an affordable, effective vaccine since 1969.

The majority of measles vaccination campaigns have been able to reach more than 90 percent of their target populations. Countries recognize the opportunity that measles vaccination campaigns provide in accessing mothers and young children and integrating the campaigns with other life-saving health interventions has become the norm. The provision of multiple child health interventions during a single campaign is far less expensive than delivering the interventions separately and has a far greater impact on a child's health than a single campaign. In addition to measles vaccine, other health interventions are often distributed during campaigns, including: administering vitamin A, which is crucial for preventing blindness in under nourished children; de-worming medicine to reduce malnutrition; doses of oral polio vaccines; and distributing insecticide treated bed nets to help prevent malaria and screening for malnutrition.

In addition to the lifesaving benefits of measles vaccines, immunization makes sound economic sense. A recent study by Johns Hopkins University revealed the economic benefits of increased investment in global vaccination programs. The study compared the costs for vaccinating against 10 disease antigens in 94 low- and middle-income countries during the period 2011–2020 versus the costs for estimated treatments of unimmunized individuals during the same period. Their findings show, on average, every $1 invested in these 10 immunizations produces $44 in savings in healthcare costs, lost wages, and economic productivity. The return on investment for measles immunization was particularly high, at $58 saved for every $1 invested.

Securing sufficient funding for measles and rubella-control activities both globally and nationally is critical. The decrease in donor funds available at a global level to support measles and rubella elimination activities makes increased political commitment and country ownership of the activities critical for achieving and sustaining the goal of reducing measles mortality by 95 percent. Implementation of timely measles and rubella campaigns is increasingly dependent upon countries funding these activities locally, which can be challenging under such downward financial pressure.

If such challenges are not addressed, the remarkable gains made since 2000 will be lost and a major resurgence in measles death and disability will occur. Measles is one of the most contagious diseases know to humans and, due to our highly interconnected world, measles can be spread globally including to countries that have already eliminated the disease. The threat of importation of measles was one of the reasons that the Global Health Security Agenda has selected measles as an important indicator of whether a country's routine immunization system is vaccinating all children.

THE ROLE OF CDC IN GLOBAL MEASLES MORTALITY REDUCTION

Since fiscal year 2001, Congress has provided funding to protect children and their families from the threat of measles and rubella in developing countries. Funding for measles and rubella globally has remained level since fiscal year 2010, at the $50 million level the American Red Cross and United Nations Foundation recommend. This support has assisted 90 countries around the world and has contributed to saving the lives of 21.1 million children.

In 2018, the number of measles cases increased 167 percent globally compared to 2016. Some regions were harder hit than others: Africa alone saw an increase of 246 percent. The most affected countries—the countries with the highest incidence rate of the disease—were Democratic Republic of the Congo (DRC), Liberia, Madagascar, Somalia and Ukraine. These five countries accounted for almost half of all measles cases worldwide.

In 2018 the support of the Measles & Rubella Initiative in 37 countries meant that nearly 350 million children were vaccinated during 45 supplemental immunization activities. For this support, we extend our deep appreciation to Congress. This support permitted the provision of technical support to Ministries of Health that specifically included: (1) planning, monitoring, and evaluating large-scale measles vaccination campaigns; (2) conducting epidemiological investigations and laboratory surveillance of measles outbreaks; (3) CDC's Global Measles Reference Laboratory to serve as the leading worldwide reference laboratory for measles and rubella. The reference laboratory provides specimen confirmation and testing as well as training for country and regional labs; and (4) conducting operations research to guide cost-effective and high-quality measles control programs.

In addition, CDC epidemiologists and public health specialists have worked closely with the WHO, UNICEF, the United Nations Foundation, and the American Red Cross to strengthen measles and rubella control programs at global and regional levels and will continue to work with these and other partners in implementing and strengthening rubella control programs. There is no doubt that CDC's financial and technical support—made possible by the funds appropriated by Congress—were essential in helping achieve the sharp reduction in measles deaths in just fifteen years.

The American Red Cross and United Nations Foundation would like to acknowledge the leadership and work provided by CDC and recognize that CDC brings much more to the table than just financial resources. The Measles & Rubella Initiative is fortunate to have a partner that provides critical personnel and technical support for vaccination campaigns and in response to disease outbreaks. CDC personnel have routinely demonstrated their ability to effectively coordinate and plan with international organizations and provide solutions to complex problems that help critical work get done faster and more efficiently.

Since fiscal year 2010, the CDC's measles and rubella elimination program has been funded at approximately $50 million. In fiscal year 2021, the American Red Cross and United Nations Foundation respectfully requests the continuation of level funding of $50 million. This investment will allow CDC to maintain measles and rubella control and elimination activities, safeguard the progress made over the last decade and protect Americans by preventing measles cases and deaths in the United States. The overall CDC Global Immunization Program, through which the Measles & Rubella Initiative is funded, has been highly successful and we support full funding for the overall account. All the programs funded through the Global Immunization Program line help to build stronger health systems. We respectfully request $50 million for CDC measles elimination activities, as part of level funding of $226 million for the entire Global Immunization account in fiscal year 2021.

Thank you for the opportunity to submit testimony, and for your continued commitment to ending preventable death and disability from measles and rubella.

[This statement was submitted by Koby J. Langley, Senior Vice President, International Services and Service to the Armed Forces, American National Red Cross, and Peter Yeo, Senior Vice President, United Nations Foundation.]

PREPARED STATEMENT OF THE AMERICAN PHYSIOLOGICAL SOCIETY

The American Physiological Society (APS) thanks the subcommittee for its ongoing support of the National Institutes of Health (NIH). The $3 billion funding boost you provided in fiscal year 2020, following on the increases you provided between fiscal years 2016 2019, have put the NIH on a path toward sustainable budget growth. These much-needed increases will help NIH address critical health problems and emerging challenges through cutting-edge research. The APS urges you to sustain this vital effort by providing the NIH budget with at least $44.7 billion in fiscal year 2021.

Breakthroughs in basic and translational research are the foundation for new drugs and therapies that help patients, fuel our economy, and provide jobs. Federal investment in research is essential because the NIH is the primary funding source for discovery research through its competitive grants program. We look to the private sector to develop new treatments, but the private sector relies upon this federally-funded research to identify where to find the next break-through . This system of public-private partnership has been critical to U.S. leadership in the biomedical sciences. A recent article in the Proceedings of the National Academy of Sciences showed that all of the 210 new molecular entities approved by the Food and Drug Administration between 2010 and 2016 were associated with NIH-supported research. Importantly, 84 of those new drugs were first-in-class, meaning they work through a novel mechanism of action or target.[1]

Federal research dollars also have a significant impact at the local level: Approximately 83 percent of the NIH budget is awarded to some 30,000 researchers who work in institutions throughout the country. They in turn use these grant funds to train students, pay research and administrative staff, purchase supplies and equipment, and cover other costs associated with their research. According to an updated 2020 report, NIH research funding in fiscal year 2019 supported more than 475,000 jobs nationwide, generating over $81 billion in total economic activity nationwide.[2]

The increases Congress has provided NIH over the last 5 years are helping to correct the devastating effects of sequestration and several years of budgets that declined in real terms due to inflation. To keep the agency on the right path forward, we urge you to continue providing meaningful and predictable annual budget in-

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[1] http://www.pnas.org/content/early/2018/02/06/1715368115.

[2] https://www.unitedformedicalresearch.org/wp-content/uploads/2019/04/NIHs-Role-in-Sustaining-the-US-Economy-FY19-FINAL-2.13.2020.pdf.

creases that will keep up with the rate of inflation and take full advantage of the incredible opportunities for discovery that are before us.

As specified in the 21st Century Cures Act, NIH continues to pursue a number of important initiatives including the Cancer Moonshot, the All of Us program (formerly the precision medicine initiative), and the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative. These programs focus resources on specific areas of scientific opportunity that are ripe for innovation, but it is important to bear in mind that these projects build upon decades of basic research. If we are to advance our knowledge and lay the groundwork for similar opportunities for innovation in the future, NIH must continue to invest in creative investigator-initiated research.

Over the past several decades, NIH has used a merit-based peer review system to identify and fund the best research proposals. To date, NIH has supported the work of 160 Nobel Laureates, including the 2019 winners of the Economic Sciences and Physiology or Medicine prizes. Thanks to NIH research, Americans can expect to live longer and healthier lives. NIH also plays an important role in training the next generation of scientists, supporting trainees through individual fellowships and institutional grants as they complete their graduate degrees and seek the post-doctoral training necessary to pursue successful independent research careers.

Today significant challenges loom before us: the growing threat to public health posed by the novel coronavirus outbreak requires a coordinated government response with a robust investment in research to advance understanding of the virus, the disease it causes and strategies to treat and prevent infection. NIH acted quickly when COVID–19 emerged as a problem in China and already has in place efforts to develop and test a vaccine and medications to treat the disease.[3]

In addition to the urgent threat posed by the novel coronavirus and other new and emerging diseases, the opioid epidemic continues to represent a national public health crisis. An aging population will bring an increase in diseases that contribute to death and disability such as heart disease, diabetes, kidney disease, arthritis, and cancer. If we are to continue to advance new and innovative ways to address these and other challenges on the horizon-including developing the workforce necessary to do so-the NIH will need stable and predictable funding increases in future years.

The APS joins the Federation of American Societies for Experimental Biology (FASEB) in urging that NIH be provided with no less than $44.7 billion in fiscal year 2021. This represents a $3 billion increase over fiscal year 2020.

RESEARCH WITH NONHUMAN PRIMATES

We would also like to draw to your attention the importance of encouraging researchers to work with the most appropriate research models for the diseases they are studying. We appreciate the language you included in Division A of the Managers' Amendment to the fiscal year 2020 Labor-HHS-Education appropriations conference report noting the importance of research with nonhuman primates while also urging NIH to seek alternatives that can reduce and replace them. Some comments on this are in order.

Once researchers who are studying nonhuman primates have answered certain questions about a disease or biological process, they can look for alternative research models. These alternatives need to provide an accurate representation of what is being studied but require either fewer animals, a different species, or a non-animal alternative. As a matter of both law and ethics, scientists must do their best to ensure that research minimizes the pain or distress animals experience. Reducing pain and distress often also has the added benefit of reducing the numbers of animals needed to get scientifically valid results. The number of nonhuman primates needed may also decrease when parts of the question can be answered by studying a different animal species or using technologies such as computer simulations or organs-on-a-chip.

The biggest challenge in biomedical research is that there are still so many unknowns. When researchers try to understand a complex biological process or a new pathogen such as the coronavirus responsible for COVID–19, their priority is to find the best research model as quickly as possible. The optimal choice is an animal whose anatomy, physiology, immune system, etc. closely resembles that of humans. For infectious diseases, complex neurological disorders and a host of other research challenges mandated by Congress, this often means a nonhuman primate species such as macaques, squirrel monkeys or marmosets. Recognizing this, NIH has stated that more nonhuman primates will be needed in the coming years.

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[3] https://grants.nih.gov/grants/guide/notice-files/NOT-AI-20-030.html.

Nonhuman primates are expected to play an important role in finding treatments and cures for COVID–19 because of how closely their immune systems resemble that of humans. In order to develop a vaccine, scientists must first determine how the virus invades cells and then find ways to prevent that from happening. While a strain of genetically modified mice developed during the 2003 outbreak of Severe Acute Respiratory Syndrome (SARS) may be useful, before such a vaccine can be given to people, it must be tested in appropriate animal models to assess its safety and effectiveness. In addition, the only treatment we can currently offer to people who have COVID–19 is supportive care to help their bodies fight the disease. Therefore, researchers also need to find animal species that develop clinical symptoms of disease. Nonhuman primates are expected to feature prominently in this research.

The APS is a nonprofit devoted to fostering education, scientific research and dissemination of information in the physiological sciences. The Society was founded in 1887 with 28 members and now has over 8,000 members, most of whom hold doctoral degrees in physiology, medicine and/or other health professions.

[This statement was submitted by Dennis Brown, Ph.D., Chief Science Officer, American Physiological Society.]

PREPARED STATEMENT OF THE AMERICAN PSYCHOLOGICAL ASSOCIATION

APA is the largest scientific and professional organization representing psychology in the U.S., numbering over 121,000 researchers, educators, clinicians, consultants and students. Many programs in the Labor-HHS-Education Appropriations bill strengthen the public health workforce and support research, education and access to needed services for the diverse populations served by psychologists. Given the challenges of responding to the COVID–19 pandemic, it is clear that the U.S. healthcare system and public health infrastructure, from bench to bedside, to community, must be strengthened, access to health and mental health services enhanced, and support for data-informed approaches to education and public welfare at all levels be made priorities.

Research Funding: To increase knowledge to advance health and education, APA supports investments in the Institute of Education Sciences (IES), National Institutes of Health (NIH), and Centers for Disease Control and Prevention (CDC).

IES.—APA supports $670 million for IES, an independent and nonpartisan statistics, research, and evaluation division of the Department of Education. This would restore the nearly 10 percent loss in research funding power since fiscal year 2011. IES supports and disseminates rigorous scientific evidence on which to base education policy and practice and conducts rigorous analysis of educational programs and initiatives, as well as innovative research into, many aspects of teaching and learning.

NIH (NIDA): Opioid Initiative.—Approximately 174 people die each day in the U.S. from drug overdose (over 100 from opioids), making it one of the most common causes of non-disease-related deaths for adolescents and young adults. To combat this crisis, APA supports at least $250 million for research related to preventing and treating opioid misuse and addiction. With additional funding for NIDA targeted at addressing this epidemic, the following areas should be among those targeted: studies to create a comprehensive care model in communities to prevent opioid misuse, expand treatment capacity, enhance access to overdose reversal medications, and enhance prescriber practice; and interventions in justice system settings to expand the uptake of medication-assisted treatment and methods such as non-pharmacological pain management to scale up these interventions for population-based impact.

NIH (NIDA): Healthy Brain and Child Development Study.—It is not currently known how infant and childhood development is affected by early exposure to opioids and COVID–19. The HBCD Study will establish a large cohort of pregnant women from regions of the country significantly affected by the opioid crisis and follow them and their children for at least 10 years. This research will help understand normative childhood brain development as well as the long-term impact of pre- and postnatal opioid and other drug and adverse environmental exposures including COVID–19. This knowledge will be critical to help predict and prevent some of the known impacts of pre- and postnatal exposure to certain drugs or adverse environments, including risk and resilience for future substance use, mental disorders, and other behavioral and developmental problems as well as the unknown effects of COVID–19 exposure. APA supports the $33.5 million requested to initiate Phase II of HBCD.

NIH Office of the Director: Office of Behavioral and Social Sciences Research (OBSSR).—OBSSR coordinates and promotes basic, clinical, and translational research in the behavioral and social sciences to support the NIH mission. Partnering with other Institutes and Centers, OBSSR co-funds highly rated grants that the ICs cannot fund alone. The Office also coordinates NIH's new, high-priority program on gun violence prevention research. APA asks the Committee to direct NIH to provide an increase of $22.5 million to OBSSR. As seen in previous pandemics including HIV, in the absence of a vaccine the only data-informed path to prevention is via people's behavior. Behavioral and social science research findings have informed our current response to COVID–19, but there must be additional research in the pipeline to improve targeted response to future disasters and pandemics, particularly for underserved and minority populations who are at greater risk of morbidity and mortality. In the short term, a National Academies study will clarify the path ahead for NIH-supported research. Infrastructure improvements in the longer term will make possible additional tools to fight pandemics and other emergencies, and faster and more targeted responses. At least $1 million of this increase should go to OBSSR's base budget, given that the OBSSR budget has remained relatively flat during this recent period of growth to the overall NIH budget.

NIH: OBSSR: National Academies Study.—Pandemics represent global health crises, which require large-scale behavior change to optimize pandemic response, and pose significant psychological, economic, and societal burdens that can be prepared for and ameliorated with an investment in scientific research. APA requests $1.5 million for the NIH Office of Behavioral and Social Sciences Research to enter into an agreement with the National Academies of Sciences, Engineering and Medicine to provide an evidence-based analysis of behavioral and social science research relevant to different dimensions of pandemic response. The analysis should include a review of research related to navigating threats, social and cultural factors including the heavier burdens on poor and marginalized populations, science communication, moral decisionmaking, governance and coping with stress and uncertainty. The Committee recommends that the results of the interdisciplinary evidence review be used to make recommendations for actions that can be immediately applied to optimize response to the current COVID–19 pandemic, and also identify important gaps that would help guide future research infrastructure development and specific research projects aimed at preventing and mitigating future pandemics.

NIH: OBSSR: Infrastructure Improvements.—APA asks for $20 million so that OBSSR may coordinate among partner NIH institutes and centers, including NIMH and NIMHD, for critical scientific infrastructure projects to advance collaboration and develop tools for the behavioral and social sciences which may include:

—Creating a social science and health data hub/cohort to serve as a data enclave with APIs [application programming interface] to various data sets to facilitate data linkage.

—Establishing one or more behavioral and social sciences research (BSSR) clinical trials networks to allow trials of behavioral interventions to be established quickly, and with more diverse populations.

NIH and CDC: Gun Violence Prevention Research.—In fiscal year 2021, APA supports $50 million in funding shared evenly between CDC and NIH to conduct research into firearm morbidity and mortality prevention.

Workforce and Access to Healthcare: To strengthen the public health workforce and improve access to healthcare, APA supports enhanced budgets for targeted programs in the Health Resources and Services Administration (HRSA) and the Substance Abuse and Mental Health Services Administration (SAMHSA). The nation's mental and behavioral health workforce must be expanded to respond adequately to the opioid epidemic and healthcare needs of our increasingly diverse and aging population. Psychologists, as researchers and practitioners, are integral to a healthcare system in which more than half of U.S. mortality is linked to behavior, and where mental and behavioral disorders are a significant health concern.

HRSA: GPE, BHWET and Geriatric Workforce Grants: HRSA projects a shortage of 14,300 psychologists by 2030 to address the growing needs for behavioral interventions, which will be exacerbated by a surge in COVID–19 related mental and behavioral health problems-including increases in anxiety, depression, and post-traumatic stress disorder. APA recommends $23 million for the interprofessional Graduate Psychology Education Program, to increase the number of health service psychologists trained to provide integrated services to high-need, underserved populations in rural and urban communities. In addition, APA recommends $120 million for the Behavioral Health Workforce Education and Training programs, including $69 million for the Behavioral Health Workforce Education and Training Grant Program (BHWET). To expand access to non-pharmacological pain management to improve pain care and reduce the incidence of opioid use disorders, APA recommends $10 million for a program for education and training in pain care, as authorized by the SUPPORT Act under Section 759 of the Public Health Service Act (42 U.S.C.

294i). As the number of Americans over age 65 will likely double between 2000 and 2030, APA further recommends $51 million for the Geriatric Workforce Enhancement Program and Geriatric Academic Career Awards to provide training for health professionals, faculty, family caregivers, and consumers in the unique needs of older adults.

SAMHSA (Minority Fellowship Program).—Given the disproportionate impact of COVID–19 on minority populations, APA requests a $2.5 million increase to $16.7 million for the MFP. This increase helps support a diverse behavioral health workforce addressing substance use disorders and mental health issues impacting minority and underserved populations.

To fill key gaps in affordability and access to education services: Given the heavy burden of student loan debt, APA supports added investments in grant programs for graduate study, including at least $35 million for the Graduate Assistance in Areas of National Need (GAANN) Program, where psychology has been recognized as a national need area. Additionally, APA urges the committee to direct the Department of Education to fully implement the nearly $800 million appropriated since 2018 for the Temporary Expanded Public Service Loan Forgiveness (TEPSLF) program. Only 1 percent of TEPSLF applications have been approved as of May 2019. Until the Department addresses concerns with the implementation and management of the PSLF, the TEPSLF program provides needed resources to support borrowers who have received incorrect information that has consequently jeopardized their eligibility for the program. To ensure that our students receive a well-rounded education, and access to mental health counseling and programs that foster safe and healthy schools, APA requests $1.6 billion for the Student Support and Academic Enrichment (SSAE) block grant under Title IV–A. APA requests level funding for CRD data collection in the Department of Education's Office of Civil Rights for collecting data on exclusionary discipline by disability status and seclusion/restraint data.

To make additional improvements in access to healthcare and the social safety net: APA urges $10 million for the Lifespan Respite Care Program under the Administration for Community Living. The Program increases the availability of quality respite for caregivers, regardless of age or disability.

Indian Health Service.— Increase funding for medical equipment by $33,706,000. Many IHS and tribal healthcare facilities are using outdated equipment. Updating equipment will allow for better mental health treatment.

SAMHSA: Suicide Prevention.—APA also supports maintaining current funding for the Garrett Lee Smith Memorial Act (GLSMA) programs, which increase young adults' access to prevention, education, and outreach services to reduce suicide risk in states, tribes, and institutions of higher education: $35.4 million for the State and Tribal Youth Suicide Prevention Program; $6.5 million for the Campus Mental and Behavioral Health Program; and $8 million for the Suicide Prevention Resource Center, an increase of $1 million over the enacted level.

APA supports the appropriation of an additional $35 million, for a total of $757.5 million, for the Community Mental Health Services Block Grant to fund a 5 percent set aside for all states to fund crisis care services. APA supports $1.7 billion for the Social Services Block Grant, to provide vital social services (e.g. protective services, special services to people with disabilities). To prevent child abuse and neglect, strengthen families, and reduce the need for foster care placement, APA supports increased funding for the Child Abuse Prevention and Treatment Act (CAPTA): $270 million for Title I and $270 million for Title II, as well as $60 million to support safe care plans for infants with prenatal substance exposure and families impacted by substance use disorders. APA also requests $19 billion for the Child Care Development Fund and $11.87 billion for Head Start to expand access to safe, affordable childcare and learning opportunities for working families. At the CDC, APA supports $4 million for Adverse Childhood Experiences Prevention and $10 million for Child Sexual Abuse Prevention.

HIV Programs: CDC Division of Adolescent and School Health (DASH).—APA urges the Committee to fund the CDC DASH at $100 million in fiscal year 2021, an increase of $66.9 million over fiscal year 2020. APA also supports SAMHSA's Minority AIDS Initiative, providing for evidence-based, culturally appropriate, HIV/AIDS-related mental health and substance use disorder treatment services among vulnerable populations. We recommend $160 million to expand efforts to prevent domestic HIV transmission and to increase treatment options for those living with comorbid conditions.

Medicare Cuts.—APA is deeply concerned about the Centers for Medicare and Medicaid Services' (CMS) final Medicare Physician Fee Schedule rule for CY 2020, which included broad changes to incentivize the use of evaluation and management services (E/M) through increased payments. APA is deeply concerned about the significant payment cuts psychologists will receive as a result of the current requirement for budget neutrality. Psychologists are the core mental and behavioral health provider in Medicare, and beneficiaries will face significant access issues in the coming months. This issue is exacerbated by the COVID–19 crisis, as psychologists struggle to find ways to treat their patients through remote access and soon may be determining how to keep their practices viable financially. Therefore, APA urges Congress to waive the budget neutrality requirements stipulated in Section 1848(c)(2) of the Social Security Act for the finalized E/M code proposal for a period of no less than 5 years. This much-needed action by Congress would provide a critical reprieve for a broad scope of healthcare providers facing substantial payment reductions in the coming months.

[This statement was submitted by Katherine B. McGuire, Chief Advocacy Officer, American Psychological Association.]

Prepared Statement of the American Public Health Association

APHA is a diverse community of public health professionals that champions the health of all people and communities. We are pleased to submit our requests for fiscal year 2021 funding for the Centers for Disease Control and Prevention and the Health Resources and Services Administration. We urge a funding level of at least $8.3 billion for CDC's programs and least $8.8 billion for the Health Resources and Services Administration. These requests do not reflect any additional emergency resources that may be needed to address the immediate and ongoing efforts to combat the COVID–19 pandemic. CDC and HRSA programs are especially critical as the U.S. grapples with the COVID–19 pandemic. Adequate funding for programs that promote public health and prevention, support surveillance of infectious disease and bolster America's public health workforce will be critical in facing the short-term and long-term health impacts of COVID–19.

Centers for Disease Control and Prevention: CDC provides the foundation for our state and local public health departments, supporting a trained workforce, laboratory capacity and public health education communications systems. It is notable that more than 70 percent of CDC's budget supports public health and prevention activities by state and local health organizations and agencies, national public health partners and academic institutions. We believe Congress should support CDC as an agency, not just its individual programs. Although we believe an even more significant increase is truly needed to address the nation's current health challenges, at a minimum, we urge a funding level of at least $8.3 billion for CDC's programs in fiscal year 2021. We are grateful for the important increases provided for CDC programs in fiscal year 2020 and urge Congress to build upon these investments to strengthen all of CDC's programs many of which remain woefully underfunded. We also urge your continued support for the Prevention and Public Health Fund which currently makes up approximately 11 percent of CDC's budget.

CDC serves as the command center for the nation's public health defense system against emerging and reemerging infectious diseases. From aiding in the surveillance, detection and prevention of the COVID–19 in the U.S., to monitoring and investigating disease outbreaks in the U.S., to pandemic flu preparedness, to educating the public about the value and importance of vaccines, CDC is the nation's—and the world's—expert resource and response center, coordinating communications and action and serving as the laboratory reference center for identifying, testing and characterizing potential agents of biological, chemical and radiological terrorism, emerging infectious diseases and other public health emergencies. Programs like CDC's Public Health Emergency Preparedness Cooperative Agreement enables states, cities and territories respond to public health emergencies. CDC oversees immunization programs for children, adolescents and adults. Childhood immunizations provide one of the best returns on investment of any public health program. For every dollar spent on childhood vaccines to prevent thirteen diseases, more than $10 is saved in direct and indirect costs. Over the past 20 years, CDC estimates childhood immunizations have prevented 732,000 deaths and 322 million illnesses. Congress must provide funding to support efforts to strengthen emergency preparedness activities and to stop current vaccine-preventable disease outbreaks and prevent more from occurring.

We thank Congress for providing CDC with dedicated funding for firearm morbidity and mortality prevention research in fiscal year 2020 and we strongly urge you to maintain and increase this funding in fiscal year 2021 to $50 million for CDC and NIH. This funding will allow CDC to conduct research into important issues including the best ways to prevent unintended firearm injuries and fatalities among women and children; the most effective methods to prevent firearm-related suicides;

and the measures that can best prevent the next shooting at a school or public place.

CDC's National Center for Environmental Health works to control asthma, protect against threats associated with natural disasters and climate change, reduce and monitor exposure to lead and other environmental health hazards and ensure access to safe and clean water. We urge you to provide at least $243 million for NCEH in fiscal year 2021, including a $5 million increase for CDC's Climate and Health program. Climate change is happening now and is threating our health in many ways including through the increased spread of vector-borne diseases, degraded air quality from ozone pollution and wildfire smoke, hotter temperatures and more extreme weather events. Increased funding will allow CDC to fund an additional 14 health departments to help them prepare for and respond to the health impacts of climate change in their communities. CDC will also be able to begin to evaluate the work of existing grantees to identify and share best practices with communities nationwide.

Programs under the National Center for Chronic Disease Prevention and Health Promotion address heart disease, stroke, cancer, diabetes and tobacco use that are the leading causes of death and disability in the U.S. and are also among the most costly to our health system. CDC provides funding for state programs to prevent disease, conduct surveillance to collect data on disease prevalence, monitor intervention efforts and translate scientific findings into public health practice in our communities. We once again strongly oppose the administration's proposal to block grant and cut funding for many of these programs.

Health Resources and Services Administration: HRSA is the primary Federal agency dedicated to improving health outcomes and achieving health equity. HRSA's 90-plus programs and more than 3,000 grantees support tens of millions of geographically isolated, economically or medically vulnerable people, in every U.S. state and territory, to achieve improved health outcomes by increasing access to quality healthcare and services; fostering a healthcare workforce able to address current and emerging needs; enhance population health and address health disparities through community partnerships; and promote transparency and accountability within the healthcare system.

We are grateful for the increases provided for HRSA programs in fiscal year 2020, however HRSA's discretionary budget authority remains over 20 percent below the fiscal year 2010 level (adjusted for inflation). We recommend Congress build upon the important increases they provided for HRSA programs in fiscal year 2020 and provide at least $8.8 billion for HRSA's total discretionary budget authority in fiscal year 2021.

HRSA programs and grantees are providing innovative and successful solutions to some of the nation's greatest healthcare challenges including the rise in maternal mortality, the severe shortage of health professionals, the high cost of healthcare and behavioral health issues related to substance use disorders—including opioid misuse. Additional funding will allow HRSA build upon these successes and pave the way for new achievements by supporting critical HRSA programs, including:

—Primary Health Care that supports over 11,000 health center sites in medically underserved communities across the U.S., providing access to high-quality preventive and primary care to more than 28 million people including over 8.4 million children and 350,000 veterans.

—Health Workforce supports the health workforce across the entire training continuum and offers scholarship and loan repayment programs to ensure a well-prepared, well-distributed and diverse workforce that is ready to meet the current and evolving healthcare needs of the nation.

—Maternal and Child Health supports initiatives that promote optimal health, reduce infant mortality, minimize disparities, prevent chronic conditions and improve access to quality healthcare for vulnerable women, infants and children; and serves more than 76 million people through the MCH block grant.

—HIV/AIDS delivers a comprehensive and robust system of care to more than 550,000 individuals impacted by HIV/AIDS, improving health outcomes for people with HIV and reducing the chance of others becoming infected, and provides training for health professionals treating people with HIV/AIDS. HRSA's Ryan White HIV/AIDS Program effectively engages clients in comprehensive care and treatment, including increasing access to HIV medication, which has resulted in 87 percent of clients achieving viral suppression, compared to just 59 percent of all people living with HIV nationwide.

—Family Planning Title X services ensure access to comprehensive family planning and related preventive health services to nearly 4 million people, thereby reducing unintended pregnancy rates, limiting transmission of sexually transmitted infections and increasing early detection of breast and cervical cancer.

—Rural Health supports community and state-based solutions to improve efficiencies in delivering rural health services and expand access, including supporting activities that aim to increase access to opioid treatment in rural areas, leverage the use of health information technology and telehealth and advise on rural health policy issues.

In closing, we emphasize that the public health system requires stronger financial investments at every stage. This funding makes up less than 1 percent of Federal spending. Cuts to public health and prevention programs will not balance our budget and will only lead to increased costs to our healthcare system. Investing in CDC and HRSA programs will enable us to meet the mounting health challenges we currently face and to become a healthier nation.

[This statement was submitted by Georges C. Benjamin, MD, Executive Director, American Public Health Association.]

PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR MICROBIOLOGY

The American Society for Microbiology (ASM) is one of the largest life science societies, composed of more than 30,000 scientists and health professionals. Our mission is to promote and advance the microbial sciences. ASM respectfully requests that Congress provide at least $44.7 billion for the National Institutes of Health (NIH) and at least $8.3 billion for the Centers for Disease Control and Prevention (CDC) in fiscal year 2021. Within the CDC budget, we call on Congress to provide $57 million for the Advanced Molecular Detection (AMD) program in the National Center for Emerging and Zoonotic Infectious Diseases. These requests do not take into account any additional emergency supplemental funding that will be necessary to support these agencies in the wake of the COVID–19 pandemic.

SUPPORT IN UNPRECEDENTED TIMES

ASM is grateful for the recent bipartisan agreements that have led to significant supplemental appropriations for CDC, NIH and other key health and preparedness programs as our nation responds to the ongoing COVID–19 pandemic. It is no longer a question of if, but when, the next pandemic will hit. Knowing that this is not our first pandemic, nor will it be our last, Congress should prioritize continued long-term investments in public health and in research at CDC and NIH. Congress should also encourage collaboration with other Federal science agencies to build on the wealth of existing knowledge and to leverage existing supercomputing and laboratory resources as well as capacity for epidemiological modeling and surveillance.

In addition to focusing on the urgent and more immediate needs of our public health agencies and infrastructure, ASM remains deeply concerned about the serious consequences of the current disruption to the broader research enterprise. As is the case in the overall economy, researchers, students, post-docs and lab personnel have had their work cut short. This has implications not only for the workforce—where hiring has been disrupted and employees furloughed—but also on the process of scientific discovery. Experiments will need to be restarted, animal colonies repopulated, and fieldwork rescheduled for an indeterminate later time. The longer the slowdown continues, the more serious the consequences will be, especially on the people who comprise the research workforce, including graduate students, postdocs, principal investigators, laboratory and technical support staff.

While our nation's research capacity has demonstrated it can absorb shocks, the scale of this one is still growing and unprecedented in duration and impact. As such, it is vital that the Federal government take measures to increase support for the research enterprise. The need for basic research continues, and providing robust, sustained and predictable funding for the NIH is the only way we will seize the unparalleled scientific opportunities in microbial research that lie before us, and the only way we will be equipped to address the research and development demands that novel infectious disease pandemics such as COVID–19 place on our scientific enterprise.

Maintaining a Strong Investment in Microbial Science Through the NIH

We thank the United States Congress for its longstanding, bipartisan support for the NIH and for its commitment to basic, translational, and clinical microbial research funded through multiple Institutes and Centers, particularly through the National Institute of Allergy and Infectious Diseases (NIAID). We especially thank Senate Appropriations Subcommittee on Labor, Health and Human Services (HHS), Education Chairman Roy Blunt and Ranking Member Patty Murray for their unwavering support for the NIH and leadership over the past 5 years, during which they and their House counterparts have worked in a bipartisan manner to place the

NIH budget back on path of meaningful growth above inflation. By increasing funding by more than 33 percent since fiscal year 2015, NIH has advanced discovery toward promising therapies and diagnostics, reenergized existing and aspiring scientists nationwide, and restored hope for patients and their families.

NIH Funding has Transformed the Microbial Sciences

We live in an extraordinary time of scientific opportunity in the field of microbial research, and NIH funding plays a unique and indispensable role in supporting the discovery and application of new knowledge to prevent, detect, and treat infectious diseases. Amidst a global pandemic, steady investment over several years in NIH allowed NIAID to rapidly scale up and initiate clinical trials, now underway at record speed, to develop a vaccine for the novel coronavirus (SARS–COV–2). The investment over time, coupled with emergency supplemental funding is funding also is facilitating the commencement of clinical trials to test antiviral drugs like Remdesivir and innovative approaches like human convalescent plasma (HCP) therapy on those who are infected with the virus in the hope that therapeutic options can be made available as soon as possible.

In non-pandemic times, investments in microbial research at NIH have led to great strides in protecting and improving human health. In addition to preparing today's scientists to combat our current pandemic, past NIH projects have led to the following advances:

—A young person diagnosed with Human Immunodeficiency Virus (HIV) today who receives treatment will have a near normal life expectancy. The AIDS death rate has dropped 80 percent from its peak in 1995.

—Routine childhood vaccinations prevent millions of cases of illness. For children vaccinated in 2009, an estimated $82 billion in costs will be saved and 20 million cases, including 42,000 early deaths, will be prevented.

—The first preventive vaccine and experimental treatments were recently deployed in Africa against the Ebola virus, marking a significant public health achievement. The Ebola virus, which ravaged West Africa in 2013 and continues to cost lives in the Democratic Republic of the Congo, has killed more than 10,000 people and severely strained regional socioeconomic stability.

—The Human Microbiome Program (HMP) has transformed our understanding of the human/microbiome ecosystem by mapping the normal bacteria that live in and on the healthy human body. Microbiome research at NIH now extends well beyond the HMP to include research at several NIH Institutes, further revealing how microbial community makeup can vary from person-to-person and may correlate with health and disease. With a better understanding of what a "normal" human microbiome looks like, researchers are now exploring how changes in the microbiome are associated with, or even cause, illnesses.

Looking Ahead: Continued Progress Requires a Sustained Commitment to Funding

Even in the face of the promise and progress highlighted above, we have seen the human and economic devastation that results when we are confronted with a pandemic caused by an emerging infectious disease such as SARS–COV–2. Novel diseases present incalculable health, economic and social challenges as we have witnessed over the past few months, but they also present opportunities for innovation and new developments. Seasonal flu continues to cost the

U.S. billions annually in direct medical costs and lost productivity due to illness, not to mention thousands of Americans lose their lives to flu each year. Through sustained funding to NIAID, scientists continue the quest for a universal flu vaccine, which will dramatically reduce the toll the virus takes on the U.S. each year, as well as reduce the chances of pandemic flu. In the past year, the first in human trials of a universal flu vaccine candidate were launched at the NIH Clinical Center. In light of the continued threat posed by COVID–19, it is imperative that we continue our efforts to combat known seasonal threats to reduce the toll that the two pathogens circulating together could take on our population.

CDC's Indispensable Role in Preventing and Controlling Infectious Disease

The programs and activities supported by CDC are essential to protect the health of the American people. ASM appreciates the important increases that Congress provided for many CDC programs in fiscal year 2020. Today's challenges reinforce the need for a strong CDC and regular investments in our public health infrastructure. We urge Congress to recommit to robust support for the CDC in fiscal year 2021, including funding for the Infectious Disease Rapid Response Reserve Fund and the Prevention and Public Health Fund. CDC aids in surveillance, detection and prevention of global and domestic outbreaks from novel Coronavirus, to Ebola, to the measles, to seasonal flu. CDC is the nation's expert resource and response center, coordinating communications and action, and serving as the laboratory reference center. We are seeing in real time during that COVID–19 pandemic how states, communities, and international partners rely on CDC for accurate information, direction, and resources to respond in a crisis.

Three areas that ASM would like to highlight under CDC are: (1) advanced molecular detection technology; (2) antimicrobial resistance; and, (3) laboratory capacity.

—The Advanced Molecular Detection (AMD) program brings cutting edge genomic sequencing technology to the front lines of public health by harnessing the power of next- generation sequencing and high performance computing with bioinformatics and epidemiology expertise to study pathogens. Due to increasing costs and demands but continued flat funding, the program's ability to support its mission is threatened. With additional funds, the AMD program can promote greater innovation, expand workforce development, and enter into productive partnerships with academic research institutions and state/local public health agencies. ASM requests $57 million in for AMD fiscal year 2021, in order for this program to fully achieve its potential.

—Multiple programs support antimicrobial resistance, which is one of the most daunting health challenges we face today. ASM requests funding for the Antibiotic Resistance Solutions Initiative at $200 million, the National Healthcare Safety Network at $25 million, and the Division of Global Health Protection at $275 million will ensure that we have the resources across multiple programs to address this urgent public health challenge.

—Support for laboratory capacity is paramount, and the Emerging and Zoonotic Infectious Disease labs are the world's reference labs. But maintaining labs costs more each year, from quality and safety initiatives, to the cost of shipments and supplies, to recruiting and retaining specialized and highly trained staff. ASM applauds the inclusion of additional funding of to $10 million in the President's fiscal year 2021 request for lab capacity at the CDC, we urge you to consider this additional funding as a floor for additional resources to this area.

ASM looks forward to working with you to ensure that researchers and public health professionals have the resources they need to apply fundamental microbial science research to meet 21st Century challenges in public health promotion, the prevention, detection and treatment of infectious diseases, and the prevention of future outbreaks.

[This statement was submitted by Allen Segal, Public Policy and Advocacy Director, American Society for Microbiology.]

Prepared Statement of the American Society for Nutrition

Dear Chairman Blunt and Ranking Member Murray:

Thank you for the opportunity to provide testimony regarding fiscal year 2021 appropriations. The American Society for Nutrition (ASN) respectfully requests at least $44.7 billion dollars for the National Institutes of Health (NIH) and $189 million dollars for the Centers for Disease Control and Prevention/National Center for Health Statistics (CDC/NCHS) in fiscal year 2021. ASN is dedicated to bringing together the world's top researchers to advance our knowledge and application of nutrition, and has more than 7,000 members working throughout academia, clinical practice, government, and industry.

NATIONAL INSTITUTES OF HEALTH

The NIH is the nation's premier sponsor of biomedical research and is the agency responsible for conducting and supporting 86 percent of federally funded basic and clinical nutrition research. Although nutrition and obesity research make up less than 8 percent of the NIH budget, some of the most promising nutrition-related research discoveries have been made possible by NIH support. NIH nutrition-related discoveries have impacted the way clinicians prevent and treat heart disease, cancer, diabetes and other chronic diseases. For example, from 2001 to 2011, the U.S. death rate from heart disease has fallen by about 39 percent and from stroke by about 35 percent.[1] However, the burden and risk factors remain high. With additional support for NIH, additional breakthroughs and discoveries to improve the health of all Americans will be made possible.

Investment in biomedical research generates new knowledge, improved health, and leads to innovation and long-term economic growth. From fiscal year 2003 to

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[1] https://www.heart.org/idc/groups/ahamah-public/@wcm/@sop/@smd/documents/downloadable/ucm_470704.pdf.

2015, the NIH lost 22 percent of its capacity to fund research due to budget cuts, sequestration, and inflationary losses. Such economic stagnation is disruptive to training, careers, long-range projects and ultimately to progress. Since fiscal year 2016, Congress has begun to restore the NIH budget but there is much work to be done; in real dollars, the NIH budget is still 16 percent below the fiscal year 2003 level. ASN recommends at least $44.7 billion dollars for NIH in fiscal year 2021 to support NIH nutrition-related research that will lead to important disease prevention and cures. A budget of $44.7 billion will allow NIH to continue its commitment to the Next Generation Researchers Initiative; provide $404 million already authorized through the 21st Century Cures Act for key research initiatives; and provide a 3 percent budget increase across NIH Institutes and Centers, allowing them to bolster research areas in need of resources. NIH needs sustainable and predictable budget growth to fulfill the full potential of biomedical research, including nutrition research, that is aimed at improving the health and wellbeing of all Americans, as well as global populations.

CENTERS FOR DISEASE CONTROL AND PREVENTION/NATIONAL CENTER FOR HEALTH STATISTICS

The National Center for Health Statistics, housed within the Centers for Disease Control and Prevention, is the nation's principal health statistics agency. ASN recommends a fiscal year 2021 funding level of $189 million dollars for NCHS to help ensure uninterrupted collection of vital health and nutrition statistics and help cover the costs needed for technology and information security maintenance and upgrades that are necessary to replace aging survey infrastructure. The U.S. is a leader in this area and a decade of flat funding has taken a significant toll on NCHS's ability to keep pace.

The NCHS provides critical data on all aspects of our healthcare system, and it is responsible for monitoring the nation's health and nutrition status through surveys such as the National Health and Nutrition Examination Survey (NHANES), that serve as a gold standard for data collection around the world. Nutrition and health data, largely collected through NHANES, are essential for tracking the nutrition, health and well-being of the American population, and are especially important for observing nutritional and health trends in our nation's children. This is an invaluable source of data that has been and can continue to be used to address major health issues as they arise.

Nutrition monitoring conducted by the Department of Health and Human Services in partnership with the U.S. Department of Agriculture/Agricultural Research Service is a unique and critically important surveillance function in which dietary intake, nutritional status, and health status are evaluated in a rigorous and standardized manner. Nutrition monitoring is an inherently governmental function and findings are essential for multiple government agencies, as well as the public and private sector. Nutrition monitoring is essential to track what Americans are eating, inform nutrition and dietary guidance policy, evaluate the effectiveness and efficiency of nutrition assistance programs, and study nutrition-related disease outcomes. Funds are needed to ensure the continuation of this critical surveillance of the nation's nutritional status and the many benefits it provides.

Through learning both what Americans eat and how their diets directly affect their health, the NCHS is able to monitor the prevalence of obesity and other chronic diseases in the U.S. and track the performance of preventive interventions, as well as assess 'nutrients of concern' such as calcium, iron, folate, iodine, vitamin D, and other micronutrients which are consumed in inadequate amounts by many subsets of our population. Data such as these are critical to guide policy development in health and nutrition, including food safety, food labeling, food assistance, military rations and dietary guidance. For example, NHANES data are used to determine funding levels for programs such as the Supplemental Nutrition Assistance Program (SNAP) and the Women, Infants, and Children (WIC) clinics, which provide nourishment to low-income women and children.

Thank you for the opportunity to submit testimony regarding fiscal year 2021 appropriations for the National Institutes of Health and the CDC/National Center for Health Statistics. Please contact John E. Courtney, Ph.D., ASN Executive Officer, at 9211 Corporate Boulevard, Suite 300, Rockville, Maryland 20850, jcourtney@nutrition.org, if ASN may provide further assistance.

Sincerely.

[This statement was submitted by Richard Mattes, M.P.H., Ph.D., RD 2019–2020, President, American Society for Nutrition.]

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF HEMATOLOGY

The American Society of Hematology (ASH) represents more than 18,000 clinicians and scientists committed to the study and treatment of blood and blood-related diseases. These diseases encompass malignant disorders such as leukemia, lymphoma, and myeloma; life-threatening conditions, including thrombosis and bleeding disorders; and congenital diseases such as sickle cell disease, thalassemia, and hemophilia. Hematologists have been pioneers in the fields of bone marrow transplantation, stem cell biology and regenerative medicine, and gene and immunotherapy.

FISCAL YEAR 2021 REQUEST: NATIONAL INSTITUTES OF HEALTH

American biomedical research has led to new medical treatments, saved innumerable lives, reduced human suffering, and spawned entire new industries, none of which would have been possible without support from the National Institutes of Health (NIH). Hematology research, funded by many institutes at the NIH, including the National Heart, Lung and Blood Institute (NHLBI), the National Cancer Institute (NCI), the National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK), the National Institute on Aging (NIA), and the National Institute of Allergy and Infectious Diseases (NIAID), has been an important component of this investment in the nation's health.

With the advances gained through an increasingly sophisticated understanding of how the blood system functions, hematologists have changed the face of medicine through their dedication to improving the lives of patients. NIH-funded research has led to tremendous advances in treatments for children and adults with blood cancers and other hematologic diseases and disorders. Hematology advances also help patients with other types of cancers, heart disease, and stroke. Basic research on blood has aided physicians who treat patients with heart disease, strokes, end-stage renal disease, cancer, and AIDS. Additional Federal investment in research will form the basis for continued scientific progress in hematology and other fields of medicine for years to come.

ASH thanks Congress for the robust bipartisan support that has resulted in several consecutive years of welcome and much needed funding increases for NIH, including the more than $2 billion increase that Congress provided in fiscal year 2020. For fiscal year 2021, ASH strongly supports the Ad Hoc Group for Medical Research recommendation that NIH receive $44.7 billion. This funding level, supported by more than 330 other stakeholder organizations, would allow for meaningful growth above inflation in the base budget that would expand NIH's capacity to support promising science in all disciplines. It also would ensure that funding from the Innovation Account established in the 21st Century Cures Act would supplement the agency's base budget, as intended, through dedicated funding for specific programs.

While we are grateful for Congress's ongoing commitment to NIH as a top national priority through the regular appropriations process, we also urge the inclusion of additional emergency supplemental investments in the NIH as Congress considers future legislation to promote the nation's physical, health, and economic resilience to the current COVID–19 pandemic and future pandemics. The extraordinary research currently underway to identify and develop potential COVID–19 vaccines, antivirals, and other medical countermeasures is all built on the scientific foundation enabled by the Federal investment in NIH. Additionally, the emergency supplemental resources provided to NIH in the recently enacted COVID–19 packages are playing an important role in identifying therapies and vaccines, as well as improving testing and diagnostic methods.

Further supplementary funding to NIH will be necessary to help preserve the momentum of the nation's investment in biomedical research and aid in ramping up labs to their prior research capacities. Researchers in every state suspended many laboratory activities for their own personal safety and to comply with physical distancing guidelines as a result of the COVID–19 pandemic. The closure of many research facilities is impacting trainees, technicians, early-stage investigators, and established investigators alike, preventing the research workforce from maintaining momentum toward better prevention, treatments, diagnostics, and cures for diseases such as blood cancers, sickle cell disease, and other hematologic diseases and conditions.

Substantial costs have been incurred for the shut-down and there will be significant additional costs for the eventual ramp-up of research activities. For example, labs will need to replace personal protective equipment that they have donated to support the critical work of first responders and healthcare providers and will also need to reestablish experimental models. This includes the need to rebuild animal colonies, breed mice and other animal models, and reestablish cell lines used for experiments that were destroyed during the preparation to close labs. This is both costly and time consuming as labs will need to replenish these colonies and retest to ensure reproducibility of previous research findings prior to proceeding this any new experimental work. Additionally, core facilities, such as those that provide DNA sequencing and flow cytometry services, support cross-disciplinary research efforts across federally funded research labs. These facilities are also closed or functioning below capacity to ensure readiness for any ongoing COVID–19 research efforts, and they also need support.

Many new clinical questions are emerging daily from this COVID–19 pandemic. Indeed, as the infections continue, new disease manifestations are developing including severe hematopoietic conditions that have turned COVID–19 into not only a pulmonary disease, but a blood disease as well. Recent emerging outcomes include coagulation and severe inflammation, or the cytokine storm, that is seen in adults and children alike and results in severe complications and even death in some affected. In response to these health issues, the Society has developed a "COVID–19 Research Agenda in Hematology." This document explores the key underlying research questions that, to date, lack scientific evidence to inform clinical practice and treatment efforts. The Society has deemed these questions to be of utmost importance to address in order to best guide physicians on the front lines when treating critically ill patients and attempting to save lives. It is imperative that answers to these questions are provided soon to help successfully defeat this virus and save as many lives as possible.

Finally, the Society is concerned about possible new policies that would place the intellectual property of peer reviewed scientific and medical research articles, published in professional journals, in jeopardy. Of particular concern is a potential proposal by the Administration to eliminate the current 12-month embargo to make federally funded scientific research published in journals freely available worldwide. If enacted, such a proposal could significantly threaten scientific rigor, discovery, and innovation. The Society urges the Subcommittee to re-affirm its support for the 2013 Holdren Memo, which ensures public access to peer-reviewed articles no later than 12 months after the official date of publication. The current 12-month embargo period allows for robust peer review and curation systems, and copyright and intellectual property protection of American science.

FISCAL YEAR 2021 REQUEST: CENTERS FOR DISEASE CONTROL AND PREVENTION

The Society also recognizes the important role of the Centers for Disease Control and Prevention (CDC) in preventing and controlling clotting, bleeding, and other hematologic disorders. This is especially important for improving the care and treatment of individuals with sickle cell disease (SCD).

Sickle cell disease is an inherited, lifelong disorder affecting approximately 100,000 Americans. Individuals with the disease produce abnormal hemoglobin which results in their red blood cells becoming rigid and sickle-shaped, causing them to get stuck in blood vessels and block blood and oxygen flow to the body, which can cause severe pain, stroke, organ damage, and in some cases premature death. Though new approaches to managing SCD have led to improvements in diagnosis and supportive care, many people living with the disease are unable to access quality care and are limited by a lack of effective treatment options.

Dedicated Federal funding is needed for CDC's SCD Data Collection Program to allow the program to be expanded to include additional states with the goal of covering the majority of the U.S. SCD population over the next 5 years. The Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018 (Public Law 115–327) authorizes CDC to award SCD data collection grants to states, academic institutions, and non-profit organizations to gather information on the prevalence of SCD and health outcomes, complications, and treatment that people with SCD experience. For fiscal year 2021, the Society urges the Subcommittee to provide at least $5 million for SCD data collection within the CDC's National Center for Birth Defects and Developmental Disabilities, Division of Blood Disorders (NCBDDD).

The current program was established with funding from the CDC Foundation. It is a population-based surveillance system, which collects and analyzes longitudinal data about people living in the U.S. with SCD. Due to limited funding, implementation of the program has occurred only in two states over the past few years—California and Georgia (approximately 10 percent of the U.S. SCD population). Data is being collected from multiple sources (newborn screening programs, Medicaid, hospital discharge data, emergency department data, vital records, and clinical data) in order to create individual healthcare utilizations profiles, which is unique because it captures all individuals with SCD regardless of insurance status. The program is also valuable because it can follow individuals over time across healthcare systems and create individual profiles of how they accessed healthcare and their outcomes.

In September 2019, CDC announced the transfer of nearly $1.2 million in fiscal year 2019 funding to help seven additional states (Alabama, Indiana, Michigan, Minnesota, North Carolina, Tennessee, and Virginia) develop systems to collect data on the issues faced by people living with sickle cell disease. This bridge funding is an important step toward improving and expanding the CDC's SCD data collection efforts; however, it is only limited to 1 year. These states have already made significant progress in building the infrastructure needed to implement the program and it is important to continue to build on this investment. Dedicated funding at $5 million for NCBDDD to carry out the SCD Data Collection Program in fiscal year 2021 will assure this.

Additionally, ASH supports the public health community's request for at least $8.3 billion in funding for the CDC in fiscal year 2021. ASH also urges continued support of the Public Health and Prevention Fund which has supported many critical projects at CDC, including investments in healthcare-associated infections. Currently the fund comprises more than 11 percent of CDC's budget. ASH is concerned about the repeated efforts to eliminate this fund because of the budgetary pressure this would place on other programs within the Subcommittee's jurisdiction.

FISCAL YEAR 2021 REQUEST: HEALTH RESOURCES AND SERVICES ADMINISTRATION

Finally, ASH seeks continued funding of the SCD Demonstration Program within the Health Resources and Services Administration (HRSA) and fiscal year 2021 level of $5.2 million. This program supports five regional grantees, whose efforts focus on enhancing access to comprehensive, state of the art SCD care for patients living with the disease by providing educational programs and technical assistance on advances in SCD treatments to a broad array of providers and assuring coordination of care with hematologists, who specialize in the disease.

Thank you again for the opportunity to submit testimony. Please contact ASH Senior Manager, Legislative Advocacy, Tracy Roades at troades@hematology.org, if you have any questions or need further information concerning hematology research or ASH's fiscal year 2021 requests.

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF HUMAN GENETICS

The American Society of Human Genetics (ASHG) thanks the Subcommittee for its continued strong support and leadership in funding the National Institutes of Health (NIH). The $2.6 billion increase provided for fiscal year 2020 reinforces our nation's commitment to the health and well-being of all Americans by investing in biomedical research and scientific innovation. ASHG urges the Subcommittee to appropriate $44.7 billion for NIH in fiscal year 2021.

My name is Tony Wynshaw-Boris. I am a professor and chair of the Department of Genetics and Genome Sciences at Case Western Reserve University. My laboratory studies the biology, specifically the genetics, of the development and function of the brain.

A BREAKTHROUGH YEAR IN GENETICS AND GENOMICS

Seeking to understand the human body and diseases in service of the public is an underlying imperative of genetics and genomics research. A recent poll conducted by ASHG and Research!America indicated that 74 percent of Americans support increased Federal funding for genetics research.[1] Indeed, thanks to sustained Federal investment in basic and translational research, we are now seeing the transformative impact of genetics research with greater insight about diseases, innovative diagnostic technology and new treatments.

My laboratory studies the pathophysiological mechanisms of human neurogenetic disorders, using animal models and more recently inducible pluripotent stem cell (iPSC) models. These studies have started with an understanding of brain development with a focus on how normal development is affected in these disorders, and in some cases, this has provided targets that could lead to novel therapies. My research underscores the importance of basic research and its application to human diseases.

Building on scientific knowledge and an enhanced understanding of disease gleaned from years of federally funded research, new treatments are now available

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[1] https://www.ashg.org/discover-genetics/public-views-of-genetics-survey/.

for patients suffering from devasting diseases who previously lacked options. In the past year alone, the FDA has approved several new drugs and gene therapies for rare diseases: Duchenne muscular dystrophy (DMD),[2] spinal muscular atrophy (SMA),[3] sickle cell disease,[4] and a drug that targets the most common mutation (90 percent) causing cystic fibrosis.[5] The FDA also approved the first-ever personalized therapy, Milasen, for a fatal neurodegenerative disease: supported in part by NIH funding, the research and clinical team took a remarkably short 10 months to go from identifying the genetic defect to designing the drug.[6]

In addition, there are numerous promising therapies currently undergoing clinical trials. This includes a gene therapy for X-linked severe combined immunodeficiency (SCID–X1), known as the "bubble boy" disease. For children suffering from this disease, common infections can be life-threatening. However, infants enrolled in the study have functioning immune systems and are living normal lives as toddlers.[7]

Basic research on the human genome and biology is fundamental to this clinical progress. For example, the naturally occurring "CRISPR-Cas9" system was discovered through federally funded basic research investigating the immune systems of bacteria.[8] Scientists are now harnessing it as a research and clinical tool to edit the human DNA code, and numerous clinical trials are underway studying its therapeutic utility for a variety of cancers, blood disorders, and congenital blindness.[9] Creative new tools based on CRISPR-Cas9 are also being explored for cancer screening [10] and rapid diagnostics for infectious diseases such as COVID–19 [11].

Genetics-based research and technology is advancing knowledge across all areas of life science research. About 20 years ago, the National Human Genome Research Institute (NHGRI) was funding over 90 percent of human genomics research at the NIH; today, NHGRI only accounts for about 15 percent, and nearly every NIH institute and center supports research on the human genome.[12] This reflects the increased use of genetics and genomics approaches for investigating diseases suffered by millions of Americans, such as cancer, cardiovascular diseases, and mental health.

For example, the Pan-Cancer Project, a large-scale study aimed at understanding cancer that involved over a thousand researchers around the globe, sequenced and analyzed the complete genomes of 38 types of cancer. A significant new discovery from this study is that mutations that occur decades before diagnosis can contribute to the onset of cancer in humans.[13]

Researchers are also exploring analytical approaches providing novel insights on how the human genome is connected with disease. Research groups are developing polygenic risk scores (PRS), a predictive value of a person's risk for disease based on multiple genes for a variety of complex diseases including cardiovascular disease, diabetes, Alzheimer's, autism, and many more.[14] The potential of PRS in healthcare as an early intervention tool may help improve outcomes and tailor clinical care.

Genetics research also impacts other scientific disciplines and Federal agencies. For example, a collaboration between NIH and NASA-funded researchers published a landmark study last year, describing genetic, physiological and other changes re-

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[2] https://www.fda.gov/news-events/press-announcements/fda-grants-accelerated-approval-first-targeted-treatment-rare-duchenne-muscular-dystrophy-mutation.

[3] https://www.fda.gov/news-events/press-announcements/fda-approves-innovative-gene-therapy-treat-pediatric-patients-spinal-muscular-atrophy-rare-disease.

[4] https://www.fda.gov/news-events/press-announcements/fda-approves-novel-treatment-target-abnormality-sickle-cell-disease.

[5] https://directorsblog.nih.gov/2019/10/31/dare-to-dream-the-long-road-to-targeted-therapies-for-cystic-fibrosis/.

[6] Kim, J., et al. 2019. Patient-Customized Oligonucleotide Therapy for a Rare Genetic Disease. N.Engl.J.Med. 381:1644–1652; https://directorsblog.nih.gov/2019/10/23/one-little-girls-story-highlights-the-promise-of-precision-medicine/.

[7] Mamcarz, E., et al. 2019. Lentiviral Gene Therapy Combined with Low-Dose Busulfan in Infants with SCID–X1. N.Engl.J.Med. 380:1525–34; https://www.nih.gov/news-events/news-releases/gene-therapy-restores-immunity-infants-rare-immunodeficiency-disease.

[8] https://www.genome.gov/dna-day/15-ways/genome-editing.

[9] https://clinicaltrials.gov/.

[10] Gootenberg, JS., et al. 2017. Nucleic acid detection with CRISPR-Cas13a/C2c2. Science. 356:438–442.

[11] https://www.broadinstitute.org/files/publications/special/COVID-19%20detection%20(updated).pdf.

[12] https://www.genome.gov/sites/default/files/media/files/2020-02/NHGRIFY2021CJ.pdf.

[13] https://directorsblog.nih.gov/tag/pan-cancer-analysis-of-whole-genomes-consortium/.

[14] https://www.genome.gov/Health/Genomics-and-Medicine/Polygenic-risk-scores.

sulting from spaceflight. The study provides a foundation for understanding how astronauts' body and health may be affected in space.[15]

NIH-FUNDED ACTIVITIES: RETURN ON INVESTMENT

Besides the immeasurable value of improving the quality of life and health of the public, NIH research funding can be quantified as a driver of economic activity. For fiscal year 2019, NIH funding supported over 475,000 jobs across the nation and stimulated about $81 billion in economic activity. The economic gain in 29 states exceeded $500 million.[16]

An overwhelming majority of Americans believe more research is needed in human genetics and support increased Federal funding for research. To echo the public's need and sentiment, the Society's vision-people everywhere realize the benefits of human genetics and genomics research-is achievable with sustained and robust funding for the NIH. ASHG joins the Federation of American Societies for Experimental Biology (FASEB), and the Ad Hoc Group for Medical Research in recommending a $44.7 billion budget for NIH for fiscal year 2021.

The American Society of Human Genetics (ASHG), founded in 1948, is the primary professional membership organization for human genetics specialists worldwide. The Society's nearly 8,000 members include researchers, academicians, clinicians, laboratory practice professionals, genetic counselors, nurses and others who have a special interest in the field of human genetics.

[This statement was submitted by Anthony Wynshaw-Boris, MD, PhD, President, American Society of Human Genetics.]

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF NEPHROLOGY AND THE AMERICAN SOCIETY OF PEDIATRIC NEPHROLOGY

On behalf of the 37 million children, adolescents, and adults living with kidney diseases in the United States, the American Society of Nephrology and the American Society of Pediatric Nephrology requests a $3 billion for NIH over fiscal year 2020 levels, including a robust funding increase for NIDDK that is at least proportional. In addition, we urge you to consider a Special Statutory Funding Program for Kidney Research at $150 million per year over 10 years, and $100 million in emergency supplemental funding to study the impact of COVID–19 and COVID–19 therapeutics and vaccines on the kidney and in people with kidney diseases.

A January 2017 Government Accountability Office (GAO) report highlighted the pressing need for investment in kidney research; GAO found that the annual cost for care of the approximately 650,000 patients in the Medicare End-Stage Renal Disease (ESRD) program exceeded the budget allocation for the entire NIH. While NIH's budget allocation has grown since that time, we still dedicate equivalent of approximately just 5 percent of the annual total cost of care for kidney failure to kidney research at the NIH.

Since the GAO study was published, the number of patients with kidney diseases and associated costs to the taxpayer have also risen. There are now 720,000 Americans living with kidney failure, and Medicare spends $35 billion managing kidney failure and $116 billion managing kidney diseases, 15 percent of all Medicare spending. Greater investment in kidney research should be an urgent priority to deliver better outcomes for patients and bring greater value to the Medicare program.

As the GAO highlighted, Congress made a commitment to treat all Americans with kidney failure through the Medicare End-Stage Renal Disease (ESRD) Program—the only health condition for which Medicare automatically provides coverage regardless of age. This unique commitment underscores the imperative for Congress to foster innovation and discovery in kidney care.

Our organizations believe the Special Statutory Funding Program for Type 1 Diabetes Research provides an ideal model to foster breakthroughs in kidney therapies and cures. This Special Diabetes Program has generated remarkable progress for diabetes patients, including the development of the Artificial Pancreas. We urge your support for an additional $150 million per year over 10 years to establish a similar program NIDDK focused kidney research—a Special Statutory Funding Program for Kidney Research—supplementing regularly appropriated funds that the NIDDK receives.

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[15] Garrett-Bakelman, FE., et al. 2019. The NASA Twins Study: A multidimensional analysis of a year-long human spaceflight. Science. 364:eaau8650; https://directorsblog.nih.gov/2019/04/23/nasa-twins-study-reveals-health-effects-of-space-flight/.

[16] https://www.unitedformedicalresearch.org/wp-content/uploads/2019/04/NIHs-Role-in-Sustaining-the-US-Economy-FY19-FINAL-2.13.2020.pdf.

NIDDK funds the vast majority of Federal research in kidney diseases, and despite the immense gap between the Federal Government's expenditures on kidney care and its investment in kidney research, NIDDK-funded scientists have produced several major breakthroughs in the past several years that require further investment to stimulate therapeutic advancements. For example, geneticists focused on the kidney have made advances in understanding the genes that cause kidney failure, and other kidney scientists have developed an innovative method to determine if new drugs cause kidney injury before giving them to patients in clinical trials. NIDDK launched the Kidney Precision Medicine Project that will pinpoint targets for novel therapies—setting the stage for personalized medicine in kidney care. Additional, sustained funding is needed to accelerate these and other novel opportunities to improve the care of patients with kidney disease and bring better value to the Medicare ESRD program.

Finally, people with kidney diseases are among the most vulnerable to infectious diseases and there is mounting evidence that COVID–19 poses a unique risk: hospitalized COVID–19 patients with kidney diseases are two and half times more likely to die from the virus.[1] The risks posed by COVID–19 are especially salient among people with kidney failure receiving in-center dialysis or living with a kidney transplant.[2] Sadly, some of the earliest COVID–19 deaths in the U.S. were among kidney patients.[3] In addition, while it is commonly understood that COVID–19 causes damage to the lungs, increasing evidence suggests that the SARS-CoV–2 virus causes kidney injury in patients without pre-existing kidney disease. Anecdotal evidence from New York and China suggest that as many as 14–30 percent of intensive care unit patients with COVID–19 lose kidney function and require emergency kidney replacement therapy.[4]

To date, NIDDK has identified several opportunities for research of the impact of COVID–19 on the kidney and on people with kidney diseases.[5] Such areas identified by NIDDK to-date include:

—Collection of biosamples that could inform the pathogenesis of COVID–19 associated kidney diseases.
—Studies to gather data from healthcare systems and ongoing clinical trials to better understand whether patients with COVID–19 and diseases in the mission of NIDDK have different outcomes based on underlying disease factors or therapies for their condition.
—Studies to identify risk factors that could lead to modification of therapy in high risk individuals such as patients with acute kidney injury and other diseases within the mission of NIDDK that are treated with immunomodulators or biologic pathway inhibitors
—Studies to identify novel pathogenic pathways and potential translational targets for the development of kidney diseases associated with COVID–19 infection using relevant in vitro and in vivo studies of the kidney.
—Pilot clinical studies designed to understand the natural history of COVID–19 related acute kidney injury, or to evaluate interventions to prevent or treat COVID–19-induced acute kidney injury.

However, as currently structured, such research is funded out of previously obligated fiscal year 2020 appropriations, limiting the scope of research NIDDK will be able to support. The scientific challenges facing the kidney community—such as the link between COVID–19 and kidney injury, the unique susceptibility of people with kidney diseases to COVID–19, and the response of people with kidney diseases to vaccines and medications developed to address COVID–19—are critical for providing optimal care during the current pandemic and improving the response to future pandemics, and require immediate and dedicated funding.

With additional funding, NIDDK could expand supported opportunities of investigation to include critical areas such as:

—Studies to identify the response of people with kidney diseases, including those with a transplant or receiving dialysis, to COVID–19 vaccines and medications, which may be different than in populations without kidney diseases

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[1] Achenbach, J. Medical databases show 1 in 10 hospitalized middle-aged coronavirus patients in U.S. do not survive. Washington Post. April 11, 2020.

[2] Abelson, R. Dialysis Patients Face Close-Up Risk From Coronavirus. New York Times. April 11, 2020.

[3] Rubin R. Finding Ways to Reduce Coronavirus Exposure During Dialysis. JAMA. Published online April 16, 2020. doi:10.1001/jama.2020.6158

[4] Bernstein, L., Johnson, C. Y., Kaplan, S., & McGinley, L. Coronavirus destroys lungs but doctors are finding its damage in kidneys, hearts and elsewhere. Washington Post. April 15, 2020.

[5] NIDDK. Notice of Special Interest (NOSI): Availability of Urgent Competitive Revision Supplements on Coronavirus Disease 2019 (COVID–19) within the Mission of NIDDK. April 9, 2020.

—Understanding infectious disease transmission among mandatory congregate populations for healthcare, including patients requiring in-center dialysis
—Interactions between COVID–19 and people with kidney diseases, such as the observed decrease of cytokine storms in kidney patients, and its impact on the development of COVID–19 prognosis and therapeutics
—Strategies to support transition to and maintain home modalities of care for kidney failure

We respectfully request that Congress provide $100,000,000 in emergency supplemental funds for NIDDK in addition to regular fiscal year 2021 appropriations, identical to what was provided in the CARES Act to the National Heart Lung and Blood Institute to study questions of similar urgency.

Thank you again for your leadership, and for your consideration of our request. Should you have any questions or wish to discuss NIDDK or kidney research in more detail, please contact Erika Miller with the American Society of Pediatric Nephrology at emiller@dc-crd.com or Rachel Meyer with the American Society of Nephrology at rmeyer@asn-online.org.

ABOUT THE AMERICAN SOCIETY OF NEPHROLOGY

The American Society of Nephrology is a 501(c)(3) non-profit, tax-exempt organization that leads the fight against kidney disease by educating the society's more than 20,000 nephrologists, scientists, and other healthcare professionals, advancing research and innovation, communicating new knowledge, and advocating for the highest quality care for patients. For more information, visit www.asn-online.org.

ABOUT THE AMERICAN SOCIETY OF PEDIATRIC NEPHROLOGY

Founded in 1969, the American Society of Pediatric Nephrology is a professional society composed of pediatric nephrologists whose goal is to promote optimal care for children with kidney disease and to disseminate advances in the clinical practice and basic science of pediatric nephrology. ASPN currently has over 600 members, making it the primary representative of the Pediatric Nephrology community in North America.

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF NEPHROLOGY

On behalf of the more than 37 million Americans living with kidney diseases, the American Society of Nephrology respectfully requests that in the Office of the Secretary of Health and Human Services (IOS), General Department Management, for the Office of the Chief Technology Officer (CTO), $25 million in be included for KidneyX, a public-private partnership to accelerate innovation in the prevention, diagnosis, and treatment of kidney diseases, in the fiscal year 2021 Labor, Health and Human Services, Education and Related Agencies Appropriations bill, and for $200 million be provided in emergency supplemental appropriations to accelerate the development of the artificial kidney to meet the needs brought to light by the COVID–19 pandemic.

ACCELERATING INNOVATION IN THE PREVENTION, DIAGNOSIS, AND TREATMENT OF KIDNEY DISEASES

More than 37 million people in the United States are living with kidney diseases, and more than 750,000 have kidney failure, for which there is no cure. Despite the significant burden of kidney diseases, there has been a dearth of innovation in this space compared to other areas of medicine. Our healthcare system has fostered a sense of complacency with current therapies and technologies, and complex barriers deter innovators and investors from entering the kidney care space to develop therapies that improve the quality of life for patients and bring better value to the system. Americans affected by kidney diseases deserve better.

The status quo for treating and managing kidney diseases is far too costly to taxpayers to continue without intervention. The Medicare program spent more than $36 billion to manage kidney failure through Medicare's End Stage Renal Disease (ESRD) program in fiscal year 2017—more than 7 percent of all Medicare spending and more than either the entire NIH or entire NASA budget. Further, the prevalence of kidney diseases is growing and costs taxpayers and the Medicare program billions: $120 billion in 2017 alone, or 34 percent of traditional Medicare spending. As the only automatic entitlement program regardless of age in Medicare, taxpayers bear the vast burden of these costs. Despite this significant burden, there has been a lack of innovation in the prevention, diagnosis, and treatment of kidney diseases for decades.

These findings highlight the need for KidneyX to address the barriers to innovation and investment. KidneyX stimulates the commercialization of new therapies while providing a catalyst for investment by the private market in three specific ways that are not currently addressed by market forces or Federal efforts:

—Providing funding to promising innovators to fill specific unmet patient product development needs-informed by patients-through a series of prize competitions.

—De-risking the commercialization process by fostering coordination among the National Institutes of Health, the Food and Drug Administration, Centers for Diseases Control and Prevention, and the Centers for Medicare and Medicaid Services to provide a clear, predictable path towards commercialization, led by the Office of the Chief Technology Officer within the HHS IOS.

—Creating a sense of urgency within the private sector to develop new therapies for people with kidney diseases, repositioning the kidney space as an attractive and untapped market.

KidneyX is already starting to deliver on its mission to accelerate breakthroughs and generate a sense of urgency to bring new solutions to kidney patients. KidneyX has launched 3 prize competitions which have jointly received more than 350 submissions and has distributed $2 million in prizes to a diverse portfolio of awardees. KidneyX launched its first prize competition Redesign Dialysis Phase 1 in 2018 followed by its second and third competitions, Redesign Dialysis Phase 2 and the Patient Innovator Prize in 2019, and plans to launch additional prizes including the moonshot Artificial Kidney Prize mandated in the Executive Order on Advancing American Kidney Health in 2020.

KidneyX is a patient-driven solution supported by an invested community. KidneyX is a true public-private partnership: the private sector has already committed $25,000,000 to KidneyX and is committed to matching Federal funding to achieve a total $250,000,000 in the first 5 years. KidneyX received $5 million in fiscal year 2020 enacted appropriations legislation.

We respectfully request that the Labor-HHS Subcommittee continue its commitment to bringing new therapies for people with kidney diseases by appropriating $25,000,000 in fiscal year 2021 for KidneyX, catalyzing private sector investment across the prevention, diagnosis, and treatment of kidney diseases. In addition, we also ask that you include the following language in the report accompanying your Committee's appropriations bill:

The Committee is aware that more than 37 million U.S. citizens are living with kidney diseases, and for more than 750,000 of those individuals, the diseases progress to kidney failure, requiring access to dialysis or kidney transplantation to live. The Committee notes that kidney failure alone accounted for more than 7 percent of Medicare spending (approximately $36 billion) in fiscal year 2017 and that kidney disease accounted for 34 percent of Medicare spending (approximately $120 billion) in fiscal year 2017. The Committee commends HHS for its efforts to improve the lives of these individuals through KidneyX.

Given the high cost of kidney disease in terms of health consequences and Federal spending, the Committee recommends that a total of $25,000,000 be added to the funds for the Office of the Secretary in fiscal year 2021 for the Office of the Chief Technology Officer, and that those funds be made available to support KidneyX. These funds would represent the first of a five-year commitment to support KidneyX at $25,000,000 each year. The Committee has included funding to support this recommendation. This funding will accelerate the development and adoption of novel therapies and technologies that improve the diagnosis and treatment of patients with kidney diseases, through a variety of fund awards, technical assistance, and other support resources and services.

INCREASING THE RESILIENCE OF KIDNEY HEALTH CARE TO COVID–19 AND FUTURE CRISES

People with kidney diseases are among the most vulnerable to infectious diseases and there is mounting evidence that COVID–19 poses a unique risk: hospitalized COVID–19 patients with kidney diseases are two and half times more likely to die from the virus.[1] The risks posed by COVID–19 are especially salient among people with kidney failure receiving in-center dialysis or living with a kidney transplant.[2]

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[1] Achenbach, J. Medical databases show 1 in 10 hospitalized middle-aged coronavirus patients in U.S. do not survive. Washington Post. April 11, 2020.

[2] Abelson, R. Dialysis Patients Face Close-Up Risk From Coronavirus. New York Times. April 11, 2020.

Sadly, the first COVID–19 death in the U.S. was a kidney patient.[3] In addition, while it is commonly understood that COVID–19 causes damage to the lungs, increasing evidence suggests that the SARS-CoV–2 virus causes kidney injury. Anecdotal evidence from New York and China suggest that as many as 14–30 percent of intensive care unit patients with COVID–19 lose kidney function and require emergency kidney replacement therapy,[4] potentially adding thousands of new cases of kidney failure to our healthcare system.

The current U.S. kidney health infrastructure relies heavily on in-center hemodialysis to treat kidney failure, a care modality that requires mass congregation of vulnerable populations and large numbers of medical personnel. People receiving in-center hemodialysis are unable to follow Federal guidelines recommending social distancing, the therapy requires sitting in close proximity to other immune-compromised patients for 12–16 hours every week.

While numerous efforts undertaken by Congress and the Administration, especially the Executive Order on Advancing American Kidney Health, have started to transform the status quo of care, the COVID–19 pandemic has demonstrated that more must be done to accelerate the development of novel therapies that could mitigate the challenges facing people with kidney failure. New technology, such as the artificial kidney, could enable more patients to safely receive the care they need at home while maintaining a higher quality of life.[5] An artificial kidney would mitigate challenges posed by the current pandemic—such as the current shortage of critical hemodialysis supplies in New York[6]—and making our kidney health system more resilient to future pandemics, natural disasters, and other crises.

The first prize competitions held by KidneyX have fulfilled their objective to accelerate innovation by focusing on redesigning dialysis and identifying patients' innovations in their own care.[7] This, in turn, has stimulated the private markets' attention to promising technologies for people with kidney failure. Based on KidneyX's Redesign Dialysis Phase 1 and 2 prize competitions, new approaches and innovators have surfaced. Wearable or implantable artificial kidney technology are progressing to stages that with appropriate support could be ready for regulatory consideration within 3 years, meeting the needs of kidney patients in the current pandemic and increasing the resilience of our kidney health system for future crises. While total to-market costs for the artificial kidney will likely exceed $400,000,000 per prototype, prize purses of $50,000,000 per prototype will be sufficient to draw the immediate attention of private investors.

We respectfully request that the Labor-HHS Subcommittee provide $200,000,000 to KidneyX in emergency supplemental funding for the accelerated development of artificial kidney technologies, shortening the runway for therapies that will increase the resilience of our kidney healthcare system.

Thank you for your consideration of this important request. Should you have questions or need additional information, do not hesitate to contact Rachel Meyer, Director of Policy and Government Affairs of the American Society of Nephrology, at rmeyer@asn-online.org.

ABOUT THE AMERICAN SOCIETY OF NEPHROLOGY

The American Society of Nephrology is a 501(c)(3) non-profit, tax-exempt organization that leads the fight against kidney disease by educating the society's more than 22,000 nephrologists, scientists, and other healthcare professionals, advancing research and innovation, communicating new knowledge, and advocating for the highest quality care for patients. For more information, visit www.asn-online.org.

[This statement was submitted by Rachel Meyer, Director of Policy and Government Affairs, American Society of Nephrology.]

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[3] Rubin R. Finding Ways to Reduce Coronavirus Exposure During Dialysis. JAMA. Published online April 16, 2020. doi:10.1001/jama.2020.6158.

[4] Bernstein, L., Johnson, C. Y., Kaplan, S., & McGinley, L. Coronavirus destroys lungs but doctors are finding its damage in kidneys, hearts and elsewhere. Washington Post. April 15, 2020.

[5] Huff, C. How artificial kidneys and miniaturized dialysis could save millions of lives. After decades of slow progress, researchers are exploring better treatments for kidney failure—which kills more people than HIV or tuberculosis. Nature. March 11, 2020.

[6] Abelson, R., Fink, S., Kulish, N., Thomas, K. An Overlooked, Possibly Fatal Coronavirus Crisis: A Dire Need for Kidney Dialysis. New York Times. April 18, 2020.

[7] Prize Competitions. KidneyX. https://www.kidneyx.org/PrizeCompetitions. Accessed April 22, 2020.

PREPARED STATEMENT OF THE AMERICAN SPEECH-LANGUAGE-HEARING ASSOCIATION

Chairman Blunt, Ranking Member Murray, members of the Subcommittee: The American Speech-Language-Hearing Association (ASHA) thanks you for the opportunity to submit testimony to the Subcommittee on the fiscal year 2021 Labor-HHS-Education funding bill. My name is Theresa H. Rodgers, ASHA's President for 2020. ASHA is the national professional, scientific, and credentialing association for 211,000 members and affiliates who are audiologists; speech-language pathologists; speech, language, and hearing scientists; audiology and speech-language pathology support personnel; and students.

ASHA thanks the members of the Subcommittee for increasing funding for the Individuals with Disabilities Education Act (IDEA) last year. Congress must continue to make significant investments in IDEA to meet the needs of the country's education system by ensuring children with disabilities receive the Free Appropriate Public Education (FAPE) to which they are entitled under law. Substantially increasing funding for IDEA is the right step in fulfilling the promise that Congress made to fund 40 percent of the average per-pupil expenditure in public elementary and secondary schools. This critical program serves more than 6.5 million children in our nation's schools, including students with communication disorders.[1] Infants and toddlers with disabilities and their families receive early intervention services under IDEA Part C, and children and youth receive special education and related services under IDEA Part B. To support special education, ASHA requests an increase to $14 billion for IDEA Part B State Grants funds for fiscal year 2021, which includes an increase to $684 million for IDEA's Part B Section 619 as well as an increase in IDEA Part C funding to $491 million for fiscal year 2021.

In light of the pandemic of Coronavirus Disease 2019 (COVID–19), ASHA is pleased that the Coronavirus Aid, Relief, and Economic Security (CARES) Act (Public Law 116–136) included over $15 billion in the Education Stabilization Fund earmarked for elementary and secondary education, through the Governor's Emergency Education Fund and the Elementary and Secondary Education Relief Fund. This funding will be essential to support states and local education agencies as they continue to provide FAPE to all students with disabilities. However, without clear data on how much of the funding is dedicated to IDEA services and supports, fiscal year 2021 funding for IDEA must be robust. As schools across the nation move to a virtual education setting, providing special education services becomes more difficult. A surge in funding is vital to ensure students with disabilities receive a continuum of care to prevent any regression.

ASHA urges your continued support for newborn hearing screening and intervention. ASHA requests a total of $30.5 million for Early Hearing Detection and Intervention (EHDI) programs, which includes $19 million for the Health Resources and Services Administration (HRSA) and $11.5 million for the Centers for Disease Control and Prevention (CDC).

Full support for EHDI is critical to ensure all newborns are screened for hearing loss. Hearing loss is a serious health condition that impacts more than 34 million Americans, and two to three out of every 1,000 children in the United States are born with a detectable level of hearing loss in one or both ears.[2] Last reauthorized in 2017, EHDI provides state grants to develop and support infant hearing screening and intervention programs through HRSA, and requires the CDC to provide surveillance of screenings, referral to treatment and diagnosis, technical assistance, and applied research. EHDI has proven to be one of the nation's most important public health programs, offering universal early hearing screening and interventions to all newborns, infants, and young children.

Failure to fund EHDI at its full authorization level may leave thousands of children with undiagnosed hearing loss and deprive children who are deaf or hard of hearing from receiving follow-up services that improve language skills and development as many healthcare appointments and treatments have been delayed or cancelled due to the COVID–19 pandemic.

When state-based universal newborn hearing screenings were established with the passage of the Child Health Act of 2000, only 46.5 percent of infants were screened for hearing loss, yet with today's EHDI programs, 98 percent of infants are

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[1] U.S. Department of Education. (n.d.). About IDEA. Retrieved May 20, 2020 from: https://sites.ed.gov/idea/about-idea/.

[2] National Institute on Deafness and Other Communication Disorders (NIDCD). (2017). Researchers help uncover a root cause of childhood deafness in the inner ear using animal model. Retrieved from https://www.nidcd.nih.gov/news/2017/childhood-deafness-research.

screened for hearing loss.[3,4] Additional resources will assist CDC and HRSA in strengthening hearing loss identification and reducing intervention service gaps that have occurred during the COVID–19 public health emergency. When hearing loss is detected late, the critical time for stimulating the auditory pathways to hearing centers of the brain is lost. Late hearing loss detection also delays speech and language development affecting social and emotional growth, academic achievement, and employment options. Funding for hearing screenings and early intervention services are a smart investment for the U.S. economy, and saves the country approximately $200 million in education costs each year alone.[5]

ASHA applauds the efforts of the Subcommittee to increase the National Institutes of Health (NIH) budget. We are supportive of efforts to increase the investment in research across all institutes involved with communication sciences and disorders. Congress must support researchers who devote their careers to finding causes and prevention of communication disorders. Communication disorders are the most prevalent of all disabling conditions and approximately 46 million Americans have a communication disorder.[6] These disorders impact the economy through costs related to lost productivity, special education services, rehabilitation needs, healthcare expenditures, and lost revenues. Continued increases in funding for the National Institute on Deafness and Other Communication Disorders (NIDCD) are needed to ensure groundbreaking research on communication sciences continues and expands. Specifically, ASHA supports a $17 million increase to the NIDCD for a total fiscal year 2021 level of $507 million.

ASHA also supports providing a $3 million increase for the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) at the Administration for Community Living (ACL). With this increase to $115 million, NIDILRR's funding for fiscal year 2021 would allow the Institute to continue supporting the wide range of applied research that it conducts and expand into new areas of emerging science to support the population of individuals with relevant disabilities.

Chairman Blunt, Ranking Member Murray and members of the Subcommittee, on behalf of ASHA and its 211,000 members, we again appreciate the opportunity to provide these comments and thank you for your efforts to eradicate delayed detection and intervention for hearing loss; support additional resources for special education services; and your continued support for patient-oriented clinical research funding. We look forward to working with you and the Subcommittee as the fiscal year 2021 appropriations process moves forward.

[This statement was submitted by Theresa H. Rodgers, MA, CCC-SLP, President, American Speech-Language-Hearing Association.]

PREPARED STATEMENT OF THE AMERICAN STATISTICAL ASSOCIATION

Dear Chair Blunt and Ranking Member Murray,

I write in support of the Bureau of Labor Statistics (BLS), the National Center for Education Statistics (NCES), and the National Center for Health Statistics (NCHS) for your consideration as you draft the fiscal year 2021 Labor, Health and Human Services, Education, and Related Agencies appropriations bill.

For BLS, thank you for your strong support of its programs through the fiscal year 2020 level of $628 million. The additional funding enables BLS to carry out and continue to improve its ongoing programs and better understand the impact of the digital economy on our workforce. I also convey our strong support for the administration's request of $645 million for the fiscal year 2021 program budget in addition to the $13 million for the BLS relocation to Suitland, Maryland. As you know, the BLS produces economic data that are essential for evidence-based decision-making by businesses and financial markets, Federal and local officials, and households faced with spending and career choices. The BLS, like every Federal statistical agency, must modernize in order to produce the gold standard data on jobs, wages,

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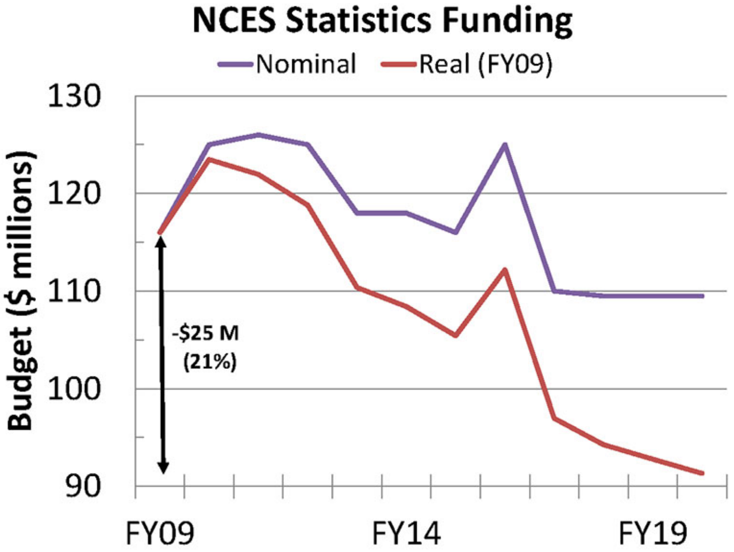
[3] Centers for Disease Control and Prevention (CDC). (2010). Summary of infants screened for hearing loss, diagnosed, and enrolled in early intervention, United States, 1999–2008. Atlanta, GA: U.S. Department of Health & Human Services, CDC. Retrieved from https://www.cdc.gov/ncbddd/hearingloss/2008-data/ehdi_1999_2008.pdf.

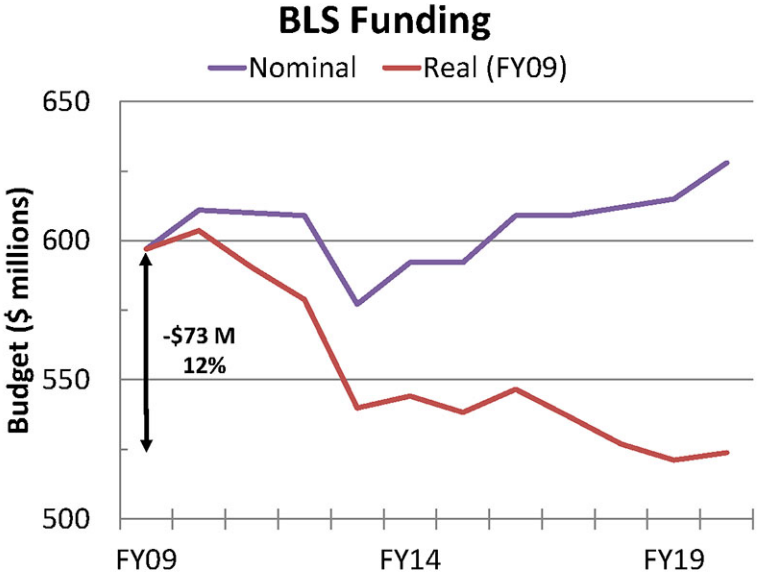
[4] Centers for Disease Control and Prevention (CDC). (2018). Summary of 2016 National CDC EHDI Data. Retrieved from https://www.cdc.gov/ncbddd/hearingloss/2016-data/01-2016-HSFS-Data-Summary-h.pdf.

[5] Gross, S.D. (2007). Education cost savings from early detection of hearing loss: New findings. Volta Voices, 14(6),38–40.

[6] National Institute on Deafness and Other Communication Disorders (NIDCD). (2019). Mission. Retrieved from https://www.nidcd.nih.gov/about/mission.

skill needs, inflation, productivity and more on which our businesses, researchers, and policymakers rely heavily. BLS' modernization efforts have been hampered by its $73 million (12 percent) loss of purchasing power since fiscal year 2009. (See enclosed graph.)





The administration's request level is a positive step towards the restoration of BLS resources. We fully support the proposals, including for the Job Openings and Labor Turnover Survey (JOLTS). The increased sample size for JOLTS will enable state-level data and more detailed industry data, which will be especially helpful to governors, regional economic development organizations, and other policymakers in the Covid–19 recovery period. We also support the proposed investments for the

Consumer Expenditure program. This program is overdue for a new design given its burden on respondents. Resources now feasible through big data and technological advances have the potential to improve inflation and poverty measurement. These improved programs will be especially informative as our country recovers from the Covid–19 pandemic.

For the NCHS, we recommend a funding level of at least $189 million—an increase of $14.6 million and realignment of $14 million in ongoing transfers—which would restore NCHS' budget to its inflation-adjusted fiscal year 2010 funding level. While NCHS work has been critical to monitoring deaths due to Covid–19, recent events, including the opioid crisis, have made clear that our public health data surveillance systems are challenged in many ways, as reported this spring in a National Academies' seminar.[1] For example, current systems are slow to alert us to "change in key indicators so that interventions can be implemented early in a crisis..." They need to be redesigned for automatic reporting and for flexibility to adjust quickly to new crises and to data collection disruption. The recommended funding level would help NCHS to address these challenges.

For the NCES, we echo our requests in a March 23 joint letter to you with the American Educational Research Associations, two former NCES commissioners, and two former chief statisticians of the United States:

> To ensure NCES continues serving its vital mission, we request inclusion of provisions in the fiscal year 2021 appropriations bill that would enable NCES to rebuild internal capacity through hiring full-time, permanent staff. We also urge at least a 5 percent budget increase for the NCES statistics account that would partially redress its more than 20 percent loss in purchasing power since fiscal year 2009.

We reiterate points from that letter in the next three paragraphs. The NCES has an ongoing staffing crisis that has reached a point this year likely to result in terminations and cutbacks of critical statistical information programs. All Federal statistical agencies conduct some of their work with government staff resources and contract with others—often specialized profit-making firms, but sometimes other Federal agencies—to conduct the remainder. The NCES has an exceptionally high budget-to-staff ratio, $3 million/FTE, which is nine times the median of other Federal statistical agencies. This means a higher proportion of the critical statistical data collection design and analysis—normally expected of Federal employees—is, instead, performed by contractors. Compared with other statistical agencies, NCES staff resources are disproportionately allocated to overseeing contractors who perform many of these essential statistical activities. We believe this shift has gone too far for THE NCES to be a healthy statistical organization and strongly recommend Congress take explicit actions to address this condition in the fiscal year 2021 appropriation process. A set-aside allocation of 20 additional staff would provide a good start to rebuild NCES staff resources.

We also urge the NCES statistics account be funded at a level of at least $115 million. As shown in the enclosed graph, this account has lost more than 20 percent of its purchasing power since fiscal year 2009, when its budget was $116 million. The loss of purchasing power is even greater since fiscal year 2010–fiscal year 2012, when the account was at $125 million or higher. (Our recommended level does not include the $3 million in the administration's request that is transferred from the statewide longitudinal data systems for the Privacy Technical Assistance Center.) The requested increase of at least 5 percent will help NCES' ability to track emerging education trends, reduce respondent burden, and provide more timely and regional data—efforts that are currently taxed due to both the loss of the agency's purchasing power and its staffing crisis.

Among the surveys that should be prioritized for continuation are the School Survey on Crime and Safety (SSOCS) and the Fast Response Survey System (FRSS), which we understand may be discontinued until staff and funding are in place. SSOCS' estimates of school crime, discipline, and disorder—as well as associated programs and policies—are essential to ensuring our schools provide safe learning environments for our nation's children. FRSS was established to collect data quickly, with minimum response burden, to inform new policies and would be especially helpful in getting our schools back on track as we recover from the Covid–19 pandemic. Increased funding will also be necessary to create and maintain the Postsecondary Student Data System, a major new project in the College Affordability Act of 2019 currently working its way through Congress for reauthorization of the Higher Education Act.

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[1] https://www.nationalacademies.org/event/05-08-2020/cnstat-public-seminars-deaths-of-despair-and-the-future-of-capitalism, at minute, 1:22.

Finally, thank you for your strong support for the National Institutes of Health. We also strongly support the NIH budget.

Sincerely.

[This statement was submitted by Ron Wasserstein, Executive Director, American Statistical Association.]

PREPARED STATEMENT OF THE AMERICAN THORACIC SOCIETY

SUMMARY: FUNDING RECOMMENDATIONS

[in millions $]

NATIONAL INSTITUTES OF HEALTH	$44.7 billion
National Heart, Lung & Blood Institute	$3.890
National Institute of Allergy & Infectious Disease	$6.345
National Institute of Environmental Health Sciences	$860.3
Fogarty International Center	$82.9
National Institute of Nursing Research	$173.4
CENTERS FOR DISEASE CONTROL AND PREVENTION	$8.300
National Institute for Occupational Safety & Health	$354.8
Asthma Programs	$34
Div. of Tuberculosis Elimination	$195.7
Office on Smoking and Health	$310

The ATS is a multi-disciplinary society of 16,000 pulmonary, critical care and sleep specialists who are on the frontlines of the COVID–19 pandemic treating individuals and conducting vital scientific research to develop diagnostics, treatments, and prevention interventions for this and all respiratory diseases, critical illnesses and sleep disorders.

LUNG DISEASE IN AMERICA

Respiratory diseases are the third leading cause of death in the U.S., responsible for one of every seven deaths. Diseases affecting the respiratory (breathing) system include COVID–19, chronic obstructive pulmonary disease (COPD), lung cancer, influenza, sleep disordered breathing, tuberculosis (TB), occupational lung disease, asthma, and critical illnesses such as sepsis.

NATIONAL INSTITUTES OF HEALTH

The coronavirus crisis has revealed the critical national public health security leadership role that the NIH holds in scientific expertise to guide the nation in critical biomedical. In order to accelerate the development of life-saving cures and treatments and innovative prevention interventions, it is essential for Congress to continue providing robust, predictable funding increases across the full spectrum of NIH-supported research. We ask the subcommittee to provide at least $44.7 billion in funding for the NIH in fiscal year 2021.

While the biomedical research community is focusing on COVID–19-related research, other critical research has been slowed or halted completely due to academic center and laboratory closures. As a result of research pauses, the scientific workforce of investigators, postdoctoral candidates and technical support staff across the U.S. is facing deep uncertainty about the future. In addition to the fiscal year 2021 appropriation of $44.7 billion, the ATS urges Congress to provide $31 billion in funding to expand COVID–19 related research, support biomedical research grant and contract supplements through NIH and other Federal agencies, research facility operating costs and additional postdoctoral fellowships and other research training positions in the next COVID–19 response package.

NATIONAL HEART, LUNG AND BLOOD INSTITUTE

The National Heart, Lung and Blood Institute (NHLBI) is conducting vital research to address morbidity and mortality among individuals with COVID–19, develop interventions to mitigate life-threatening cardiovascular, respiratory and hematological complications of the disease and develop new therapeutics, including for high-risk populations. In addition to the fiscal year 2021 appropriation of $3.890 billion, the ATS urges Congress to provide supplemental funding of $300 million to permit NHLBI to sustain and expand its investment in basic, clinical, and translational across heart, lung, blood and sleep scientific research to address these critical needs related to COVID–19 and prepare for additional waves of disease in the coming months.

Even though respiratory disease is the third leading cause of death in the U.S., respiratory research is underfunded. The COPD death rate has doubled within the last 30 years and is still increasing, while the rates for the other top causes of death (heart disease, cancer, and stroke) have decreased by over 50 percent. Despite the rising respiratory disease burden, research funding for the disease is disproportionally low relative to funding invested for the other three leading causes of death. In order to stem the devastating effects of respiratory disease, NIH, including NHLBI research funding must grow.

Chronic Obstructive Pulmonary Disease

Chronic Obstructive Pulmonary Disease (COPD) is the fourth leading cause of death in the United States and the third leading cause of death worldwide. CDC estimates that 12 million patients have COPD; an additional 12 million Americans are unaware that they have this life-threatening disease. COPD costs the economy almost $50 billion a year, including $29 billion in direct health expenditures and $29 billion in indirect costs such as lost wages.

The COPD National Action Plan, released in 2017, aims to expand surveillance and research of the disease, develop public health interventions, and increase public awareness of the disease. The ATS urges Congress to provide NIH's National Heart, Lung and Blood Institute (NHLBI) with $75 million in fiscal year 2021 for implementation of the COPD National Action Plan. In addition, we urge the subcommittee to provide $5 million for CDC for creation of a Chronic Disease Education and Awareness Program to provide competitive grants supporting public health efforts for COPD and other chronic diseases, as proposed in the fiscal year 2020 House Labor-HHS–ED bill. We also urge CDC to include COPD-based questions to future CDC health surveys, including the National Health and Nutrition Evaluation Survey (NHANES), the Behavioral Risk Factor Surveillance System (BRFSS) and the National Health Information Survey (NHIS).

CENTERS FOR DISEASE CONTROL AND PREVENTION

CDC is our front-line national public health agency responding to COVID–19. In order to halt the COVID–19 pandemic, it is critical that the agency receives sustained funding increases. The ATS supports a funding level for the CDC that enables it to effectively respond to infectious disease outbreaks such as COVID–19, provide vital support to state and local public health programs and continue to support chronic disease prevention and occupational safety and training and health research. The ATS recommends a funding level of at least $8.300 billion for the CDC in fiscal year 2021.

ANTIBIOTIC RESISTANCE

According to the CDC's 2019 report, Antibiotic Resistance Threats in the United States up to 35,000 deaths occur in the U.S. annually due to antibiotic resistant bacteria including drug resistant pneumonia and sepsis infections. The rise of antibiotic resistance shows the need to increase efforts through the CDC, NIH and other Federal agencies to monitor and prevent antibiotic resistance and develop rapid new diagnostics and treatments. This includes the following recommendations for CDC programs:

—$200 million for the Antibiotic Resistance Solutions Initiative
—$37.5 million for the Advanced Molecular Detection (AMD) Initiative

We urge the committee to provide $6.345 billion for the National Institutes of Allergy and Infectious Disease (NIAID) to spur research into rapid new diagnostics and treatments and $230 million for the Biomedical Advanced Research and Development Authority (BARDA) to support antimicrobial research and development.

TOBACCO CONTROL

Tobacco use is the leading preventable cause of death in the U.S., responsible for one in five deaths annually. Tobacco cessation and prevention activities are among the most effective and cost-effective investments in disease prevention. The CDC's Office on Smoking and Health (OSH) is the lead Federal program for tobacco prevention and control and created the "Tips from Former Smokers" Campaign, which has prompted hundreds of thousands of smokers to call 1–800–QUIT–NOW or visit smokefree.gov for assistance in quitting—with even more smokers making quit attempts on their own or with the assistance of their physicians. The ATS recommends fiscal year 2021 funding of $310 million for the Office of Smoking and Health.

ASTHMA

Asthma is a significant public health problem in the U.S. Approximately 25 million Americans currently have asthma. In 2017, 3,564 Americans died because of asthma exacerbations. Asthma is the third leading cause of hospitalization among children under the age of 15 and is a leading cause of school absences from chronic disease. African Americans have the highest asthma prevalence of any racial/ethnic group and the age-adjusted death rate for asthma in this population is three times the rate in whites. We ask that the subcommittee provide $34 million in fiscal year 2021 for CDC's National Asthma Control Program.

SLEEP

Several research studies demonstrate that sleep-disordered breathing and sleep-related illnesses affect an estimated 50–70 million Americans. The public health impact of sleep illnesses and sleep disordered breathing is still being determined, but is known to include increased mortality, traffic accidents, cardiovascular disease, obesity, mental health disorders, and other comorbidities. The ATS recommends a funding level of $1 million in fiscal year 2021 to support activities related to sleep and sleep disorders at the CDC, including surveillance activities and public educational activities. The ATS also recommends an increase in funding for research on sleep disorders at the NHLBI's Nation Center for Sleep Disordered Research (NCSDR).

TUBERCULOSIS

Tuberculosis (TB) is the leading global infectious disease killer, ahead of HIV/AIDS, claiming 1.5 million lives each year. In the U.S., every state reports cases of TB annually and in 2019, twenty-one states reported TB increases. Drug resistant tuberculosis was identified as a serious public health threat to the U.S. in CDC's 2019 report on antimicrobial resistance. And there are up to 13 million people in the U.S. with latent TB infection (LTBI), the reservoir of future active cases. Yet CDC's domestic TB program has been flat funded since fiscal year 2014, leaving states ill-equipped to manage drug resistant TB and unable to do LTBI testing and preventive treatment. The continued global pandemic of this airborne infectious disease demand that the U.S. strengthen our investment in global and domestic TB control and research to develop new TB diagnostic, treatment, and prevention tools.

The ATS recommends a funding level of $195.7 million in fiscal year 2021 for CDC's Division of TB Elimination and $21 million for CDC's Global TB program through the Center for Global Health. We urge the NIH to expand research to develop new tools to address TB. Additionally, in recognition of the unique public health threat posed by drug resistant TB, the ATS urges BARDA to support research and development into new drug-resistant TB diagnostic, treatment, and prevention tools.

Most TB programs around the country report that TB program staff and some TB hospital units have been moved to focus almost exclusively on COVID–19. The COVID–19 emergency in the U.S., and its economic impact, has put enormous strain on state and local budgets that fund the majority of TB services. CDC's global TB program is providing critical technical assistance to countries struggling to address COVID while maintaining TB services. In addition to the fiscal year 2021 appropriations for these programs, the ATS urges Congress to provide $30 million for CDC, state, and local tuberculosis (TB) programs and $20 million for CDC's global TB program in the next COVID–19 response legislation.

PEDIATRIC LUNG DISEASE

The ATS is pleased to report that infant death rates for various lung diseases have declined for the past 10 years. Many of the precursors of adult respiratory disease start in childhood. For instance, many children with respiratory illness grow into adults with COPD. It is estimated that 6.2 million children suffer from asthma. The ATS encourages the NHLBI and NICHD to sustain and expand research efforts to study lung development and pediatric lung diseases.

CRITICAL ILLNESS

The burden associated with the provision of care to critically ill patients is enormous and is anticipated to increase significantly as the population ages. Approximately 200,000 people in the United States require hospitalization in an intensive care unit because they develop a form of pulmonary disease called Acute Lung Injury. Despite the best available treatments, 75,000 of these individuals die each year from this disease. This is the approximately the same number of deaths each year due to breast cancer, colon cancer, and prostate cancer combined. Investigation into diagnosis, treatment and outcomes in critically ill patients should be a priority, and the NIH should be funded and encouraged to coordinate investigation in this area.

RESEARCHING AND PREVENTING OCCUPATIONAL LUNG DISEASE

The ATS urges the subcommittee to provide at least $354.8 million in funding for the National Institute for Occupational Safety and Health (NIOSH). NIOSH, within the CDC, is the primary Federal agency responsible for conducting research and making recommendations for the prevention of work-related illness and injury.

LEGISLATIVE RIDERS

We urge the Senate to refrain from considering legislative riders in this and all appropriations bills. By refraining from considering legislative riders, Congress can more swiftly complete its constitutional obligation for completing appropriations bills in a timely manner.

[This statement was submitted by Juan C. Celedon, MD, DrPH, ATSF, President, American Thoracic Society.]

PREPARED STATEMENT OF THE AMERICAN UROGYNECOLOGIC SOCIETY

The American Urogynecologic Society (AUGS) thanks the Subcommittee for the opportunity to submit comments for the record regarding our recommendations for prioritizing research on pelvic floor disorders at the National Institutes of Health in fiscal year 2021. AUGS is a national medical society whose mission is to promote the highest quality of care in Female Pelvic Medicine and Reconstructive Surgery (FPMRS, aka Urogynecology) through excellence in education, research, and advocacy.

Pelvic floor disorders, which include pelvic organ prolapse and urinary and bowel incontinence, impact more than 25 million women annually in the United States, alone.

Pelvic organ prolapse occurs when the pelvic floor muscles and connective tissue supporting the pelvic organs (the bladder, uterus and cervix, vagina, and rectum) weaken or tear and can no longer support these organs. This causes one or more of the pelvic organs to fall downward into the vagina, like a hernia. Women may feel or see tissue coming out of the opening of their vagina as this condition advances. The risk factors and causes of pelvic floor damage leading to pelvic organ prolapse include:

Pregnancy and Childbirth: One in three women who has given birth has pelvic organ prolapse. Being pregnant and having a vaginal delivery can damage the pelvic muscles and nerves, allowing the organs to drop. This is particularly true for women who have had a large baby, many babies or needed forceps to deliver during a challenging birth.

Aging and Menopause: Loss of estrogen with menopause, along with other changes with aging, can weaken the pelvic floor.

Certain Health Conditions: Health problems that involve repeated straining (such as obesity, chronic cough, and chronic constipation).

Genetics: Genes help determine the strength of the connective tissue, so a woman is more likely to develop pelvic organ prolapse if her mother had the condition.

Pelvic organ prolapse is a common problem, with 1 out of 8 women undergoing surgery for prolapse at some point in their life. Some studies have shown a prevalence difference in racial and ethnic populations. More research is needed to better understand disparities in access to care and care-seeking behaviors so that we can understand these disparities. Pelvic organ prolapse can occur in reproductive age women but becomes more common as women age and after menopause. Treatment of pelvic organ prolapse requires significant healthcare resources; the annual cost of ambulatory care for pelvic floor disorders in the United States from 2005 to 2006 was almost $300 million. Non-surgical treatments require frequent healthcare visits and surgical treatments are imperfect with 20 percent of women experiencing recurrences within 10 years. Surgical repair of prolapse is performed twice as commonly as incontinence surgery and constitutes the most common inpatient procedure performed in women older than 70 years.

This has prompted many scientists to seek improved surgical solutions. However, when innovations are poorly studied and quickly promoted to a large surgical population, well-intentioned efforts can backfire. For example, after a period of rapid adoption, concern over the safety and efficacy of vaginal mesh—augmented prolapse repairs resulted in a ban by the FDA in 2019. Clinicians and patients still struggle to find reliable and safe treatments for pelvic organ prolapse. Advances in care must be well studied prior to wide adoption, and outcomes must be tracked on a large scale to identify high quality approaches that lead to significant improvements in women's health.

The other two most common types of pelvic floor disorders are urinary and bowel incontinence. Over half of people aged 65 and older living at home reported urinary and/or bowel incontinence, according to the Centers for Disease Control and Prevention. In fact, these conditions are leading causes for admission to nursing homes as families are challenged for caring for their loved ones.

Urinary incontinence is loss of bladder control that can lead to involuntary leakage of urine. The symptoms range in severity from occasional incidents to daily or nightly occurrences. It can happen at any age but is more prevalent in older individuals. The most common types of urinary incontinence are the following:

> *Stress Incontinence*.—Women most commonly develop stress urinary incontinence from changes that happen in pregnancy or childbirth which weaken the support to the urethra and urethral sphincter. Urine leaks when pressure is exerted on the bladder during coughing, sneezing, laughing, exercising or lifting something heavy.
>
> *Urge Incontinence*.—A sudden, intense urge to urinate that is followed by an involuntary loss of urine. It can cause the need to urinate frequently, and often throughout the night. Urge incontinence happens because of altered bladder nerve signaling and is also referred to as "overactive bladder."
>
> *Mixed Incontinence*.—This is a combination of stress and urge incontinence and is the most common form of incontinence in older women.
>
> *Overflow Incontinence*.—Frequent or constant dribbling of urine due to a bladder that doesn't empty completely. Often, these patients also have a neurological condition.
>
> *Functional incontinence*.—A physical or mental impairment (such as arthritis or Alzheimer's disease) may limit the ability to reach a bathroom in time.

Incontinence has a substantial financial impact to society. In the United States, direct and indirect costs of overactive bladder are estimated at $76 billion in 2015. By the year 2020, the costs of overactive bladder evaluation and treatment are projected to account for $82.6 billion of U.S. healthcare expenditures, making it a huge public health burden.

Women who suffer from pelvic floor disorders experience a significant adverse impact on quality of life, resulting in restrictions in activities, social isolation, depression and physical discomfort. We believe the financial and personal toll caused by pelvic floor disorders require a renewed focus at the National Institutes of Health to improve prevention and treatment strategies for these conditions. As part of this effort, we strongly urge that technology be harnessed to identify trends in clinical care and efficacy associated with the use of new innovations to treat pelvic floor disorders to ensure patient safety and better patient outcomes.

The AUGS urges the Subcommittee to adopt the following language in the report accompanying the fiscal year 2021 Labor-HHS-Education appropriations bill to achieve these objectives.

Pelvic Floor Disorders.—The Committee recognizes that Pelvic Floor Disorders, including such conditions as urinary incontinence, accidental bowel leakage and pelvic organ prolapse, have a large financial impact on individuals and society, and significant negative quality of life impact for more than 25 million women annually, in the USA alone. We urge NICHD, NIDDK and NIA to work together on the development of universally accepted disorder specific data sets and biorepositories for the purpose of research studies on patient outcomes of current and future therapies used to treat pelvic floor disorders and the pathogenesis of these conditions. The Committee requests that NICHD, NIDDK and NIA provide a report on current research and future initiatives to address pelvic floor disorders in the fiscal year 2022 Congressional Justification and provide timely updates to the Committee on advances being made with respect to prevention, treatment and understanding the mechanisms of these conditions.

Thank you in advance for your favorable consideration of this report language request and for your support for prioritizing research on pelvic floor disorders. Your leadership on this issue will provide hope to millions of women suffering from these conditions.

PREPARED STATEMENT OF KATE ANDREWS

My interest in more funding for research for RX and a cure for schizophrenia is needed desperately. Our adopted son was accepted to 3 colleges in NC. He was a freshman attended NC State in Raleigh NC in November 2017. The campus police called our home at 11.00 p.m. to report our son was on campus grounds staring into the tunnel. He was staring and would not answer their questions—he was catatonic. And since that night our world was turned upside down, four hospital stays and three group homes, my husband and I have had a life where we would become angry, worried, frustrated, and depressed. Our son as of April 1 has finally been stabilized. He left the group home on March 16, 2020. He is living in a tiny apartment from the housing authority. His disability was a god send, but when in the group home his allowance for clothing toiletries, and any recreation was 60.00 a month, and his cell phone is 40.00. This diagnosis is schizoaffective and he becomes delusion and manic without his multiple RX. He takes for his mental health. and takes RX to help with the many bad side effects of his antipsychotic medicine and his mood stabilizer...so scary to have to see your families be torn apart watching your child turn from a confident intelligent person to someone who barely can communicate. And all in their prime of life. Had just turned 19 when he had his psychotic break...he was so delusional he had his entire college paid for and attended less than 3 months. Schizophrenia is a debilitating disease and robs persons of fulfilling their hopes and dreams, without family support I would shutter to think where our son would be today, possibly homeless or incarcerated as so many schizophrenic are.

PREPARED STATEMENT OF THE ANIMAL WELFARE INSTITUTE

The Animal Welfare Institute appreciates the opportunity to submit testimony on fiscal year 2021 spending priorities for the U.S. Department of Health and Human Services. We are requesting report language for the Department pertaining to Protecting Animals With Shelter (Section 12502, Public Law 115–334) and pertaining to the post-research retirement of animals used in government financed experiments.

PROTECTING ANIMALS WITH SHELTER (SECTION 12502 OF THE FARM BILL)

When there is violence in the home, it can be directed at everyone-spouse or partners, children, elderly family members, and companion animals. Abusers are well aware of the bond between their victims and their pets. They exploit that bond to frighten, control, manipulate, and even "punish" their human victims.

Unfortunately, few domestic violence survivors have access to shelters that can protect them and their pet; in fact, large numbers delay escaping out of fear for the safety of the pets left behind. Several surveys bear the grim statistics:

—As many as 48 percent of the battered women reported they had delayed leaving a dangerous situation out of concern for their companion animals' safety.

—Between 49 percent and 86 percent reported that their pets had been threatened, harmed, or killed by their partners.

—85 percent of domestic violence shelters indicated that women coming to their facilities spoke of incidents of pet abuse.

Congress has wisely sought to address this shortage of resources. Section 12502 of Public Law 115–334, the Agriculture Improvement Act of 2018, authorizes a grant program to provide emergency and transitional shelter and housing options for domestic violence survivors with companion animals. It is urgent that Congress now appropriate the full authorized funding and direct the agencies involved to take all necessary steps to implement the program. If shelters and other service providers can help domestic violence survivors find a safe place for their companion animals, they will be better able be to bring everyone to safety. The PAWS provision will greatly increase their capacity to meet these critical needs. We respectfully request that the Committee reiterate its interest in having all departments involved in this grant program work together to ensure its speedy implementation.

Requested Report Language: The Committee directs the Secretary of Health and Human Services to continue consultations with the Secretary of Agriculture, as well as with the Secretary of Housing and Urban Development and the Attorney General, and enter into any memoranda of understanding as needed, in order to finalize the requirements for grant application and implementation under Section 12502 of Public Law 115–334, the Agriculture Improvement Act of 2018, to provide emergency and transitional shelter and housing options for domestic violence survivors with companion animals.

POST-RESEARCH ADOPTION OF ANIMALS USED IN EXTRAMURAL RESEARCH

Animals used for laboratory testing deserve the opportunity to experience normal lives with families or through sanctuary care once they are no longer needed for any research protocol. Most animals used for research spend their lives in cages, often isolated from one another, and are forced to undergo procedures that produce trauma and suffering. Instead of needlessly killing them after their use in experiments is over, laboratories should give them a second chance. The retirement and adoption of research animals can be rewarding for the caretakers and scientists as well, who often want to see the animals moved to positive environments when no longer needed for research. NIH has instituted policies and procedures to facilitate the retirement of animals no longer needed for research, but that policy covers only NIH intramural research. We respectfully request that NIH be directed to extend this policy to NIH-funded extramural research.

Requested Report Language: The Committee commends the National Institutes of Health and other agencies for instituting policies and procedures to facilitate the placement of animals no longer needed for research with families or nonprofit shelters or sanctuaries. This is a far more humane and less wasteful practice than euthanizing otherwise healthy animals. We note, however, that the NIH policy covers only NIH intramural research. Animals used in NIH-funded extramural research also should not be needlessly euthanized at the end of the experiment if they are determined to be healthy enough to be adopted or retired. The Committee directs NIH to require grantees receiving extramural funds from NIH for research using animals to implement post-research adoption policies that are at least as comprehensive as the NIH intramural policy. The committee requests that NIH provide a written update on this effort within a year.

[This statement was submitted by Nancy Blaney, Director, Government Affairs, Animal Welfare Institute.]

PREPARED STATEMENT OF THE ARTHRITIS FOUNDATION

On behalf of the 54 million adults and 300,000 children living with doctor-diagnosed arthritis in the United States, the Arthritis Foundation thanks Chairman Blunt and Ranking Member Murray for the opportunity to provide written testimony to the Appropriations Subcommittee on Labor, Health and Human Services (HHS), and Education and Related Agencies for fiscal year 2021. We respectfully request robust funding for the Centers for Disease Control and Prevention (CDC) Arthritis Program, and estimate full funding for the program is approximately $54 million.

Arthritis affects 1 in 4 Americans and is the leading cause of disability in the United States, according to CDC. It limits the daily activities of over 23 million Americans and causes work limitations for 40 percent of the people with the disease. This translates to over $300 billion a year in direct and indirect costs. There is no cure for arthritis, and for some forms of arthritis like OA, there is no disease-modifying pharmaceutical therapy. Research is critical to build towards a cure, develop better treatments with fewer severe side effects, and identify biomarkers and therapies for types of arthritis for which none exist. A strong investment in public health research and programs is essential to making breakthroughs in treatments, finding a cure for arthritis, and for delivering those breakthroughs to the people who suffer from this debilitating disease.

The CDC Arthritis Program is the only Federal program dedicated solely to arthritis. Today, the program provides grants to 13 states to support evidence-based disease management programs. The program aims to connect all Americans with arthritis to resources to help them manage their disease. Evidence-based programs like EnhanceFitness help keep older adults active, and have shown a 35 percent improvement in physical function, resulting in fewer hospitalizations and lower health costs compared to non-participants. In addition, Walk With Ease is an evidence-based group walking program that encourages people with arthritis to start walking and stay motivated to keep active. The program allows participants to meet a few times per week to receive health education on an arthritis or exercise-related topic following by stretching activities, and a group walk. A recent CDC-funded randomized controlled trial found that the program can help reduce arthritis symptoms, reduce disability, and improve strength and balance.

Not only does the Arthritis Program provide resources to people with arthritis, it also supports data collection on the prevalence and severity of arthritis. Due to this support, we know that 24.9 percent of people in Missouri and 22.2 percent of people in Washington have doctor-diagnosed arthritis; about 44 percent and 43 percent, respectively, of people in those states report activity limitations due to arthritis.

Given the high prevalence and severity of this disease, the Arthritis Program is woefully under-funded compared to the investment in other chronic diseases. From a historical perspective, funding for the program was cut by 25 percent in fiscal year 2015, bringing the fiscal year 2015 total down from $13 million to $9.5 million. As a result, program staff had to cut program activities between 10 and 50 percent, with some eliminations, and were unable to make new investments in arthritis programs. While $1.5 million was restored in fiscal year 2016, the Arthritis Program is still not operating at its funding level of $13.3 million during fiscal year 2010. Combined with previous flat funding, the program has lost millions of dollars in purchasing power over the last decade.

We estimate that a robust allocation for the Arthritis Program would total at least $54 million in fiscal year 2021. With this level of funding, the program would be able to:

—Provide funding to states to fully operationalize a National Arthritis Program. Today, the CDC Arthritis Program funds only 13 state programs around the country (AR, KS, MA, MN, MS, NH, NY, NC, OR, RI, UT, VA, and WA). These programs play a vital role in the dissemination of proven strategies and programs, and all states should receive funding to operate an arthritis program;

—Expand national partnerships that are critical to promoting awareness, increasing primary provider referrals for non-pharmacologic management of chronic pain, and providing access to arthritis self-management and physical activity programs; and

—Invest in robust data and intervention and prevention research to better understand arthritis.

We thank the Subcommittee for its commitment to the health and wellbeing of all Americans. As you write the fiscal year 21 Labor-HHS-Education appropriations bill, we hope you will provide robust funding for the CDC Arthritis Program in order to continue investments that improve the lives of people with chronic diseases like arthritis. Please contact Vincent Pacileo, Director of Federal Affairs, at vpacileo@arthritis.org, with any questions.

PREPARED STATEMENT OF THE ASSOCIATION FOR CAREER AND TECHNICAL EDUCATION AND ADVANCE CTE

Chairman Blunt, Ranking Member Murray, and distinguished members of the subcommittee, on behalf of the Association for Career and Technical Education (ACTE), the nation's largest not-for-profit association committed to the advancement of education that prepares youth and adults for career success, and Advance CTE, the nation's longest-standing not-for-profit that represents State Directors and leaders responsible for secondary, postsecondary and adult Career Technical Education (CTE) across all 50 states and U.S. territories, we respectfully request that the subcommittee increase funding for the Perkins Basic State Grant program, administered by U.S. Department of Education's Office of Career, Technical, and Adult Education, to $1.963 billion in the fiscal year 2021 Labor, Health and Human Services, Education, and Related Agencies appropriations bill. It is vital that Congress continues to build upon the recent increases to the Strengthening Career and Technical Education for the 21st Century Act (Perkins V) in order to fully support the implementation of the law and the 11.8 million learners it serves across the nation.[1]

High-quality CTE programs are delivering real results. Across the country, CTE programs are preparing learners for promising career paths and giving employers and our economy a competitive edge. CTE programs provide unique opportunities for learners to engage with employers and participate in internships, apprenticeships and other meaningful on-the-job experiences. In addition, these programs produce strong outcomes for the learners they serve. The average high school graduation rate for students concentrating in CTE is 95 percent, compared to a national adjusted cohort graduation rate of 85 percent.[2] Additionally, students involved in CTE are far less likely to drop out of high school than other students, a difference

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[1] Perkins Collaborative Resource Network, Perkins Data Explorer, customized Consolidated Annual Report data. Retrieved from https://perkins.ed.gov/pims/DataExplorer.

[2] Perkins Collaborative Resource Network, Perkins Data Explorer, customized Consolidated Annual Report data. https://perkins.ed.gov/pims/DataExplorer; U.S. Department of Education, Office of Elementary and Secondary Education, Consolidated State Performance Report, 2010–11 through 2016–17.

estimated to save the economy $168 billion each year.[3] Furthermore, those students are highly likely to continue their education—91 percent of high school graduates who earned two to three CTE credits enrolled in college.[4]

The outcomes for adult learners are also significant: 84 percent of adults concentrating in CTE programs either continued their education or were employed within 6 months of completing their program.[5] In fact, 90 percent of Americans agree that apprenticeships and skills training programs prepare individuals for a good standard of living.[6]

Expanding funding for CTE programs will create a brighter future for communities—leading to more career options for learners, better results for employers, and increased growth for our economy. Investing in CTE programs provides substantial benefits for not just the students enrolled, but for states and communities across the country. In Wisconsin, taxpayers receive $12.20 in return for every dollar invested in the technical college system.[7] Oklahoma's economy reaps a net benefit of $3.5 billion annually from graduates of the CareerTech System.[8] Individuals who receive a certificate or degree from California Community Colleges almost double their earnings within 3 years,[9] while every dollar spent on secondary CTE students in Washington state leads to $26 in lifetime earnings and employee benefits.[10] If we are serious about providing learners with the real-world skills, hands-on opportunities and real options for college and rewarding careers that come with CTE and making progress toward closing the skills gap, then there is no better time than now to invest $1.963 billion in CTE State Grants; this would be a strong down payment on doubling the Federal investment in CTE State Grants by fiscal year 2024, which is the long-term goal of our organizations.

CTE programs prepare students for careers in in-demand fields and provide an affordable pathway to both a family-sustaining career and financial independence. Healthcare occupations, many of which require an associate degree or industry credential, are projected to grow 14 percent by 2028—adding almost 2 million new jobs.[11] Half of all STEM occupations, which offer students high-skilled, high-wage career opportunities, require less than a bachelor's degree.[12] There are currently about 30 million "good jobs"—jobs that pay a median income of $55,000 or more and require education below a bachelor's degree.[13]

Additionally, the demand for workforce credentials is growing. The number of individuals earning certificates or associate degrees in CTE fields, such as manufacturing, healthcare, and STEM, rose 71 percent from 2002 to 2012.[14] Students can pursue these valuable credentials at community and technical colleges for a fraction

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[3] Kotamraju, P. Measuring the return on investment for CTE. Techniques: 28–31, 2011. Retrieved from https://files.eric.ed.gov/fulltext/EJ943149.pdf.

[4] U.S. Department of Education, National Center for Education Statistics, Data Point: Career and Technical Education Coursetaking and Postsecondary Enrollment and Attainment: High School Classes of 1992 and 2004, 2016. Retrieved from https://nces.ed.gov/pubs2016/2016109.pdf.

[5] Includes only states that report data on adult CTE learners to the U.S. Department of Education. Perkins Collaborative Resource Network, Perkins Data Explorer, customized Consolidated Annual Report data. Retrieved from https://perkins.ed.gov/pims/DataExplorer/Performance.

[6] New America, Varying Degrees 2018: Executive Summary. Retrieved from https://www.newamerica.org/education-policy/reports/varying-degrees-2018/executive-summary/.

[7] Wisconsin Technical College System, The Technical College Effect, 2016. Retrieved from https://www.wistechcolleges.org/sites/default/files/POSTER8.5x11-2016update2__0.pdf.

[8] Snead, M. C., The Economic Contribution of CareerTech to the Oklahoma Economy: Cost-Benefit Analysis of Career Majors (fiscal year 2011), 2013. Retrieved from https://www.okcareertech.org/about/costbenefit-analysis-of-career-majors/cost-benefit-analysis-of-career-majorsfy-11-pdf.

[9] Foundation for California Community Colleges, California Community Colleges, n.d. Retrieved from https://foundationccc.org/Portals/0/Documents/NewsRoom/FactSheets/ccc-facts-figures.pdf.

[10] Workforce Training and Education Coordinating Board, Workforce Training Results 2020. Retrieved from https://www.wtb.wa.gov/wp-content/uploads/2020/01/2020-Dashboard.pdf.

[11] U.S. Department of Labor, Bureau of Labor Statistics, Occupational Outlook Handbook, Healthcare Occupations. Retrieved from https://www.bls.gov/ooh/healthcare/home.htm.

[12] Rothwell, J. The Hidden STEM Economy, Brookings Institution, 2013. Retrieved from https://www.brookings.edu/research/the-hidden-stem-economy/.

[13] Georgetown University Center on Education and the Workforce, Good Jobs that Pay Without a BA, 2017. Retrieved from https://goodjobsdata.org/wp-content/uploads/Good-Jobs-wo-BA-final.pdf.

[14] U.S. Department of Education, Office of Planning, Evaluation and Policy Development, Policy and Program Studies Service, National Assessment of Career and Technical Education: Final Report to Congress, 2014. Retrieved from https://www2.ed.gov/rschstat/eval/sectech/nacte/career-technical-education/final-report.pdf.

of the cost of tuition at other institutions: $3,730, on average for the 2019–2020 academic year.[15]

Highly-skilled workers deliver direct benefits to American employers through enhanced productivity and innovation; however, the increased demands on the workforce pipeline are a persistent barrier to economic growth. A projected three million workers are needed to fill infrastructure jobs in the next few years, including careers in construction, transportation and telecommunications.[16] Meanwhile, 89 percent of executives agree there is a talent shortage in the U.S. manufacturing sector, 5 percent higher than 2015 results.[17] These industries still need talent, even in the current economic climate.

Funding Perkins V at adequate levels will ensure that educators can equip students with the skills they will need for in-demand fields. This will become increasingly pressing as the country continues to combat the current health pandemic and economic crisis. Already, healthcare jobs are projected to have the largest increase of any occupational sector.[18] Filling these and other positions created, as well as ensuring that each individual is able to access the training needed for employment, is critical.

CTE programs can serve even more learners and employers—but only if they receive more resources. According to The Bureau of Labor Statistics Job Openings and Labor Turnover Survey (JOLTS) Highlights for January 2020, for 23 consecutive months, there were more open jobs in the U.S. than there were unemployed Americans.[19] While the current economic forecast is unclear, the significant gaps for skilled workers remain; we anticipate that many workers will need to be reskilled to rejoin the economy. Learner demand for CTE programs, especially programs in in-demand sectors, is greater than supply. With current and anticipated demand growing, more resources are needed. And there's widespread support for CTE: 94 percent of parents approve of expanding access to CTE.[20] However, a survey of school districts offering CTE found that the top barrier to offering CTE in high school was a lack of funding or the high cost of the programs.[21] As the chart below demonstrates, between fiscal year 2004 and fiscal year 2020, funding for CTE State Grants declined by over $77 million dollars, the equivalent of $427 million inflation-adjusted dollars (i.e., 28 percent in inflation-adjusted dollars).

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[15] College Board, Average published charges, 2018–19 and 2019–20. Retrieved from https://research.collegeboard.org/trends/college-pricing/figures-tables/average-published-charges-2018-19-and-2019-20.

[16] Kane, J. W., and Tomer, A. Infrastructure skills: Knowledge, tools, and training to increase opportunity, Brookings Institution, 2016. Retrieved from https://www.brookings.edu/research/infrastructure-skills-knowledge-tools-and-training-to-increase-opportunity/.

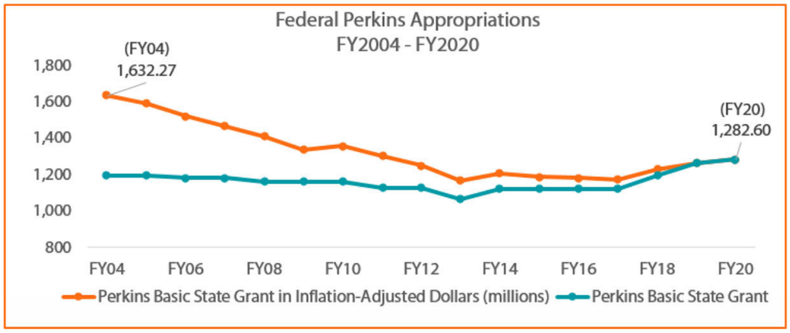
[17] Deloitte and the Manufacturing Institute, Skills Gap and the Future of Work Study, 2018. Retrieved from http://www.themanufacturinginstitute.org/~/media/E323C4D8F75A470E8C96D7A07F0A14FB/DI_2018_Deloitte_MFI_skills_gap_FoW_study.pdf; Deloitte and the Manufacturing Institute, The skills gap in U.S. manufacturing 2015 and beyond, 2015. Retrieved from http://www.themanufacturinginstitute.org/~/media/827DBC76533942679A15EF7067A704CD.ashx.

[18] U.S. Department of Labor, Bureau of Labor Statistics, Occupational Outlook Handbook, Healthcare Occupations. Retrieved from https://www.bls.gov/ooh/healthcare/home.htm.

[19] U.S. Department of Labor, Bureau of Labor Statistics, Job Openings and Labor Turnover Survey (JOLTS) Highlights; January 2020. Retrieved from https://www.bls.gov/web/jolts/jlt_labstatgraphs.pdf.

[20] Hart Research Associates, Public School Parents on the Value of Public Education: Findings from a National Survey of Public School parents conducted for the AFT, September 2017. Retrieved from https://www.aft.org/sites/default/files/parentpoll2017_memo.pdf.

[21] U.S. Department of Education, National Center for Education Statistics, Career and Technical Education Programs in Public School Districts: 2016–17. Retrieved from https://nces.ed.gov/pubs2018/2018028.pdf.



Taking a longer view, before fiscal year 2018, the investment in CTE State Grants had been relatively flat since 1991 without being tied to inflation, and the program's buying power had fallen by approximately $933 million in inflation-adjusted dollars—a 45 percent reduction over a quarter century.[22]

Congress recognized the need to begin to reverse this trend and from fiscal year 2018 to fiscal year 2020 provided an additional $175 million for CTE State Grants, bringing the total investment to $1.283 billion. While the past three budgets represented initial down payments to meet increased need, a significant, robust investment in CTE programs is still imperative to account for persistent underfunding, the lack of inflation-adjusted increases, and most importantly the overwhelming growth in demand for these programs from both learners and the American economy. Congress should build on the momentum from recent years and continue to strengthen the investment in CTE State Grants in fiscal year 2021. And, Americans agree: 93 percent of voters support increasing the investment in skills training.[23]

Though we are in the midst of a public health crisis facing the country right now, and economic ramifications are likely, we respectfully still request this increase in Federal CTE funding. Now more than ever, individuals need access to upskilling and reskilling opportunities to be part of the evolving workforce, and CTE programs will be adapting, as always, to the needs of business and industry in the current economy. We applaud their commitment to growing our investment in Perkins V, and we urge the subcommittee to make CTE a top priority in the fiscal year 2021 Labor, Health and Human Services, Education, and Related Agencies appropriations bill.

Thank you for your thoughtful consideration of our request. For more information or if you wish to discuss our request, please contact ACTE's Government Relations Manager Michael Matthews (mmatthews@acteonline.org) or Advance CTE Policy Associate Meredith Hills (mhills@careertech.org).

Prepared Statement of the Association for Clinical Oncology

The Association for Clinical Oncology (ASCO), the world's leading professional organization representing nearly 45,000 physicians and other professionals who treat people with cancer, thanks this subcommittee for its long-standing commitment to support federally funded research at the NIH and NCI. ASCO is extremely grateful for the $2.6 billion increase for the NIH in fiscal year 2020. This strong commitment to scientific discovery will help the research community continue current momentum and sustain our nation's position as the world leader in biomedical research. We are in an exciting and promising era of medical research; new discoveries are leading to major improvements in the way we care for patients with cancer, and every major medical breakthrough in cancer started with the NIH and NCI. ASCO appreciates this opportunity to provide the following recommendations for fiscal year 2021 funding to build on our nation's investment in biomedical research:

—*National Institutes of Health (NIH):* $44.7 billion

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[22] U.S. Bureau of Labor Statistics, CPI Inflation Calculator. Retrieved from https://data.bls.gov/cgi-bin/cpicalc.pl.

[23] ALG Research, Poll Finds Overwhelming Support for More Funding for Skills Training, 2019. Retrieved from https://www.nationalskillscoalition.org/news/press-releases/body/Poll-Finds-Overwhelming-Support-for-More-Funding-for-Skills-Training.pdf.

- *National Cancer Institute (NCI):* $6.928 billion
  - *Beau Biden Cancer Moonshot Initiative:* $195 million
- *Centers for Disease Control and Prevention's (CDC) Division of Cancer Prevention and Control (DCPC):* $559 million
  - *Cancer Registries Program:* $70 million

Robust, sustained funding for the NIH and NCI will continue the extraordinary progress towards understanding the cause of cancer, its progression, and our ability to prevent, diagnose and treat this disease.

The NIH: A Good Investment

In fiscal year 2019, the NIH provided over $30 billion in extramural research to scientists in all 50 states and the District of Columbia.[1] NIH research funding also supported more than 475,000 jobs and generated nearly $81 billion in economic activity last year.[2] Federal funding supported nearly a quarter of the studies highlighted in ASCO's 2020 Clinical Cancer Advances report, our 15th annual report on progress against cancer. Some of the most notable federally funded advances highlighted in the 2020 report are:

- Neoadjuvant combinations of immunotherapies have paved the way for more successful, less invasive surgeries for patients with advanced melanoma
- Targeted therapies now provide alternatives to immediate surgery in the treatment of renal cell carcinoma
- Upfront systemic treatments make surgery possible for more patients with pancreatic cancer
- Long-term data now shows that vaccines against the human papillomavirus are reducing cervical cancer risk in real-world settings
- Biomarker-driven treatment approaches have opened the door to personalized care for metastatic pancreatic cancer
- Combinations of different types of therapies now suggest that survival can be extended for many patients without increasing toxicity
- A growing number of targeted therapies offer hope to patients with difficult to treat cancers

Sustained and steady funding of the NIH and NCI is critical to maintaining the pace of scientific discovery and continued progress against cancer, such as the advances outlined above.

Over the last few years, you have prioritized Federal funding for biomedical research, increasing the NIH budget by $2.6 billion in fiscal year 2020, and providing a combined increase of $11.6 billion in the last five fiscal years. This investment has allowed the agency to regain some of the ground that was lost over a decade of flat funding. The funding levels we are requesting for fiscal year 2021 would allow for meaningful growth above biomedical inflation for the first time in over a decade and would allow the extraordinary progress of the last few years to continue. Failure to continue the historic investment in research places health outcomes, scientific leadership, and economic growth at risk.

The NCI: More Support Needed

Cancer is the second leading cause of death in the United States, and it is estimated that more than 1.8 million Americans will be diagnosed with cancer this year, with an estimated 606,000 succumbing to the disease. Additionally, cancer costs the U.S. economy more than $216 billion annually in direct treatment costs and lost productivity.[3]

ASCO thanks you for your continued inclusion of funding for the Beau Biden Cancer Moonshot Initiative in fiscal year 2020. The Cancer Moonshot Initiative continues its work towards modernizing clinical trials, establishing a direct patient engagement network, developing a national cancer data ecosystem, continuing advances in precision oncology, developing effective immunotherapies for a broader array of cancers, including pediatrics, and creating an adult immunotherapy network. Adequate funding is needed to make progress in each of these areas over the coming years. Funding for this Initiative should supplement rather than supplant predictable increases in the underlying NCI budget. In fact, funding for the Initiative peaked at $400 million in fiscal year 2019, and dropped to $195 million in fiscal year 2020.

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[1] National Institutes of Health; https://www.nih.gov/about-nih/what-we-do/impact-nih-research.

[2] United for Medical Research; https://www.unitedformedicalresearch.org/wp-content/uploads/2019/04/NIHs-Role-in-Sustaining-the-US-Economy-FY19-FINAL-2.13.2020.pdf.

[3] American Cancer Society; https://www.cancer.org/research/cancer-facts-statistics/all-cancer-facts-figures/cancer-facts-figures-2019.html.

The NCI is the largest funder of cancer research in the world, and the majority of its funding goes directly towards supporting research at NCI and at cancer centers, hospitals, community clinics, and universities across the country. While the NCI has received modest funding increases over the last few years, funding has not kept up with the growing number of research grants and applications as compared to other NIH Institutes or Centers. In fact, over the last 5 years R01 grant applications submitted to the NCI rose by 50 percent, while funding for NCI only grew by 20 percent over the same time period. This means NCI is funding a smaller proportion of grant applications compared to previous years—only 8 percent of applications received funding in 2019 compared to 28 percent in 1997. Even after counting the additional funding NCI has received through the Cancer Moonshot Initiative, NCI's budget has simply not kept up with scientific opportunity. The funding requests submitted today would give the NCI the ability increase the grants its able to fund to 15 percent of those submitted.[4]

Bringing the Research to the Patient

NIH-funded translational research and clinical trials have significantly improved the standard of care in many diseases. Clinical trials and translational research yield insight critical to the development of targeted therapies, which identify patients most likely to benefit and help patients who will not benefit avoid the cost and pain of treatment unlikely to help them. This is where science becomes practice-changing for patients in America.

ASCO has developed the Targeted Agent and Profiling Utilization Registry (TAPUR^{tm}) Study, which provides access to targeted therapies for patients age twelve and older and who have been identified as candidates for benefitting from those treatments because of a promising tumor biomarker target identified in their cancer. The TAPUR Study evaluates use of these molecularly targeted anti-cancer drugs and collects data on clinical outcomes. As of March 2020, there are over 1800 participants enrolled in the TAPUR Study at 117 sites in 21 states. Without Federal investment spurring the pipeline of new cancer treatments, studies such as TAPUR would not be possible.

To maintain access to research for cancer patients, ASCO urges a substantial increase in funding for the National Clinical Trials Network (NCTN) and NCI Community Oncology Research Program (NCORP). Just last year, the NCI awarded 53 grants to researchers in the NCORP community, at 46 sites, who have assembled more than 1,000 affiliates across the country to conduct research. The NCORP network now covers 44 states DC.[5] An increase in NCI's budget would enable the Institute to maintain or increase the number of accruals to trials and cover the cost of conducting the research.

Finally, we are in an unprecedented era for cancer research, with more targeted and patient-specific therapies in development. However, access to clinical trials remains a wide-spread issue for many patient populations. Specifically, underserved communities, including patients on Medicaid face several barriers when trying to access clinical trials. Diversity and generalizability of cancer clinical trials is crucial for making trial results applicable more broadly and to ensure positive clinical outcomes for all patients. We hope to continue our work with Congress, NCI and the Centers for Medicare and Medicaid Services (CMS) to improve access to clinical trials for underrepresented patient populations.

Cancer Registries: Harnessing Data

Accessible data is crucial to understanding cancer at a broader level. ASCO joins the broader cancer community in requesting $559 million for the Centers for Disease Control and Prevention's (CDC) Division of Cancer Prevention and Control (DCPC), and $70 million for the CDC's Cancer Registries Program. Cancer registries are a critical tool for providers and researchers, providing unparalleled cancer surveillance, identifying emerging trends amongst different patient cohorts, illustrating the impact of early detection, and showing the impact of treatment advances on cancer outcomes. Registries allow providers to collect data in real time and improve cancer research, public health interventions and treatment protocols. While we work towards greater trials inclusion, registries help ensure we have data from underrepresented patient cohorts such as racial and ethnic minorities, women and children, and rural populations.

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[4] National Cancer Institute; https://www.cancer.gov/about-nci/budget/plan/2020-annual-plan-budget-proposal.pdf.

[5] National Cancer Institute; https://ncorp.cancer.gov/news/2019-08-19.html.

Mitigating the Effects of COVID–19 and Continuing the Work Towards Cures

Modern cancer research delivers new treatments to patients faster than ever, thanks to continuing innovation in research and regulatory infrastructure. Between August 2018 and July 2019, the FDA approved 17 new anti-cancer therapeutics. Since 1991 the cancer mortality rate has declined by 29 percent, and between 2016 and 2017 we experienced the largest single-year drop in cancer mortality ever reported, a 2.2 percent decline. Today two out of three people with cancer will leave at least 5 years past diagnosis and there are 16.9 million American cancer survivors.[6] The investments Congress has made in cancer research has helped make this progress possible.

While we have made great progress in the field of cancer care, we are in an unprecedented public health crisis that has affected all corners of our healthcare system. Many labs across the country have had to suspend or adjust their research as a result of the COVID–19 pandemic. Individuals in the research community are at risk of losing their employment as well as their current research progress. Unfortunately, the longer our clinical trials network is stagnant, the more patients will miss out on potentially life-saving treatments. Once this crisis subsides, flexibility and robust funding will be critical to get the nation's trials and research enterprise fully running again. It is vital that Congress acts now to provide relief in the form of continued funding for the research community to ensure sustained advances in healthcare therapies.

To continue the momentum gained over the last few years, lawmakers and researchers will need to work together to mitigate COVID–19 related disruptions to research and restore momentum across the nation's medical research network. Therefore, I urge you to prioritize the important role NIH and NCI play in medical innovation and economic growth by protecting and strengthening federally funded research in fiscal year 2021.

ASCO again thanks the subcommittee for its continued support of cancer patients in the U.S. through funding for the NIH and NCI. We look forward to working with all members of the subcommittee on an fiscal year 2021 budget that continues to advance U.S. cancer research. Please contact Kristin Palmer at Kristin.Palmer@asco.org with any questions.

[This statement was submitted by Monica Bertagnolli, MD, FASCO, Chair, Association for Clinical Oncology.]

PREPARED STATEMENT OF THE ASSOCIATION FOR PSYCHOLOGICAL SCIENCE

APS RECOMMENDATIONS FOR FISCAL YEAR 2021 APPROPRIATIONS

- —As a member of the Ad Hoc Group for Medical Research, APS recommends at least $44.7 billion for NIH in fiscal year 2021. This would be a $3 billion increase over NIH's program level funding in fiscal year 2020. This funding level would allow for meaningful growth above inflation in the base budget that would expand NIH's capacity to support promising science in all disciplines beyond the directed funding included in the 21st Century Cures Act.
- —APS asks the Committee to continue to engage with NIH regarding NIH's redefinition of clinical trials to include basic research and asks the Committee to include strong and direct fiscal year 2021 report language to reject this redefinition. The Committee included very direct report language in the fiscal year 2018 Omnibus directing NIH to "delay enforcement of the new policy" and "consult with the basic research community to determine reporting standards best suited to this kind of research." However, NIH is choosing to ignore the intent of the Committee, and is continuing to move forward with a policy that reclassifies a significant amount of basic research as a clinical trial and subjects this research to the added regulations and cost of clinical trials. APS encourages NIH to develop a compromise, in collaboration with the behavioral science research community, which encourages registration and reporting of research but does not require applications to go through clinicaltrials.gov or be called a clinical trial.
- —APS asks Congress to urge NIH to establish an advisory panel to review and recommend programs and structures that will result in a stronger basic, applied, and clinical behavioral science research and training enterprise at NIH in recognition of the central role of behavior in health. Behavior is involved in

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[6] ASCO; https://www.asco.org/research-guidelines/reports-studies/clinical-cancer-advances-2020.

the development, treatment, or prevention of virtually every public health issue facing this Nation, including the ongoing coronavirus pandemic and other viruses and diseases, opioid addiction, cancer, diabetes, mental illness, violence, traumatic brain injury, and alcoholism.

—Finally, APS urges the Committee to favorably consider the requests of the Psychological Clinical Science Accreditation System (PCSAS) to urge the modification of HRSA and National Health Service Corps regulations to permit the graduates of PCSAS-accredited schools to be eligible for employment in these programs. APS believes that the strong emphasis on science in PCSAS accreditation offers promise of improved prevention and treatment interventions which will strengthen HRSA and the National Health Service Corps programs.

Chairman Blunt and Members of the Subcommittee, thank you for the opportunity to provide testimony as you consider funding priorities for fiscal year 2021. I am Sarah Brookhart, Executive Director of the Association for Psychological Science (APS). APS is a nonprofit organization dedicated to the advancement of scientific psychology nationally and internationally. Mr. Chairman, APS recognizes and appreciates your leadership and the leadership of this Subcommittee in supporting public health research.

FUNDING FOR THE NATIONAL INSTITUTES OF HEALTH AND POLICY ISSUES

As previously noted, APS recommends an fiscal year 2021 funding level of $44.7 billion for NIH, which would enable real growth over health research inflation as an important step to ensuring stability in the Nation's research capacity over the long term. The Administration's request of $38.7 billion in fiscal year 2021, translating to a $3.0 billion cut, is reckless and shortsighted. Cuts to NIH would affect every American, including patients, their families, researchers, and communities where NIH investment spurs economic growth. In addition to funding priorities, APS is concerned about several policy issues at NIH.

Clinical Trials Definition

APS continues to be concerned that NIH is moving forward with the implementation of a new definition of clinical trials that encompasses significant amounts of basic research with humans. This NIH action ignores over 3,500 comments critical of this change, the opposition of 35 current and former members of NIH Advisory Councils (as conveyed in a letter to Director Collins), and concerns expressed by the Committee in its fiscal year 2018 Conference report language. Basic research by definition is aimed at furthering knowledge about underlying processes and conditions involved in a particular phenomenon. Clinical trials are explicitly designed to test the safety and effectiveness of treatment or prevention interventions on health outcomes. The new definition of clinical trial encompasses basic research studies which are not traditionally considered to be a clinical trial by NIH or by the scientific community. With this definition, NIH subjects entire areas of basic research to inappropriate and unnecessary requirements that add significantly to the cost and time of each project and also create a significant economic burden for university and government review and training programs. To help reverse this policy change, we urge the following fiscal year 2021 report language in the NIH Office of the Director:

Clinical Trials Policy.—The Committee supports the NIH delay of implementation of registering and reporting requirements for basic experimental studies with humans and notes that the fiscal year 2020 Conference Agreement asked NIH to continue to work with the basic research community to achieve a balanced registration and reporting strategy that meets the interests of study participants, investigators, and taxpayers. The NIH policy to require all basic research involving humans to register and apply for funding as a clinical trial has been objected to by the community, as it creates additional red tape and costs that are unnecessary to meet the shared goal of transparency. NIH is directed to not classify basic research involving humans as clinical trials and to work with the community to develop an alternative registering and reporting system that will meet the shared goals of transparency and oversight. The Committee further requests a report that describes the new plan within 60 days of this bill being enacted into law.

Behavioral Science at NIH

The NIH mission is to "seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability." However, increasingly, APS has concerns about the status of behavioral science at NIH, specifically regarding the continued disparity between the central role of behavior in all areas of health and the low level of direct support for basic and applied behavioral science research and training at NIH. APS therefore requests that the following language be included in your report directing the Director of NIH to convene a special advisory panel of behavioral scientists and other scientific community experts to complete an assessment providing recommendations on how to better integrate and realize the benefits to overall health from behavioral research at NIH:

Behavioral Research.—The Committee believes that a more robust and focused NIH commitment to behavioral science research and training would yield significant improvements to the Nation's health due to the important connections between behavior and health. Most of the leading public health issues facing our nation-including cancer, addiction, heart disease, mental illness, diabetes, violence, and AIDS—are rooted in individual and social behavior, yet behavioral science is decentralized across NIH's institutes and the NIH commitment to manage and directly fund this important research is limited. The Committee therefore requests that the Director convene a special advisory panel of behavioral scientists and other community experts to complete an assessment providing recommendations on how to better integrate and realize the benefits to overall health from behavioral research at NIH. The Committee requests that this assessment be finalized before the end of fiscal year 2021 and be submitted to Congress.

APS notes that the ongoing coronavirus pandemic provides a key illustration of the important connections between behavior and health. Basic behavioral science research informs relevant topics ranging from perceptions of risk and decisionmaking to individual and group social processes and behavior. Psychological scientists study the science of behavior change and how to encourage individuals to adopt behavioral practices or adapt existing ones. Clinical psychological scientists examine issues of mental illness, which may be widespread in emergency contexts. Behavioral science can also determine ways to implement behavior-based interventions to help contain the spread of the virus. APS believes that the scientific community would be better prepared to study, understand, predict, and guide behavior related to the coronavirus if behavioral science research and funding were better supported and centralized at NIH.

UPDATING HRSA AND NATIONAL HEALTH SERVICE REGULATIONS

APS urges the Committee to favorably consider the requests of the Psychological Clinical Science Accreditation System (PCSAS) to urge the modification of HRSA and National Health Service Corps regulations to permit the graduates of PCSAS accredited schools to be eligible for employment in these programs. APS believes that the strong emphasis on science in PCSAS accreditation offers promise of improved prevention and treatment interventions which will strengthen HRSA and the National Health Service Corps programs. Prior to 2012, the American Psychological Association (APA) was the only accrediting body for clinical psychology programs, and therefore many agency regulations are outdated and refer to the program eligibility need for APA accreditation. This historical artifact needs to be updated for many programs, including those of HRSA and the National Health Service Corps. The language needed to urge these changes follows:

Health Workforce Eligibility Requirements.—The Committee notes that the eligibility requirements for the Behavioral Health Workforce and Training Program and the Graduate Psychology Education Program need to be updated for accreditation changes that have occurred since the eligibility requirements were established. The eligibility requirements of these two programs require that applicants must be accredited by accrediting organizations recognized by the Department of Education. This fails to recognize the well-established and respected Council for Higher Education Accreditation (CHEA), which has 3,000 university members and accredits over 60 different accrediting bodies. In September 2012, CHEA recognized the Psychological Clinical Science Accreditation System (PCSAS), which has since that date has accredited 43 clinical psychological doctoral programs which are all recognized to be among the 50 top programs in clinical psychology in the country. We note that the Department of Veterans Affairs recognized PCSAS in 2016. That is, PCSAS is already federally recognized. In order to insure that HRSA's health workforce programs continue to have access to the best qualified applicants, including those who graduate from PCSAS programs, the Committee urges HRSA to make administrative accommodations to accomplish this necessary update similar to the accommodations HRSA has provided for other similarly situated professions.

Clinical Psychological Training for Public Health Service Corps.—The Committee supports the review by the Surgeon General's office to update HHS regulations to permit the graduates of the 43 doctoral programs in clinical psychology accredited by the Psychological Clinical Science Accreditation System (PCSAS) to be employed by the Public Health Service Corps. This update is necessary as PCSAS was recognized in September 2012 by the Council for Higher Education Accreditation (CHEA) and now accredits 43 programs that are among the highest ranked clinical psychology program in the country. The Veterans Administration, the Association of Psychological Postdoctoral and Internship Centers, and others have already updated their regulations to permit the employment of the graduates of PCSAS accredited programs. The Committee urges that the Surgeon General's office finalize and implement these changes as soon as possible.

SUMMARY AND CONCLUSION

Chairman Blunt, again we wish to thank the Subcommittee for its past leadership. We believe that reducing barriers to research and training in behavioral science is warranted by the central role of behavior in many of our most pressing health problems and by the enormous potential of psychological science and other behavioral science disciplines to reduce the suffering experienced by the millions of people with behavior-based conditions. APS shares your commitment to addressing the health needs of the Nation and appreciates the opportunity to provide this testimony.

[This statement was submitted by Sarah Brookhart, Executive Director, Association for Psychological Science.]

PREPARED STATEMENT OF THE ASSOCIATION FOR RESEARCH IN VISION AND OPHTHALMOLOGY

EXECUTIVE SUMMARY

The Association for Research in Vision and Ophthalmology (ARVO), on behalf of the vision research community, thanks Congress, especially the House and Senate Appropriations Subcommittees on Labor, Health and Human Services, Education, and Related Agencies (LHHS), for the strong bipartisan support for the National Institutes of Health (NIH) funding increases from fiscal years 2016 through fiscal year 2020. The $11.6 billion NIH increase has helped the agency regain some of the ground lost after years of effectively flat budgets. ARVO also thanks Congress for the bipartisan agreements that provide supplemental appropriations for NIH as the research community responds to COVID–19.

ARVO urges Congress to continue this support and urges Congress to appropriate $44.7 billion for the NIH in fiscal year 2021, a $3 billion or 7.2 percent increase over the fiscal year 2020 program level and allowing for—

—meaningful growth above inflation in the base budget to support promising science across all NIH Institutes and Centers;

—funding from the Innovation Account established through the 21st Century Cures Act, which would supplement NIH's base budget, as intended, through dedicated funding for specific programs and funding for early-stage investigators.

Due to the strain COVID–19 is placing on the research infrastructure and strict limits of the fiscal year 2021 discretionary spending caps, ARVO supports bipartisan proposals to exempt NIH from the fiscal year 2021 caps. ARVO also requests that the LHHS bill is structured to facilitate emergency funding, as necessary, to maintain the momentum of research emerging from past NIH investment such that the return-on-investment is fully realized with new diagnostics and therapies.

ARVO also urges Congress to appropriate $875 million for the National Eye Institute (NEI), a $51 million or 6.2 percent increase over enacted fiscal year 2020. The NEI is the world leader in sight-saving and vision-restoring research. Congress must ensure robust NEI funding to continue to address the challenges of The Decade of Vision 2010–2020—as recognized by Congress in H. Res. 366 in 2009—which include an aging population, disproportionate risk/incidence of eye disease in fast-growing minority populations, and the impact on vision from numerous chronic diseases and their treatments/therapies.

Despite the total fiscal year 2016–2020 funding increases of $146 million, NEI's enacted fiscal year 2020 budget of $824.1 million is just 21 percent greater than the pre-sequester fiscal year 2012 budget of $702 million. Averaged over the eight fiscal years, the 2.6 percent annual growth rate is less than the average annual biomedical inflation rate of 2.8 percent, thereby eroding purchasing power, which in fiscal year 2019 was below that of fiscal year 2012 and equivalent to that in fiscal year 2000. Maintaining the momentum of vision research is vital to vision health, as well as overall health and quality of life. Since the U.S. is the world leader in vision research and training the next generation of vision scientists, the health of the global vision research community is also at stake.

ARVO recognizes that due to the pandemic, the NEI now faces additional challenges, as both the working-age population and students may potentially rely exclusively on electronic devices and e-learning platforms well into our new normal. As increased rates of myopia, dry eye, and eye strain are associated with lengthy exposure to these devices, NEI research will be instrumental in ensuring eye health is continually prioritized throughout the continuum of life.

NEI LEADS IN GENETIC AND REGENERATIVE MEDICINE RESEARCH

The NEI has been a leader in genetics/genomics research and regenerative medicine.

- —Genetics/Genomics: Vision researchers worldwide participating in NEI's Glaucoma Genetics Collaboration Heritable Overall Operational Database (NEIGHBORHOOD) Consortium have identified 133 genetic variants that predict within 75 percent accuracy a person's risk for developing glaucoma related to elevated intraocular pressure (IOP). Among the 133 variants, 68 had not been previously linked to IOP, and their loci point to cellular processes, such as lipid metabolism and mitochondrial function, that contribute to IOP. By understanding these cellular processes that can increase IOP and cause optic nerve damage, clinicians may be able to make an earlier diagnosis and researchers may be able to develop neuroprotective therapies to potentially halt disease progression.
- —NEI-funded research has also made discoveries of dozens of rare eye disease genes possible, including the discovery of RPE65, which causes congenital blindness called Leber congenital amaurosis (LCA). As of late 2017, NEI's initial efforts led to a commercialized, Food and Drug Administration (FDA)-approved gene therapy for this condition. These gene-based discoveries are forming the basis of new therapies that treat the disease and potentially prevent it entirely. Success in this field is driving now similar promising research for the most common blinding diseases, such as Age-related macular degeneration (AMD).
- —Regenerative Medicine: NEI is at the forefront of regenerative medicine with its Audacious Goals Initiative (AGI) for Regenerative Medicine, which launched in 2013 with the goal of restoring vision. Initially asking a broad constituency of scientists within the vision community and beyond to consider what could be done if researchers employed this new era of biology, the AGI currently funds major research consortia that are developing innovative ways to image the visual system. Researchers can now look at individual nerve cells in the eyes of patients in an examination room and learn directly whether new treatments are successful. Another consortium is identifying biological factors that allow neurons to regenerate in the retina. In addition, the AGI is gathering considerable momentum to develop disease models that may result in clinical trials for therapies within the next decade.
- —In late 2019, NEI began a first-in-human clinical trial that tests a stem cell-based therapy from induced pluripotent stem cells (iPSC) to treat geographic atrophy, also known as the "dry" form of Age-related Macular Degeneration (AMD), the leading cause of vision loss among people age 65 and older. This trial converts a patient's own blood cells to iPSCs, which are then programmed to become retinal pigment epithelial (RPE) cells. RPE cells nurture and keep alive the photoreceptor cells necessary for vision but die in geographic atrophy causing the loss of photoreceptors and vision and cannot be replaced by the retina itself. The new therapy replaces dying RPE with iPSC-derived RPE cells keeping remaining photoreceptors alive and thereby stopping the loss of vision.

NEI FUNDING DEMONSTRATES SIGNIFIGANT RETURN ON INVESTMENT

Optical coherence tomography (OCT) is a technology developed with Federal research funding through the NIH, which has led to significant cost savings by helping to diagnose conditions that lead to vision loss among patients more efficiently. In 2017, ARVO shared the story of OCT, including the significant associated cost savings:

- —$9 billion: Medicare savings from clinicians using OCT to optimize the injection schedule of anti-VEGF drugs for patients with wet-AMD
- —$2.2 billion: Wet-AMD patient savings from reduced spending on drug copays
- —$0.4 billion: Total investment over 20 years made by NIH and NSF to invent and develop the technology
- —2,100%: Return on taxpayer investment [http://www.ajo.com/article/S00029394(17)30419-1/fulltext]

CONGRESS MUST ROBUSTLY FUND THE NEI AS IT ADDRESSES THE INCREASING BURDEN OF VISION IMPAIRMENT AND EYE DISEASE

NEI's fiscal year 2020 enacted budget of $824.1 million is less than 0.5 percent of the $167 billion annual cost (inclusive of direct and indirect costs) of vision impairment and eye disease, which was projected in a 2014 Prevent Blindness study to grow to $317 billion—or $717 billion in inflation-adjusted dollars—by year 2050. Of the $717 billion annual cost of vision impairment by year 2050, 41 percent will be borne by the Federal Government as the Baby-Boom generation ages into the Medicare program. A 2013 Prevent Blindness study reported that direct medical costs associated with vision disorders are the fifth highest—only less than costs associated with heart disease, cancers, emotional disorders, and pulmonary conditions. The U.S. is spending only $2.50 per-person, per-year for vision research, while the cost of treating low vision and blindness is at least $6,680 per-person, per-year. [http://costofvision.preventblindness.org/].

In a May 2016 JAMA Ophthalmology article, NEI-funded researchers reported that the number of people with legal blindness will increase by 21 percent each decade to 2 million by 2050, while best-corrected visual impairment will grow by 25 percent each decade, doubling to 6.95 million people—with the greatest burden affecting those 80 years or older. [http://jamanetwork.com/journals/jamaophthalmology/article-abstract/2523780?resultClick=1].

Investing in vision health is an investment in overall health. NEI's breakthrough research is a cost-effective investment, since it leads to treatments and therapies that may delay, save, and prevent health expenditures. It can also increase productivity, help individuals to maintain their independence, and generally improve the quality of life—as vision loss is associated with increased depression and accelerated mortality.

In summary, ARVO requests fiscal year 2021 NIH funding of at least $44.7 billion and NEI funding of $875 million. We also thank the Subcommittee for the opportunity to submit this written testimony, especially as it assesses current and future challenges associated with the COVID–19 pandemic.

The Association for Research in Vision and Ophthalmology (ARVO) is the largest eye and vision research organization in the world. Members include nearly 12,000 eye and vision researchers from over 75 countries. ARVO advances research worldwide into understanding the visual system and preventing, treating and curing its disorders.

PREPARED STATEMENT OF THE ASSOCIATION OF AMERICAN CANCER INSTITUTES

The Association of American Cancer Institutes (AACI), representing 100 premier academic and freestanding cancer centers across the nation, appreciates the opportunity to submit this statement for consideration by the subcommittee. Jennifer Pegher, Executive Director of AACI, submits this request for the Department of Health and Human Services budget for the National Institutes of Health (NIH) as the subcommittee aims to begin considering fiscal year 2021 funding. AACI requests a $3 billion increase for the NIH for fiscal year 2021, bringing the recommended funding level for the NIH to $44.7 billion. This proposed level of NIH funding would ensure that academic cancer centers conducting lifesaving research can continue to discover and deliver new therapies for patients with cancer.

AACI CANCER CENTERS

AACI cancer centers are beacons of discovery, largely funded by the NIH and National Cancer Institute (NCI). In order to ensure continued progress, these agencies rely on stable, predictable Federal funding to invest in groundbreaking cancer research.

Cancer centers develop and deliver state-of-the-art therapies and provide comprehensive care, from prevention to survivorship, to patients. These centers are at the forefront of the national effort to eradicate cancer, yet progress in cancer research is complex and time-intensive. However, the pace of discovery and translation of novel basic research to new therapies could be accelerated if researchers could count on an appropriate and predictable investment in Federal cancer funding.

According to the American Cancer Society, the mortality rate from cancer in the United States has declined 29 percent since its peak in 1991. This translates to more than 2.9 million deaths avoided between 1991 and 2017—progress tied to the commitment of Congress to fund the NIH and NCI. AACI appreciates the commitment of Congress to steadily increase NIH funding since fiscal year 2013. We hope Congress will continue that commitment in fiscal year 2021.

With excitement mounting about the scientific opportunities ahead and our potential to leverage the resulting advances to benefit cancer patients nationwide, it is imperative that Congress robustly funds the agencies responsible for advancing cancer research. The broad portfolio of science supported by the NIH and NCI is essential for improving our basic understanding of cancer and has contributed to the health and well-being of Americans.

THE PRESIDENT'S FISCAL YEAR 2021 BUDGET PROPOSAL

AACI cancer centers believe the partnership between the Federal Government and academic cancer centers is critical, and cancer centers continue to make strides in biomedical research thanks to the support of the Federal Government. Without such support, research projects with the potential to discover breakthrough therapies would not be possible.

The drastic cuts to the NIH and NCI outlined in the fiscal year 2021 budget proposed by President Trump on February 10 would be a major setback for cancer research. We believe the proposed, roughly $3 billion, cut to the NIH budget is a step in the wrong direction. In order to sustain and accelerate progress against cancer, we must continue to increase NIH funding.

PAYLINE

Uncertainty surrounding research project grants (R01s) from year to year and a decline in cancer center resources often drives promising scientists to explore opportunities abroad or outside of the biomedical research community. For most academic cancer centers, the majority of NCI grant funds are used to sustain shared core resources that are essential to basic, translational, clinical, and population cancer research, or to provide matching dollars that allow departments to recruit new cancer researchers to a university and support them until they receive their first grants. It is imperative that we enable America's scientists to master their craft.

For fiscal year 2020, R01 grants for established and new investigators are being funded to the 10th percentile, up from the 8th in fiscal year 2019. Though the funding rate is still below the 15th percentile target, moving back into the double digits is a welcome sign of progress. However, the NCI's grant success rate has not kept pace with other NIH institutes, which have an average success rate around 19 percent, suggesting there is still work to do.

CONCLUSION

Now is the time for Congress to invest in biomedical research in general and cancer research in particular. According to the American Cancer Society, there will be an estimated 1.8 million new cancer cases diagnosed in the United States in 2020. Fortunately, improvements in early detection, cancer staging, and surgical techniques, as well as the development of innovative therapies, have contributed to better outcomes for patients with cancer. AACI joins our colleagues in the biomedical research community in recommending that the subcommittee recognize the NIH as a national priority by enacting a final fiscal year 2021 spending package that includes $44.7 billion for the NIH and $6.9 billion for the NCI.

A robust Federal investment in our nation's NCI-Designated Cancer Centers and academic cancer centers will allow the cancer research community to build on decades of momentum to make continued progress against cancer.

[This statement was submitted by Jennifer Pegher, Executive Director, Association of American Cancer Institutes.]

PREPARED STATEMENT OF THE ASSOCIATION OF AMERICAN MEDICAL COLLEGES

The Association of American Medical Colleges (AAMC) is a not-for-profit association dedicated to transforming healthcare through innovative medical education, cutting-edge patient care, and groundbreaking medical research. Its members comprise all 155 accredited U.S. and 17 accredited Canadian medical schools; nearly 400 major teaching hospitals and health systems, including 51 Department of Veterans Affairs medical centers; and more than 80 academic societies. Through these institutions and organizations, the AAMC serves the leaders of America's medical schools and teaching hospitals and their 173,000 full-time faculty members, 89,000 medical students, 129,000 resident physicians, and more than 60,000 graduate students and postdoctoral researchers in the biomedical sciences.

The COVID–19 pandemic has illustrated how sustained support for the research, education, and patient care missions of medical schools and teaching hospitals is essential to ensure a resilient healthcare infrastructure that is prepared to respond to both novel and existing threats. The AAMC is grateful to Congress for investments made through supplemental emergency funding packages to date, which take important steps to provide relief for healthcare providers and critical safety net providers, including major teaching hospitals and faculty physicians, for both increased clinical spending and losses associated with COVID–19; for expansion of testing capacity and contact tracing; for additional student loan relief and funding for higher education., and for additional COVID–19-related medical research. We look forward to continuing to work with lawmakers as discussions around additional emergency funding needs progress.

To continue to fulfill these important missions over the long-term, the AAMC requests continued support through the regular appropriations process as well for the following Federal priorities essential in assisting medical schools and teaching hospitals to fulfill their missions of education, research, and patient care in fiscal year 2021: $44.7 billion for the National Institutes of Health (NIH), including funds provided through the 21st Century Cures Act for targeted initiatives; $460 million in budget authority for the Agency for Healthcare Research and Quality (AHRQ); $790 million for the Title VII health professions and Title VIII nursing workforce development programs, and $465 million for the Children's Hospitals Graduate Medical Education (CHGME) program, at the Health Resources and Services Administration (HRSA)'s Bureau of Health Workforce; and continued support for student aid through the Department of Education. The AAMC appreciates the Subcommittee's longstanding, bipartisan efforts to strengthen these programs.

We recognize the constraints the committee faces as a result of the fiscal year 2021 discretionary spending cap. To enable the necessary support for the broad range of critical Federal priorities, the AAMC urges Congress to exempt key programs that support the nation's COVID–19 response from the fiscal year 2021 caps, and also to approve a funding allocation for the Labor-HHS subcommittee that enables full investment in the priorities outlined below.

National Institutes of Health. Congress's longstanding bipartisan support for medical research has contributed greatly to improving the health and well-being of all Americans. The foundation of scientific knowledge built through NIH-funded research drives medical innovation that improves health through new and better diagnostics, improved prevention strategies, and more effective treatments. Over half of the life-saving research supported by the NIH takes place at medical schools and teaching hospitals, where scientists, clinicians, fellows, residents, medical students, and trainees work side-by-side to improve the lives of Americans through research. This partnership is a unique and highly productive relationship, one that lays the foundation for improved health and quality of life and strengthens the nation's long-term economy.

The AAMC thanks Congress for the bipartisan support that resulted in the inclusion of $41.7 billion in the fiscal year 2020 omnibus spending bill for medical research conducted and supported by the NIH, which builds off meaningful increases for NIH since fiscal year 2016. Additionally, the AAMC thanks the Subcommittee for recognizing the importance of retaining the salary cap at Executive Level II of the Federal pay scale. The AAMC is concerned that proposals to undermine salary support would limit the number of grantees with sufficient funds to conduct research and ultimately weaken research nationwide. This consequence would directly counter the Subcommittee's efforts over the years to strengthen the nation's research enterprise.

In fiscal year 2021, the AAMC supports the Ad Hoc Group for Medical Research recommendation that Congress provide $44.7 billion for NIH, including funds provided through the 21st Century Cures Act for targeted initiatives. This funding level would continue the momentum of recent years by enabling meaningful base budget growth over biomedical inflation to help ensure stability in the nation's research capacity over the long term. Securing a reliable, robust budget trajectory for NIH is key in positioning the agency—and the patients who rely on it—to capitalize on the full range of research in the biomedical, behavioral, social, and population-based sciences.

Scientific discoveries rely on support from Congress. We must continue the current trajectory if we are to strengthen our nation's research capacity and solidify our global leadership in medical research, ensure a biomedical research workforce that reflects the racial and gender diversity of our citizenry, and inspire a passion for science in current and future generations of researchers.

Agency for Healthcare Research and Quality.—Complementing the medical research supported by NIH, AHRQ sponsors health services research designed to improve the quality of healthcare, decrease healthcare costs, and provide access to essential healthcare services by translating research into measurable improvements in the healthcare system. As the only Federal agency with the sole purpose of generating evidence to make healthcare safer; higher quality; and more accessible, equitable, and affordable, AHRQ also works to ensure such evidence is available across the continuum of healthcare stakeholders, from patients to payers to providers. The AAMC joins the Friends of AHRQ in recommending $471 million in budget authority for AHRQ in fiscal year 2021.

Health Professions Funding.—HRSA's Title VII health professions and Title VIII nursing workforce development programs allow grantees to test educational innovations, respond to changing delivery systems and models of care, and are instrumental to increasing the supply, distribution, and diversity of the healthcare workforce. These programs improve access to and quality of care for vulnerable populations—including elderly, children and families living on low incomes and in rural and underserved communities. Additionally, as we face ever-changing public health threats impacting patients across the country, such as COVID–19, continued investment in Titles VII and VIII programs is essential to addressing the health challenges of today and the future.

Through loans and scholarships to students, and grants and contracts to academic institutions and non-profit organizations, these programs fill the gaps in the supply of health professionals not met by traditional market forces. The full spectrum of Title VII programs, from workforce diversity programs to geriatric programs, is essential in preparing medical professionals to adapt to the changing needs of the nation's aging and diverse population. Studies demonstrate that the programs graduate more minority and disadvantaged students and prepare providers that are more likely to practice in rural and underserved areas.

The Title VII and Title VIII programs also support faculty development, curriculum development, and continuing education opportunities. These are all essential components to ensure faculty and providers are equipped to meet the nation's changing needs and train the next generation of health professionals. The AAMC joins the Health Professions and Nursing Education Coalition (HPNEC) in recommending $790 million for these critical workforce programs in fiscal year 2021.

In addition to funding for Title VII and Title VIII, HRSA's Bureau of Health Workforce also supports the CHGME program, which provides critical Federal graduate medical education support for children's hospitals to prepare the future primary care and specialty care workforce for our nation's children. We support $465 million for the CHGME program in fiscal year 2021. We also encourage Congress to provide robust funding to the Rural Residency Program, providing funding to rural residency tracks, encouraging future physicians to practice in those communities.

The AAMC encourages Congress to provide long-term sustained funding for the National Health Service Corps, through its mandatory and discretionary mechanisms. We support $490 million in total funding for the program in fiscal year 2021. This $60 million (14 percent) increase is the first stage of a 5-year systematic doubling of the NHSC to meet the needs of all federally designated health professions shortage areas. As the nation faces multiple health professional shortages, sustained investments in workforce programs are necessary to help care for our nation's most vulnerable populations.

Additional Programs.—The AAMC supports robust, sustained funding for public health infrastructure to begin to reverse years of chronic underfunding. In addition to increased funding for the Centers for Disease Control and Prevention, the AAMC recommends at least $474 million for the Hospital Preparedness Program, as well as $40 million to continue the regional preparedness program created to address Ebola and other special pathogens, including funding for regional treatment centers, frontline providers, and the National Ebola Training and Education Center (NETEC). The AAMC appreciates that the president's fiscal year 2021 budget proposal requests $4 million to support grants to medical schools and teaching hospitals to develop curricular resources on medication-assisted treatment. The AAMC supports the programs authorized under Sections 3202 and 7101 of the SUPPORT Act (Public Law 115–271) to enhance medical education, and we encourage their full funding.

The AAMC urges the Subcommittee to sustain student loan and forgiveness programs for health professions students at the Department of Education, including GradPLUS loans and Public Service Loan Forgiveness (PSLF). With doctors, residents, fellows, and medical students on the front lines of COVID–19, it is imperative that these health professions are rewarded for their public service, and make sure there are affordable loans to fund a student's medical education. The average graduating debt of medical students is currently $200,000, and total repayment can range from $365,000 to $440,000.

Once again, the AAMC appreciates the opportunity to submit this statement for the record and looks forward to working with the Subcommittee as it prepares its fiscal year 2021 spending bill.

PREPARED STATEMENT OF THE ASSOCIATION OF FARMWORKER OPPORTUNITY PROGRAMS

Chairman Blunt and Ranking Minority Member Murray:

Thank you for the opportunity to present to you and your subcommittee the testimony of the Association of Farmworker Opportunity Programs (AFOP) in support of the nation's more than 50-year commitment to providing eligible agricultural workers the opportunity to achieve the American Dream for themselves and their families. As you begin work on your fiscal year 2021 Labor-Health and Human Services-Education appropriations bill, AFOP encourages you to build on the foundations laid by the highly successful programs described below by adequately funding them in the coming fiscal year: National Farmworker Jobs Program (NFJP), United States Department of Labor (DOL) Employment and Training Administration ($98,896,000); and Susan Harwood Training Grants, DOL Occupational Safety and Health Administration ($10,537,000). Not only do these programs maximize the Federal Government's investment in them, they also generate for employers the qualified and healthy workers essential to their growth. These programs also dramatically change peoples' lives for the better, often in rural areas, allowing them to enjoy economic success and participate more fully in our great nation. Thank you for supporting these very effective programs and the excellent results they bring for society's most vulnerable.

NATIONAL FARMWORKER JOBS PROGRAM

NFJP is the bedrock of the nation's commitment to helping agricultural workers upgrade their skills in and outside agriculture, providing employers with what they increasingly say they need: hardworking, committed, well-trained, skilled workers. Administered by DOL, NFJP provides funding through a competitive grant process to 52 community-based organizations and public agencies nationwide that assist workers and their families to attain greater economic stability. One of DOL's most successful employment training programs, NFJP helps agricultural workers acquire the new skills they need to start careers that offer higher wages and a more stable employment outlook. In addition to employment and training services, the program provides supportive services that help agricultural workers retain and stabilize their current agriculture jobs, as well as enable them to participate in up-training and enter new careers. NFJP housing assistance helps meet a critical need for the availability and quality of agricultural worker housing, and supports better economic outcomes for workers and their families. NFJP also facilitates the coordination of services through the American Job Center network for agricultural workers so they may access other services of the public workforce system.

The agricultural workers who come to NFJP seek training to secure and excel in the in-demand jobs employers say they find challenging to fill. In doing so, the workers establish the financial foundation that allows them and their families to escape the chronic unemployment and underemployment they face each year. Many NFJP participants enter construction, welding, healthcare, and commercial truck-driving. Others train for the solar/wind energy sector, culinary arts, and for positions such as machinists, electrical linemen, and a variety of careers in and outside of agriculture. To be eligible for NFJP, workers must be low-income, depend primarily on agricultural employment, and provide proof of American citizenship or work authorization. Additionally, male applicants must have registered with the Selective Service.

Agricultural workers are some of the hardest working individuals in this country, enduring tremendous physical and financial hardships in providing produce Americans eat every day. Yet, agricultural workers remain among the nation's most vulnerable employees and job seekers, facing significant barriers to work advancement, including:

—The average agricultural worker family of four earns just $20,000 per year, well below the national poverty line.

—English-language fluency is a substantial challenge for many.

—More than half the children of migratory agricultural workers drop out of school, and, among all agricultural workers, the median highest grade completed is 9th grade (National Agricultural Workers Survey).

—Due to poverty and their rural locations, most agricultural workers have extremely limited access to transportation.

Despite these barriers, NFJP continues to be one of the most successful Federal job training programs, exceeding all DOL's goals. In 2018 alone, NFJP service organizations provided more than 10,000 agricultural workers with services, according to DOL. These NFJP providers have served more than an estimated 150,000 agricultural workers and their family members over the last 10 years. Funding program this year at $98,896,000 would allow NFJP to train even more dependable, capable workers to take on the nation's most challenging jobs. Also, consistent appropriations for youth agricultural workers (ages 14- to 24-years) will allow this cohort, so often overlooked and ignored by anti-poverty programs, to stay in school, and, if not in school, to avail themselves of crucial training to get a good job and establish themselves as productive and successful members of society.

AGRICULTURAL WORKER HEALTH & SAFETY

AFOP also recommends continued appropriations for the DOL Occupational Safety and Health Administration Susan Harwood grant program, through which AFOP has augmented pesticide safety training with curricula to help workers recognize and avoid the dangers of heat stress so common in the fields. In supporting this funding, you can arm the nation's agricultural workers with the knowledge they need to keep themselves safe on the job. The NFJP network of some 257 trainers in 30 states trains agricultural workers on how to protect against pesticide poisoning and heat stress. Trainers then follow up with agricultural workers to assess knowledge gained and retained, and changes in labor practice. Since 1995, more than 492,000 agricultural workers have become certified as trained in safety precautions, and hundreds of thousands of family members, children, and community agencies have also received safety training. The network collaborates with universities, community organizations, local governments, and businesses to maximize its unparalleled access to agricultural workers and their families. By reaching agricultural workers with heat stress prevention and pesticide safety training, the network's trainers offer access to other services and create a ripple effect of positive impact—improving the quality of life for agricultural workers and their families—which is what NFJP organizations do best.

Thank you for supporting these worthy programs. AFOP stands ready to assist you in any way as you proceed with your very important work.

[This statement was submitted by Daniel J. Sheehan, Executive Director, Association of Farmworker Opportunity Programs.]

PREPARED STATEMENT OF THE ASSOCIATION OF INDEPENDENT RESEARCH INSTITUTES

The Association of Independent Research Institutes (AIRI) thanks the Subcommittee for its long-standing and bipartisan leadership in support of the National Institutes of Health (NIH). We continue to believe that science and innovation are essential if we are to improve our nation's health, sustain our leadership in medical research, and remain competitive in today's global information and innovation-based economy. AIRI urges the Subcommittee to provide NIH with at least $44.7 billion in fiscal year 2021. AIRI also urges the Subcommittee to reject the harmful investigator salary cap policies proposed in the President's fiscal year 2020 budget request, as any changes to salary policy would disproportionately impact independent research institutes.

First, we would like to deeply thank the Subcommittee for providing another increase of $2.6 billion for NIH in the fiscal year 2020 minibus appropriations bill. The Subcommittee's support of NIH is strongly demonstrated by these much-needed funds for life-saving biomedical research. However, there is still much more to do. NIH is tackling vast, interdisciplinary problems such as the opioid crisis, the development of a universal flu vaccine, and Alzheimer's disease. In addition, the ongoing public health crisis associated with the coronavirus outbreak and COVID–19 pandemic reminds us that now is not the time to pull back or slow down on needed investments in the nation's biomedical research ecosystem. Continued budget certainty is needed for the agency to predictably fund new and ongoing grants and consider new initiatives necessary to improving human health. NIH will also begin to explore how emerging technologies such as artificial intelligence and machine learning can provide opportunities to deepen our understanding of chronic diseases and systemic health inequities, and advance clinical care. To ensure cutting-edge research at independent research institutes is not disrupted, AIRI strongly supports a topline of $44.7 billion for NIH in fiscal year 2021.

AIRI is a national organization of more than 90 independent, non-profit research institutes that perform basic and clinical research in the biological and behavioral sciences. AIRI institutes vary in size, with budgets ranging from a few million to hundreds of millions of dollars. In addition, each AIRI member institution is governed by its own independent Board of Directors, which allows our members to focus on discovery-based research while remaining structurally nimble and capable of adjusting their research programs to emerging areas of inquiry. Investigators at independent research institutes consistently exceed the success rates of the overall NIH grantee pool, and they receive about 10 percent of NIH's peer-reviewed, competitively awarded extramural grants.

The partnership between NIH and America's scientists, research institutions, universities, and medical schools is unique and highly-productive, leveraging the full strength of our nation's research enterprise to foster discovery, improve our understanding of the underlying cause of disease, and develop the next generation of medical advancements that deliver more treatments and cures to patients.

Not only is NIH research essential to advancing health, it also plays a key economic role in communities nationwide. In fiscal year 2019, NIH invested $30.82 billion, or almost 80 percent of its budget, in the biomedical research community. This investment supported more than 476,000 jobs nationwide and generated nearly $81 billion in economic activity across the U.S.[1] AIRI member institutes are particularly relevant in this regard, as they are located across the country, including in many smaller or less-populated states that do not have major academic research institutions. In many of these regions, independent research institutes are major employers and local economic engines, and they exemplify the positive impact of investing in research and science.

The NIH model for conducting biomedical research, which involves supporting scientists at universities, medical centers, and independent research institutes, provides an effective approach to making fundamental discoveries in the laboratory that can be translated into medical advances that save lives. AIRI member institutions are private, stand-alone research centers that set their sights on the vast frontiers of medical science. However, AIRI member institutes are especially vulnerable to reductions in the NIH budget, as they do not have other reliable sources of revenue to make up the shortfall.

AIRI opposes the harmful investigator salary proposal in the President's fiscal year 2021 budget that would reduce the salary cap to Executive Level V from Executive Level II for extramural researchers. This policy would disproportionately affect early-career investigators and independent research institutes and hinder AIRI members' ability to recruit and retain talented researchers. The caps also negatively affect the confidence of future researchers in the viability of a career in biomedical sciences, severely harming the competitiveness and capacity of the U.S. biomedical enterprise.

The Federal Government has an irreplaceable role in supporting investigators and medical research. No other public, corporate, or charitable entity is willing or able to provide the broad and sustained funding for the cutting-edge research necessary to yield new innovations and technologies of the future. NIH supports long-term competitiveness for American workers, forming one of the key foundations for U.S. industries like biotechnology, medical devices, and pharmaceutical development, among others. Unfortunately, any erosion to the national commitment to medical research could threaten our ability to support a medical research enterprise that takes full advantage of existing and emerging scientific opportunities.

AIRI member institutes' flexibility and research-only missions provide an environment particularly conducive to creativity and innovation. Independent research institutes possess a unique versatility and culture that encourages them to share expertise, information, and equipment across research institutions, as well as neighboring universities. These collaborative activities help minimize bureaucracy and increase efficiency, allowing for fruitful partnerships in a variety of disciplines and industries. Also, unlike institutes of higher education, AIRI member institutes focus primarily on scientific inquiry and discovery, allowing them to respond quickly to the research needs of the nation.

AIRI deeply thanks the Subcommittee for its important work dedicated to ensuring the health of the nation, and we appreciate this opportunity to urge the Subcommittee to continue the success of NIH by providing $44.7 billion in fiscal year 2021 and reaffirming support for NIH's current investigator salary policies to strengthen our nation's investment in life-saving medical research.

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[1] NIH's funding information and economic impact data comes from United for Medical Research's 2020 State-By-State Update, https://www.unitedformedicalresearch.org/wp-content/uploads/2019/04/NIHs-Role-in-Sustaining-the-US-Economy-FY19-FINAL-2.13.2020.pdf.

PREPARED STATEMENT OF THE ASSOCIATION OF STATE AND TERRITORIAL HEALTH OFFICIALS

On behalf of the Association of State and Territorial Health Officials (ASTHO), I respectfully submit this testimony on fiscal year 2021 appropriations to the U.S. Department of Health and Human Services (HHS). ASTHO is requesting $8.3 billion for the Centers for Disease Control and Prevention (CDC), including $824 million for the Public Health Emergency Preparedness Program (PHEP), and $170 million for the Preventive Health and Health Services Block Grant (Prevent Block Grant). Under the Assistant Secretary for Preparedness and Response (ASPR), we are requesting $474 million for the Hospital Preparedness Program (HPP) and $45.6 million to sustain the Regional Treatment Network for Ebola and Other Special Pathogens (RTNESP) and the National Ebola Training and Education Center (NETEC). Additionally, we are requesting $8.8 billion in discretionary funding for the Health Resources and Services Administration (HRSA) and $2 million to support a study by the National Academies of Sciences, Engineering, and Medicine to understand opportunities to improve the health of U.S. territories and freely associated states, given the health disparities that exist within those populations and the critical role our territories and freely associated states play in our nation's health security. Additionally, we are seeking a $500 million increase for the Substance Abuse and Mental Health Services Administration (SAMHSA) Substance Abuse Prevention and Treatment (SAPT) Block Grant to support state and territorial efforts to address the opioid epidemic and the continued need to prevent addiction in our states and territories.

ASTHO is the national nonprofit organization representing the public health agencies of the United States, the U.S. territories and freely associated states, and the District of Columbia. ASTHO members, the chief health officials of these jurisdictions, are dedicated to ensuring excellence in public health practice. The mission of our nation's governmental health agencies is to protect and improve the health of the population, everywhere, every day. The work of public health is often invisible, and sometimes it is only in a crisis when the value and importance of sustained investment in public health becomes apparent. Those crises, unfortunately, happen all too often: the current 2019 novel coronavirus (COVID–19) outbreak, measles and hepatitis A outbreaks, natural disasters, rising obesity rates, the opioid epidemic, and many others highlight the important work of disease prevention and health protection that is at the core of public health's mission.

Just like our transportation system, our healthcare system, and our air traffic control system, the governmental public health system needs a predictable, sustained, and increased investment to deliver the essential public health services all Americans expect and enjoy. We appreciate Congress providing increased public health funding in the fiscal year 2020 appropriations bills and we acknowledge the non-defense discretionary caps do not significantly increase for fiscal year 2021. Therefore, our appropriations requests represent modest investments over the previous fiscal year to ensure governmental public health continues our mission of promoting optimal health to all. ASTHO's "22x22" campaign, endorsed by 100 national organizations, urges Congress to increase funding for the CDC by 22 percent by fiscal year 2022. For fiscal year 2021, we request $8.3 billion for CDC overall. This increase is important because Federal investment in public health has not kept pace with inflation nor the considerable challenges posed by infectious disease outbreaks, extreme weather events, and other emergencies. According to a 2017 Trust for America's Health report, only 3 percent of all health spending is directed to public health, while the other 97 percent (out of $3.36 trillion total) is spent on healthcare. Finally, the waning public health workforce strains the ability of state and local public health departments to protect and promote the health of the population. The "22x22" campaign is an effort to bolster CDC's funding over the next 4 years to eventually reach $8.8 billion for the agency by fiscal year 2022. One of the most striking examples of the need for increased, predictable, and sustained funding for the CDC is the recent COVID–19 outbreak. Addressing outbreaks requires a strong, coordinated response from Federal, state, territorial, and local governments. In these scenarios, the CDC—and the funding it provides to these entities-is critical. While we are grateful for the emergency supplemental funding to bolster response efforts, state and territorial health departments need consistent, sustained, and predictable funding to accomplish their important health protection mission. Establishing and maintaining solid public health systems allow health departments to prevent, protect, respond, and recover from events, as well as reduce human and financial tolls.

Critical to public health preparedness and response is the support public health receives from the PHEP Cooperative Agreement, for which we request $824 million.

Since its establishment in 2002, the program has invested in states and territories to create and maintain foundational capabilities. It is critical to provide stable and sufficient health emergency preparedness funding to maintain a standing set of core capabilities, so they are ready when needed. The program funding—once at $918 million in 2002—is 26 percent lower at $675 million today, with public health threats not experiencing similar declines. In close partnership with the PHEP program is the Hospital Preparedness Program (HPP). ASTHO requests $474 million for HPP. As the only source of Federal funding that supports regional healthcare system preparedness, HPP promotes a sustained national focus to improve patient outcomes, minimizes the need for supplemental state and Federal resources during emergencies, and enables rapid recovery. The work of these programs is something that we should all be proud of and, therefore, continue to increase funding for both. In addition to the HPP, we are requesting that Congress provide $45.6 million to sustain the Regional Treatment Network for Ebola and Other Special Pathogens (RTNESP) and the National Ebola Training and Education Center (NETEC) that are under ASPR's leadership.

Prevention is the best form of treatment. For this, ASTHO requests $170 million for the Prevent Block Grant. Programs funded by the Prevent Block Grant cannot be adequately supported or expanded through other funding mechanisms. States use these flexible dollars to offset funding gaps in programs that address the leading causes of death and disability. The success of the Prevent Block Grant is achieved by using evidence-based methods and interventions, reducing risk factors, leveraging other funds, and continuing to monitor and reevaluate funded programs.

While vital, CDC is not the only Federal agency that supports safety net programs in states and territories. ASTHO is requesting $8.8 billion for discretionary funding for HRSA. HRSA administers programs that focus on improving care for tens of millions of Americans who are medically underserved or face barriers to needed care by strengthening the health workforce.

ASTHO is also encouraged by the Administration's plan to end the HIV epidemic and improve maternal health in America. State and territorial health officials look forward to working with Federal and local partners across the country to bring effective strategies to scale. State, territorial, local, and tribal jurisdictions and our community-based organizations and healthcare partners must have the resources necessary to enhance and deliver these evidence-based public health interventions and not pull funds from other vital public health programs.

State and territorial health departments are on the front lines of responding to the current crisis in our country caused by substance misuse, addiction, and drug overdoses. ASTHO is appreciative of previous investments in public health toward this effort and supportive of an increase of $500 million, or a total of $2.4 billion, for the Substance Abuse Prevention and Treatment Block Grant at SAMHSA to sustain activities and continue the response to the opioid epidemic and substance abuse and misuse disorders more broadly.

Health outcomes data from territories and freely associated states (FAS) indicates that the health of these populations is far worse, in comparison to the U.S. mainland population. Therefore, ASTHO requests that Congress fund a study conducted by the National Academies of Science, Engineering, and Medicine to better understand the health impacts of policy on the U.S. territories and FAS. The results of this research can guide investments, policy, and support and, ultimately, improve the health of those who reside in these insular areas and are part of the past and future fabric of our nation.

ASTHO appreciates the attention and diligence of this committee in previous fiscal years to provide increased funding for governmental public health. In these challenging but important times for public health, we urge Congress to continue its support for state and territorial public health.

[This statement was submitted by Michael Fraser, PhD, MS, CAE, FCPP, Chief Executive Officer, Association of State and Territorial Health Officials.]

PREPARED STATEMENT OF THE ASSOCIATION OF UNIVERSITY PROGRAMS IN OCCUPATIONAL HEALTH AND SAFETY

On behalf of Association of University Programs in Occupational Health and Safety (AUPOHS), we respectfully request that the fiscal year 2021 Labor, Health and Human Services Appropriations bill include no less than $354,800,000 for the National Institute for Occupational Safety and Health (NIOSH), including not less than a $2 million increase over the fiscal year 2020 level for the Education and Research Centers (ERCs), the Agriculture, Forestry and Fishing (AFF) Program, and the Total Worker Health Program (TWH).

As demonstrated by the COVID–19 pandemic, occupational injury and illness create a striking burden on America's health, well-being and productivity. America's essential workers are heroes who continue to face personal risk, illness and death in the workplace for the good of the country. Although the true toll of COVID–19 on American workers is yet unknown, the impact is high, illustrated by the finding that approximately 10 percent of Americans infected by COVID–19 are healthcare workers. High rates of infection are seen in other essential worker groups such as those attending to our elderly and disabled in nursing homes and long-term care facilities, agricultural production workers maintaining our food supply, correctional facility workers, and others.

Even before the pandemic, despite significant improvements in workplace safety and health over the last several decades, 14 workers were dying daily from workplace injuries, and 145 people were dying from work-related diseases. In the pre-pandemic era, annually, 2.8 million workers were seriously injured on the job. One third of those injured workers required time off and 5,000 workers lost their lives to job injuries. According to the 2018 Liberty Mutual Workplace Safety Index, U.S. businesses were spending more than $1.1 billion a week on serious, nonfatal workplace injuries. The economic consequences related to workplace illness from the pandemic will no doubt have a staggering, compounding impact for years to come.

These figures are especially tragic because many work-related fatalities, injuries and illnesses are preventable. To improve this situation effective, professionally directed, health and safety programs are required. Furthermore, by fostering workplaces that promote overall employee health and well-being, employers, employees, families, and communities benefit from improved productivity and reduced healthcare costs. NIOSH is the primary Federal agency responsible for conducting research and making recommendations for the prevention of work-related illness and injury and for promoting worker health and well-being.

NIOSH responded quickly to the pandemic and continues to perform an important service for employers and employees in the face of COVID–19. Importantly, it is the Federal agency that is charged with certifying and approving Personal Protective Equipment (PPE), including the masks that are necessary to protect U.S. workers from inhalation exposures to chemical and biological agents including the virus. During the pandemic, NIOSH has accelerated the approval process for establishing the safety and quality of new masks and other PPE. In addition, NIOSH has deployed teams across the country in response to industry requests for assistance, including more than 15 meatpacking plants that experienced outbreaks. NIOSH has contributed leadership and expertise, contributing to Federal guidance and decision tools for industries including mass transit, restaurants and bars, childcare facilities, schools, youth programs and camps, among others, including recent guidance for companies returning to work or expanding work operations.

The NIOSH supported extramural Centers, including the Education and Research Centers (ERCs), Centers in the Agriculture, Forestry and Fishing (AFF) Program, and the Total Worker Health(r) Centers of Excellence, have responded aggressively to the pandemic. These Centers have been proactive in providing resources, employer assistance, training, and research that are helping to drive improvements in our nation's response. The work that the Centers are undertaking during this crisis underscores the need for increased funding for NIOSH and the Centers in the fiscal year 2021 Labor HHS bill.

As of May 15, 2020, all Centers have received and responded to requests to assist in COVID–19 response. The requests have come from employers, community organizations, health departments, workers, and city or state officials, among others. The assistance that has been requested and provided includes access to our content expertise on how COVID–19 affects the workplace and strategies for keeping workplaces safe and maintaining or restoring business operations, policy recommendations, resource recommendations, training of employers, training for workers, as well as providing interviews and information for the general public through media requests, and a creation of websites and toolkits. Webinars and trainings by the Centers are reaching thousands of organizations. Eighty-five percent of Centers report that these trainings focus on employers. Specific audiences for trainings include public health professionals and other health and safety professionals, healthcare workers, low-wage workers, and researchers.

Generating high quality information to help inform decisionmaking and conducting research to improve worker safety are central tenets of the Centers. Examples of COVID–19 related research includes:

—Surveying farmworkers about COVID–19 health and economic impacts.

—Development of new Personal Protective Equipment (PPE) fabric to filter and deactivate the virus.

—Development of a tool for assessing the impact of COVID–19 on employers and employees, specifically including agricultural producers, small businesses, and healthcare facilities.

—Assessing the impact of remote work and return to work on workplace health and safety climate, stress levels, mental health, work-family conflict, and leadership.

As workplaces rapidly evolve, changes continue to present new health risks to workers that need to be addressed through occupational safety and health research. In addition to the long-term implications of the pandemic on the American workplace and workforce, there are other ongoing trends that must be addressed. For example, NIOSH is advancing the understanding of how emerging technologies such as robotics, nanotechnology, and advanced manufacturing can be managed to ensure safe operation. In addition, the opioid crisis is impacting millions of American workers and workplaces. NIOSH and the Centers developed a multipronged approach to identify high-risk work conditions leading to opioid misuse and to opioid use disorder.

Through 18 university-based centers, the ERCs provide local, regional, and national resources for those in need of occupational health and safety assistance—industry, labor, government, academia, non-governmental organizations and the public. Collectively, the ERCs provide graduate-level education in the occupational health and safety disciplines and offer professional workforce development training and research resources to every Federal Region in the U.S. Importantly, the ERCs play a crucial role in preparing a workforce of occupational safety and health professionals trained to identify and mitigate vulnerabilities to terrorist attacks and to increase readiness to respond to biological, chemical, or radiological attacks. Occupational health and safety professionals work with emergency response teams to minimize disaster losses, as exemplified by their lead role in protecting the safety of 9/11 emergency responders in New York City and Virginia. In 2017, occupational health and safety professionals worked to minimize hazards among workers involved in clean up and restoration in the face of the extreme devastation caused by Hurricanes Harvey, Irma and Maria in Texas, Florida, Puerto Rico and the U.S. Virgin Islands. In 2020, the ERC's have responded quickly by providing employers across the country with accessible, concise information on the workplace implications of COVID–19.

NIOSH also focuses research and outreach efforts on the nation's most dangerous worksites that often impact lives in more rural parts of America. The Centers for Agricultural Safety and Health were established by Congress in 1990 (Public Law 101–517) in response to evidence that agricultural, forestry and fishing workers suffer substantially higher rates of occupational injury and illness than other U.S. workers. According to 2018 bureau of labor statistics data, these agricultural workers are more than 6 times more likely to die on the job than the average worker. Food security depends on a healthy and safe agricultural workforce—a sector that has been hit particularly hard during the pandemic. Even prior to COVID–19, the sector averaged 540 fatalities per year resulting in the highest fatality rate of any employment sector in the nation. Today the Agriculture, Forestry, and Fishing (AFF) Initiative includes ten regional Agricultural Centers and one national children's farm safety and health center. The AFF program is the only substantive Federal effort to ensure safe working conditions in these vital production sectors. While agriculture, forestry, and fishing constitute some of the largest industry sectors in the U.S. (DOL 2011), most AFF operations are small: nearly 78 percent employ fewer than 10 workers, and most rely on family members, immigrants, part-time, contract and/or seasonal labor. Many of these agricultural workers are excluded from labor protections, including OSHA oversight, on the vast majority of American farms. More than 1 in 100 AFF workers incur nonfatal injuries resulting in lost workdays each year. These reported figures do not even include men, women, and youths on the most dangerous farms—those with fewer than 11 full-time employees. The lifesaving, cost-effective work of the AFF program is not replicated by any other agency. For example, state and Federal OSHA personnel rely on NIOSH research in the development of evidence-based standards for protecting agricultural workers and would not be able to fulfill their mission without the AFF program. Also, staff members of USDA's National Institute of Food and Agriculture interact with NIOSH occupational safety and health research experts in order to learn about the cutting-edge research and new directions in this area.

The AFF program activities have made demonstrated impacts on safety and health. In response to COVID–19, they have engaged in a collective effort to develop guidance for use by the production agriculture industry, including checklists, FAQs, and resource guides. They have translated COVID–19 information for Spanish-speaking workers and have shared COVID–19 resources with industry partners, agricultural communities, and governmental agencies. In addition, they are continuing other important work to ensure the safety and productivity of American agricultural workers. For example: (1) AFF research has shown that rollover protective structures (ROPS or roll bars) and seatbelts on tractors can prevent 99 percent of overturn-related deaths. (2) AFFs have created training materials in partnership with producers to deliver evidence-based practical solutions that reduce exposures when handling pesticides and other farm chemicals among farmers workers and their children. (3) Partnering with fishing communities, the AFFs have developed and tested improved life-jacket designs that are comfortable enough to wear while working, markedly improve chances of survival in the event of a fall overboard. (4) The AFFs have conducted ongoing studies and outreach efforts to ensure the safety of our nation's 86,000 workers in forestry & logging, an industry with a fatality rate more than 30 times higher than that of all U.S. workers.

NIOSH supports six Centers of Excellence for Total Worker Health (TWH) that conduct multidisciplinary research and test practical solutions to emerging challenges. The TWH Centers partner with government, business, labor, and community to improve the health and productivity of the workforce. The TWH Centers have been heavily relied upon by employers and employees to address the impact of COVID–19 not only from an infectious disease perspective, but to address the impact on mental health, stress, burnout, and resiliency of essential workers, workers abruptly working remotely, and those furloughed or laid off. Even prior to the pandemic, the TWH Centers' research, education, and outreach activities occur in workplaces, such as hospitals, factories, offices, construction sites, and small businesses, resulting in immediate and measurable improvements in health and safety. For example, most U.S. employers had already reported that stress and mental health were major concerns for the effectiveness and well-being of their workforce. Consequences can include higher rates of substance use, poor sleep, musculoskeletal disorders, poorer mental health, obesity, cardiovascular disease, and cancer. In turn, ill health impacts job performance, increasing risks for serious injury, absenteeism, and reduced productivity. TWH Centers conduct solutions-focused research in partnership with employers and employees to address these challenges.

TWH Centers conduct new and ongoing programs that address safety, health, well-being, and productivity of the American workforce. For example: (1) TWH Centers have developed and evaluated interventions to reduce injuries and disease among workers in corrections to reduce risk factors for cardiovascular disease and workplace burn-out in officers. (2) In acute care hospitals, they have uncovered the effects of harassment and bullying on workplace injury and mental healthcare costs for patient care workers. (3) A national online and telephonic advising program for small business owners is now providing advice on COVID–19 as small businesses seek to reopen or increase activity. The TWH Centers are an investment in the American economy, helping valued employees return home at the end of a productive day safe and healthier.

We urge you to recognize the important contribution of NIOSH, including the ERCs, the AFF Program, and the TWH Program to the health and productivity of our nation's workforce. Thank you for the opportunity to submit testimony.

[This statement was submitted by Lee S. Newman, MD, MA, President, Association of University Programs in Occupational Health and Safety.]

PREPARED STATEMENT OF AUTISM SPEAKS

My name is Angela Geiger, and I am the President and Chief Executive Officer of Autism Speaks. Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families. We do this through advocacy and support; increasing understanding and acceptance of people with autism; and advancing research into causes and better interventions for autism spectrum disorder and related conditions.

We are grateful for the bipartisan leadership that both the Chairs and Ranking Members of the full committee and subcommittee have provided in supporting investments in autism research, training, and services over many years. As you consider this year's requests, we look again to your leadership to build on the significant progress that has been made and provide investments to meet the tremendous needs that continue to exist. We understand that the Committee is considering public witness requests for fiscal year 2021 during an unprecedented time for our country—having to carefully balance the annual appropriations process and the need for additional COVID–19 relief with overall budget considerations. The testimony included here reflects our request based on conditions that existed prior to the outbreak of the coronavirus, and the pandemic has no doubt exacerbated many of the challenges that the autism community experiences.

We thank you for the opportunity to submit testimony in support of autism funding within the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), Health Resources and Services Administration (HRSA), Department of Education (DOE), and other agencies under your jurisdiction. For fiscal year 2021 we request that the Committee invest at least $150 million above current levels in autism-related activities. This request would help to align the Federal investment in autism-related activities with the budget recommendation of the 2016–2017 Interagency Autism Coordinating Committee Strategic Plan for Autism Spectrum Disorder. While the NIH, DOE, CDC, and HRSA are the largest funders of autism-related research, training, and services, multiple other agencies fund important autism-related efforts as well. We urge the subcommittee to use the Interagency Autism Coordinating Committee recommendations and strategic objectives to guide investment across the agencies.

As you are aware, the CDC's most recent estimate released in late March of this year was that 1 in 54 eight-year-olds in the United States have an autism spectrum disorder (ASD) diagnosis. Just 10 years ago that number was 1 in 150. No single factor accounts for this increase; much of it comes as a result of increased awareness and earlier diagnosis. In addition, the CDC also recently reported for the first time an estimate of the number of autistic adults, finding that 5.4 million, or 1 in 45 adults, are on the autism spectrum.

Much of the progress in autism research that has been made is due in part to your work and support. As a result of research funded by this committee, the age at which autism can be reliably diagnosed has gone down from 3 years to 15 months. The sooner a child receives a diagnosis, the more likely it is that the child will receive the interventions and services that can improve the child's life. Because of the research you've funded we now know that individuals on the spectrum are more likely to have certain co-morbid health conditions like anxiety and epilepsy. Because of the research you have funded, clinical practice guidelines have been developed for children with autism and are being disseminated to healthcare providers around the country.

The research you have supported has been remarkably important in better understanding the biology of autism, better understanding the numbers of individuals across the country with an autism spectrum disorder diagnosis, and better understanding the types of interventions and supports that can benefit the autism community. This important knowledge was brought to us by autism research—and in many ways, it is because of this progress that we know that so much more needs to be done. Here are just a few examples of questions that additional research can answer:

—How can we develop personalized interventions and therapies to mitigate the co-morbid health conditions that occur in higher rates among autistic individuals?

—How can we promote evidence-based supports and services to assist the 70,000 autistic youth who every year transition out of school-age services?

—Even though autism can be diagnosed at 15 months, the average age of diagnosis remains at about 4 years old, and even later in low-income communities. What evidence-based practices can we use to help diagnose autism earlier across the board?

—There are tremendous gaps in services and supports across the lifespan, from children receiving a diagnosis and intervention services to adults who often have very limited access to supports. How can we ensure that at a community level everyone gets the support they need to lead a fulfilling and productive life?

—There is a dearth of research on issues affecting autistic adults. What can be done to not only better understand service and support needs, but also why autistic adults have higher premature death rates and poorer health outcomes than the rest of the population?

These are just several among many research questions that need to be answered. To be sure, studies that address these questions are ongoing, but the scale of the challenges faced by our community require urgent, increased, and sustained investment. The Interagency Autism Coordinating Committee (IACC), the congressionally created body whose primary responsibility is to advise the Federal Government on autism-related investments, recommended in its most recent Strategic Plan a doubling by 2020 of 2015 levels of investment in autism research. Even with this investment, the IACC stated that the "increases recommended by the IACC would not be sufficient to accomplish all of the research goals identified by the plan."

Furthermore, the IACC pointed out in their plan that the total annual cost of autism in the United States has been estimated to be at least $236 billion. By contrast, for 2015 combined autism research funding among Federal and private sources is less than 1 percent—a tiny fraction of the estimated annual total cost of autism. We understand that particularly at this juncture in our country that resources are finite. However, autism research is far less expensive than the cost of autism to families and society, and additional investments can help reduce those costs through early identification and intervention.

Fortunately, because of the Committee's previous investments and the decisions made by the agencies funded through this bill, there are tremendous opportunities to build off existing programs and bring even more knowledge from research to services. For example:

—In their fiscal year 2021 Congressional Budget Justification, the National Institutes of Mental Health (NIMH) highlighted the research they have funded to help identify ASD as early as possible. In that same document, they encourage more research into screening methods that can be used in infancy and point out the gaps that exist in translating screening methods into tools pediatricians can use.

—The CDC receives only enough funding to monitor the prevalence of children with ASD in 11 states. For those 11 states, that information is invaluable in driving efforts at a state and local level. Additional resources would allow more states to monitor prevalence and drive enhancements to services.

—HRSA has been funding extraordinarily important efforts to develop clinical medical standards for treating autistic individuals and then translating those standards into practice. More investment in this area would not only enhance the development of those standards but could rapidly increase their dissemination to communities across the nation.

—HRSA has also funded important research related to the transition to adulthood. There has been a significant lack of investment in research on issues facing autistic individuals across the lifespan, and there are opportunities to build off this existing work to close that gap.

We hear every day from individuals and families in the autism community about their successes, challenges, and everything in between. The research that you have funded has brought to the autism community a range of lasting changes and significant improvements in the lives of autistic individuals and their families. We are at a pivotal moment, and now is the time to seize on the tremendous opportunity we have to address the significant gaps we know persist and continue to make progress so that every person on the spectrum can achieve their full potential.

[This statement was submitted by Angela Geiger, President and Chief Executive Officer, Autism Speaks.]

PREPARED STATEMENT OF JILL RENEE BERKEL

My son (Richard Berkel) is not a substance abuser and was attending college at age 18 when he developed schizophrenia. He has an identical twin brother who does not have schizophrenia and we have no history of schizophrenia in our family.

For 18 months, I tried to get my son medical, community and professional help through traditional means to stabilize his condition. Private medical and Medicaid care was ineffective. The local Mental Health agency in our county also provided little or no help. (Hiring more case workers does not necessarily provide help for individuals with schizophrenia. Our visits with them were valueless.) NAMI was also not helpful. The NAMI support groups are extremely painful and one hears story after story of homelessness, suicide, and years of trying to get help but there is none to be had.

I did learn through NAMI that schizophrenia is a treatable condition and that individuals with it can lead extremely productive lives, once stabilized. Long term (6–8 months or more) treatment is needed but does not currently exist in a private setting.

I looked into moving to another state to get help, but found that this problem is pervasive in all states. It seems in every state, the only long-term treatment facilities that exist belong to the state and can only be accessed by a court order by a judge.

In October of 2019, he was arrested which gave him access to a state mental hospital. Unfortunately, the hospital released him prior to stabilization, returned him to jail where they plan to drop the charges and send him home.

I am a college educated professional, blindsided by this illness of my son and will be 64 years old this year. As a single mom, I have my own physical health issues that are aggravated by stress. I lost gainful employment from distractions dealing with his condition and am currently unemployed. I have limited ability, education and resources to deal with his illness.

Please do the right thing and put the NIMH funding where it will do the most help for those individuals that need it!:

The National Institute of Mental Health (NIMH) is the main Federal Government agency for research into mental illness. The NIMH was authorized through the passage of the National Mental Health Act in 1946 to better help individuals with mental health disorders through better diagnosis and treatments. With a budget of almost $2 billion in 2020, the NIMH conducts research and funds outside investigators to better understand mental illness and develop new treatments to reduce the burden these disorders have on individuals.

Unfortunately, the NIMH has a recent history of ignoring those with the most severe mental illnesses. As Treatment Advocacy Center Founder Dr. E. Fuller Torrey wrote in Psychiatric Times earlier this month:

"Congress awarded the National Institute of Mental Health an additional $98 million as part of the National Institutes of Health budget resolution in December 2019, which brings the NIMH budget to just under $2 billion and represents a 35 percent increase since 2015, one of the largest increases in the history of the NIMH. Yet, during the 5 years from 2015 through 2019, NIMH funded a total of 2 new drug treatment trials for schizophrenia and bipolar disorder, according to clinicaltrials.gov. This contrasts with the 5-year period from 2006 through 2010 when NIMH funded 48 such trials. NIMH has thus almost entirely given up its role of evaluating drugs for the treatment of 2 disorders (emphasis added)."

In December 2019, the NIMH released a draft of their five-year strategic plan for public comment. They reported receiving more than 6,000 responses over the winter holidays, including from our organization identifying concrete examples of research initiatives the NIMH could be pursuing today to help people with serious mental illness recover and live better lives. Despite this robust response, NIMH made no substantive changes to the research goals or objectives in the final version released to the public earlier this week.

The NIMH research goals for 2020–2025 heighten the existing imbalance in NIMH research. In doing so, they offer little hope for new or better treatments for individuals who are currently afflicted with a mental illness during their lifetime, especially a serious mental illness. This failure is inexcusable given the large increase in research funding given to NIMH in recent years.

Future NIMH funding must be used to correct the existing imbalance, not worsen it, especially now that the COVID–19 pandemic has upended the mental health treatment system and will likely result in an exacerbation of symptoms in people currently affected and an increase in serious mental illnesses among Americans.

Those with the most severe forms of mental illness deserve to be prioritized.

Thank you for your consideration of this request.

Sincerely.

PREPARED STATEMENT OF JANICE K. BLACKBURN

I am not a mental health expert by profession, but I wish to share with the Subcommittee my personal experience concerning the critical need for more effective antipsychotic medications that treat the symptoms of schizophrenia without producing serious adverse effects on the schizophrenic patient. Thank you for your consideration of the following comments.

I am troubled by the National Institute of Mental Health's reduction in recent years of clinical trials for new medications to treat the symptoms of schizophrenia. I am even more concerned that NIMH's new five-year strategic plan does not indicate a change in the agency's direction toward a renewed focus on the development of more effective antipsychotic medications.

As the aunt of a young man who suffers with schizophrenia, I am quite familiar with the plight of those suffering from this dreadful disease as they attempt to find a medication that is effective and which does not produce debilitating side effects. My nephew has suffered physically and/or emotionally as he has taken a series of prescribed medications that create various problems in his daily life—problems that cause him to be greatly discouraged in his efforts to live as normal a life as possible. Such discouragement has repeatedly led to his discontinuing his medications over the years. As the Subcommittee is doubtlessly aware, when a person with schizophrenia discontinues his/her medication, the costs to the person, their loved ones, the healthcare system, law enforcement and society at large can be huge. In my nephew's case, the costs have been considerable but, fortunately, without serious physical injury to him or others.

Obviously, in order to minimize the risks to the schizophrenic patient and others that arise when such patients abandon the path of compliance by discontinuing their prescribed medications, more effective antipsychotic medications with fewer serious side effects are needed. I hope that this Senate Subcommittee will take steps to ensure that the NIMH will renew its focus on the development of more effective antipsychotic medications with fewer serious side effects.

PREPARED STATEMENT OF THE BRAIN INJURY ASSOCIATION OF AMERICA

Dear Chairman Blunt, Ranking Member Murray and Committee Members:

The Brain Injury Association of America (BIAA) appreciates the opportunity to submit testimony in support of fiscal year 2021 appropriations for Federal programs serving the 2.5 million children and adults who sustain a traumatic brain injury (TBI) each year and the 5.3 million Americans living with a disability as a result of TBI.

REQUEST

BIAA urges you to:

Increase funding to the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) by $15 million to expand the TBI Model Systems program as follows:

- —Increase the number of competitively funded centers from 16 to 18 while increasing the per-center support by $200,000;
- —Increase the number of multicenter TBI Model Systems Collaborative Research projects from one to three, each with an annual budget of $1 million; and
- —Increase funding for the National Data and Statistical Center by $100,000 annually to allow all participants to be followed over their lifetime.

Appropriate $19 million to the TBI State Partnership Grant Program, housed in ACL's Administration on Disabilities' Independent Living Administration of the Administration, to provide funding to all states, territories, and the District of Columbia.

Appropriate $6 million to the Protection & Advocacy Grant Program, administered by ACL's Administration on Intellectual and Developmental Disabilities, to increase the amount awarded to each state.

Appropriate $23 million to the Centers for Disease Control and Prevention (CDC) as follows:

- —$7 million for CDC's TBI program authorized by the TBI Program Reauthorization Act of 2018,
- —$2 million for CDC's falls prevention program,
- —$9 million for CDC's injury control research centers, and
- —$5 million in new funding for a national concussion surveillance system.

DISCUSSION

The TBI Model Systems are a collection of 16 research centers located across the United States that conduct disability and rehabilitation research. The TBI Model Systems are the only source of non-proprietary longitudinal data on what happens to people with brain injury across the lifespan. They are a key source of evidence-based medicine and serve as a "proving ground" for future researchers. TBI Model Systems sites work closely with the Department of Veterans Affairs on research to improve the treatment of Veterans with brain injuries. It is in the nation's interest to expand our knowledge in caring for all persons who sustain TBIs.

The TBI State Partnership Grant Program (and its predecessor known as the Federal TBI Program) has sought to establish and/or strengthen access to systems of care for individuals who sustain brain injuries and their families. Currently 27 states are funded at either $300,000 or $150,000 to address the varied medical, healthcare, and community-based service and support needs across an array of public and private agencies and providers for individuals with co-occurring substance use and TBI, service members and veterans with TBI, seniors with TBIs from falls, adults and youth with TBI in the corrections system, student athletes managing concussions, and children transitioning from hospital to school after TBI. It is important to understand that families are the primary caregivers to individuals with brain injury. Indeed, no state has a full array of services and supports needed following injury. States that are not participating in the grant program may not have an identified or central contact for individuals and families.

The Protection and Advocacy TBI (PATBI) Grant Program funds the governor-designated P&A in each state and territory at $50,000 to provide advocacy assistance in finding, maintaining or advancing in employment, finding a home, accessing needed supports and services such as personal attendant services, assistive technology, and obtaining appropriate mental health, substance abuse, and rehabilitation services to avoid institutionalization.

The TBI Program Reauthorization Act of 2018 authorizes the Centers for Disease Control and Prevention to make grants to states to conduct TBI surveillance and public education programs. Funding of $7 million is needed for these activities. In addition, at least $5 million is needed in order for CDC to establish a national surveillance system to accurately determine the incidence of sports—and recreation-related concussions among youth aged 5 to 21 years as authorized by the TBI Program Reauthorization Act of 2018.

CONTACT

The Brain Injury Association of America is the nation's oldest and largest brain injury patient advocacy organization. Our mission is to advance brain injury awareness, research, treatment and education that improves the quality of life for people affected by brain injury. For further information, please contact Susan Connors at shconnors@biausa.org.

[This statement was submitted by Susan H. Connors, President/Ceo, Brain Injury Association of America.]

PREPARED STATEMENT OF CAST

CAST is a non-profit organization that uses educational technology coupled with expertise in the learning sciences to ensure all learners can and do reach their full potential. Our primary lever for change is Universal Design for Learning (UDL), a framework pioneered at CAST that harnesses technology and instructional practices to remove barriers to learning in digital as well as physical settings. Our aim is to create a level playing field where all learners have equitable opportunities to succeed.

UDL encourages the design of flexible learning environments that anticipate learner variability and provide alternative routes or paths to success; UDL acknowledges that variability across all learners is the norm rather than the exception. In support of the important portfolio of projects that include investments at the Federal level, in fiscal year 2021, CAST requests the following: (1) U.S. Department of Education (ED)—continue to fund all education programs at no less than the funding levels provided in fiscal year 2020 and prioritize UDL as a necessary priority for all competitive grants. (2) U.S. Department of Labor (DOL)—require all Federal investments in apprenticeships, career training and employment to incorporate UDL as defined in the Higher Education Act, and as referenced and endorsed as a best practice in the National Technology Plans of 2010 and 2016, as well as the National Ed Tech Developer's Guide of 2015.

We view additional funding appropriated to both the U.S. Departments of Education and Labor as an investment in the future. In our view, the COVID–19 pandemic is creating an inflection point that while unanticipated, can also be viewed as an opportunity to assure equitable access to education and workforce training. All students, young adults and others seeking an education as well as career training, including those who may struggle due to low literacy, language, disability or other factors can be taught remotely when they have the right technology including accessible materials and when their teachers and instructors have the right tools and training.

CAST is directly engaged with teachers and students across the United States in implementing the UDL framework-including during this abrupt, nationwide transition to online and remote learning. Without question, our work with States, districts, schools, and individual educators, as well as students and parents, convinces us that students of all ages and their families are depending on us to support them in their right to receive a high-quality education, even in these difficult circumstances. We urge you to help states and districts tackle an unprecedented crisis and turn it into an opportunity that changes the future for good.

Since pioneering UDL more than 30 years ago, CAST has brought UDL into K–12 schools, into postsecondary settings and increasingly into career and technical education programs. CAST's work is grounded in the vision of creating a world where "learning has no limits." UDL is now included in every major law impacting America's educational system, having emerged as a key element in Federal education policy. By investing in expanding both the knowledge and use of UDL, multiple Federal agencies, state education systems, school districts, federally funded education and labor programs and private foundations have made proactive and "on-the-fly" individualization of curricula possible in practical, cost-effective ways, and helped ensure that many educational technologies have built-in supports, scaffolds, and challenges to help learners understand, navigate, and engage with the learning environment.

The Subcommittee plays a significant role in ensuring that investments continue in UDL so that both education and employment settings embrace the framework of UDL to ensure the country's educational and economic success. Funding provided annually has expanded access to UDL through Title II of the Every Student Succeeds Act and the Higher Education Act—to support teacher and school leader preparation and professional learning for educators—and through the Strengthening Career and Technical Education for the 21st Century Act—to support better workforce preparation and employment outcomes for special populations including veterans, English learners, and individuals with disabilities.

Research-to-practice initiatives have been successfully seeded through ED's Education Innovation and Research programs including Ready to Learn as well as in National Activities that fall under the Individuals with Disabilities Education Act. Training and Employment initiatives for the DOL also receive important funding in support of UDL.

A sample of successful initiatives led by CAST and funded by the U.S. Department of Education include:

—*Student Engagement in Science/Social Science:* Through the Office of Elementary and Secondary Education, CAST led the Co-Organize Your Learning (CORGI) project. CORGI is a Google application (app) designed for students and teachers to use to collaboratively answer questions requiring higher order reasoning. CORGI helps students engage in science and social science classrooms and enhances their content learning. Students involved in the first pilot showed statistically significant improvements in U.S. History and Biology. There was also a positive differential effect for the students when compared with non-participants. CORGI is in its next phase at ED and is being used for STEM education in research funded by the National Science Foundation which expands the application's capacity for use with more students.

—*Digital Learning Materials:* Through the Office of Special Education, CAST leads the Center on Inclusive Software for Learning (CISL) in creating a suite of innovative tools designed to support today's diverse learner needs by making digital educational materials—including open educational resources (OERs)—accessible, flexible, and engaging for all students. CISL is exploring key aspects of digital learning such as: which learning supports should be prioritized when designing curricula? and how can OERs be made more accessible across content areas and for various grade levels and types of learners?

—*Accessible Educational Materials:* Through the Office of Special Education, the National Center on Accessible Educational Materials (AEM Center) continues to provide resources and technical assistance to educators, parents, students, publishers, conversion houses, accessible media producers, and others interested in providing accessible education materials including OERs consistent with Federal requirements under the National Instructional Materials Accessibility Standard. CAST helps teachers, administrators, assistive technology specialists, and curriculum creators to improve and customize curriculum to improve student access to materials and interoperability with student data, assistive technology, and content management systems. This work significantly impacts access to education in K–16 settings. CAST is also leading the OSEP-supported Center on Inclusive Technology & Education Systems, working with LEAs to create and disseminate a framework so that educational technology, assistive technology, and information technology can be better integrated in support of students with disabilities.

—*Teacher Training/Student Engagement (CA, NH, MA, WI):* As part of the Office of Special State Personnel Development Grants, CAST continues to lead statewide initiatives that focus on training teachers to build school and district capacity to improve student engagement and achievement through use of UDL in instructional practice.

—*Science Assessments/STEM Education:* CAST has a long list of STEM-focused initiatives and the most current focus on:

  —*OESE/OSEP:* Expansion of Co-Organize Your Learning (CORGI) project to enhance student engagement and learning through a Google application (app) designed for students and teachers to use to collaboratively answer questions requiring higher order reasoning.

—*OSEP:* To develop and test UDL-aligned science assessments for students with significant cognitive disabilities; and,

—*Institute for Education Sciences:* To conduct an efficacy trial of the UDL for Learning Science Notebook (UDSN), to support elementary school students with learning disabilities in active science learning. Results have shown the tool's supports for science learning and the science inquiry process have statistically significant effects on science performance and motivation for science learning.

Also, adoption of UDL in career and technical education (CTE) and employment training continues to grow. Examples include:

—*Collaboration with the National Alliance for Partnerships in Equity:* To support a major initiative to broaden participation in STEM and CTE which brings together six intermountain states to scale up the use of evidence-based practices already shown to improve equity in CTE and increase access to STEM career training.

—*Large-Scale Employment Training Initiatives:* To ensure UDL is a foundational element of national programs like YouthBuild and Jobs for the Future.

—*Training CTE Faculty:* To bring training to CTE faculty in the application of UDL to help their students achieve educational and career goals.

Increasingly, education and training programs of every level and type are incorporating significant digital and online components. Yet, despite the promise of flexibility, customized, learning solutions, and anywhere/anytime educational opportunity often associated with digital learning—especially for learners with challenges such as those based in poverty, language, disability, or something else, the reality is often dismal. Leveraging the UDL framework is essential to mitigating the current impact of digital learning because the population of digital learners is predictably diverse, and every federally supported training program must plan for that to ensure the effectiveness of these investments. This urgency is only intensified by the need for the U.S. educational system to respond to the COVID–19 pandemic with a wholesale shift to digital learning methods. CAST has received numerous requests from across the country for guidance during this crisis, and we have joined national coalitions and partners to ensure that learning will not be limited, even and especially for the country's most vulnerable children and youth, in these unprecedented times.

CAST urges the Subcommittee to further invest in UDL. In doing so, Congress would increase the capacity of States, districts and schools to provide more robust professional learning and other needed technical assistance so that teachers can be provided the tools and resources they need to teach and provided educational services and support to students. It is imperative that all learners, including first-time career seekers or adults desiring new opportunities, have access to workforce development and career pathway strategies and programs that are designed from the beginning with the variability of their learning in mind. Continuing to invest in educational innovations that incorporate effective implementation of UDL while prioritizing the need to include UDL as part of the infrastructure of workforce and CTE faculty training makes sense. As with K–12 education, this need is intensified by the retraining that will be required across the country as companies and industries adopt new workflow and safety protocols in response to COVID–19.

CAST appreciates the opportunity to provide recommendations to the Senate's fiscal year 2021 appropriations bill. We look forward to working with you as you develop a final appropriations bill that recognizes UDL as a vital component to K–16 education and to increasing and sustaining a well-trained and vital workforce.

PREPARED STATEMENT OF THE CDC COALITION

The CDC Coalition is a nonpartisan coalition of more than 140 organizations committed to strengthening our nation's prevention programs. We represent millions of public health workers, clinicians, researchers, educators and citizens served by CDC programs. We believe Congress should support CDC as an agency, not just its individual programs. Although we believe an even more significant increase is truly needed to address the nation's current health challenges, at a minimum, we urge a funding level of at least $8.3 billion for CDC's programs in fiscal year 2021. This request does not reflect any additional emergency resources that may be needed to address the immediate and ongoing efforts to combat the COVID–19 pandemic. We are grateful for the important increases provided for CDC programs in fiscal year 2020 and urge Congress to continue efforts to build upon these investments to strengthen all of CDC's programs. Additionally, we continue to oppose any effort to repeal or cut the Prevention and Public Health Fund which makes up about 11 percent of CDC's budget and funds critical prevention programs.

CDC serves as the command center for the nation's public health defense system against emerging and reemerging infectious diseases. From aiding in the surveillance, detection and prevention of the current COVID–19 outbreak globally and in the U.S. to playing a lead role in the control of Ebola in West Africa and the Democratic Republic of the Congo, to monitoring and investigating disease outbreaks in the U.S., to pandemic flu preparedness to combating antimicrobial resistance, CDC is the nation's—and the world's—expert resource and response center, coordinating communications and action and serving as the laboratory reference center for identifying, testing and characterizing potential agents of biological, chemical and radiological terrorism, emerging infectious diseases and other public health emergencies. CDC serves as the lead agency for bioterrorism and other public health emergency preparedness and response programs and must receive sustained support for its preparedness programs. Given the challenges of terrorism and disaster preparedness we urge you to provide adequate funding for the Public Health Emergency Preparedness grants which provide resources to our state and local health departments to help them protect communities in the face of public health emergencies. We urge you to provide adequate funding for CDC's infectious disease, laboratory and emergency preparedness and response activities in order to ensure we are prepared to tackle both ongoing COVID–19 pandemic and other public health challenges and emergencies that will likely arise during the coming fiscal year.

Injuries are the leading causes of death for people ages 1–44. Unintentional and violence-related injuries, such as older adult falls, firearm injury, child maltreatment and sexual violence, account for nearly 27 million emergency department visits each year. In 2013, injury and violence cost the U.S. $671 billion in direct and indirect medical costs. In 2018, opioids killed nearly 47,000 individuals nationwide. CDC provides states with resources for opioid overdose prevention programs and to ensure that health providers to have information to improve opioid prescribing and prevent addiction and abuse. In 2018, there were over 39,740 U.S. firearm-related fatalities. We thank Congress for providing CDC with dedicated funding for firearm morbidity and mortality prevention research and we strongly urge you to maintain and increase this funding in fiscal year 2021. The National Center for Injury Prevention and Control must be adequately funded to conduct research, prevent injuries, and help save lives.

In 2017, over 647,000 people in the U.S. died from heart disease, the nation's number one killer, accounting for about 23 percent of all U.S. deaths. More males than females died of heart disease in 2017, while more females than males died of stroke that year. Stroke is the fifth leading cause of death and is a leading cause of disability. In 2017, over 146,000 people died of stroke, accounting for about one of every 19 deaths. CDC's Heart Disease and Stroke Prevention Program, WISEWOMAN, and Million Hearts work to improve cardiovascular health. More than 1.8 million new cancer cases and over 600,000 deaths from cancer are expected in 2020. In 2015 the direct medical costs of cancer was $80.2 billion. The National Breast and Cervical Cancer Early Detection Program helps millions of low-income, uninsured and medically underserved women gain access to lifesaving breast and cervical cancer screenings and provides a gateway to treatment upon diagnosis. The Colorectal Cancer Control Program focuses on improving screening rates among targeted, low-income populations aged 50 -75 years in targeted states and territories through evidence-based interventions using partner health systems. CDC funds grants to all 50 states, DC, 7 tribes and tribal organizations, and 7 U.S. territories and Pacific Island jurisdictions to develop comprehensive cancer control plans, bringing together public and private stakeholders to set priorities and implement cancer prevention and control activities to address each state's particular needs.

Cigarette smoking causes more than 480,000 deaths each year. CDC's Office of Smoking and Health funds important programs and education campaigns such as the Tips From Former Smokers campaign which has already helped more than 500,000 individuals quit smoking and millions more to make a serious quit attempt. We must continue to support this and other vital programs to reduce the enormous health and economic costs of tobacco use in the U.S.

Of the more than 34 million Americans living with diabetes, more than 7 million cases are undiagnosed. Each year, about 1.5 million people are newly diagnosed with diabetes. Diabetes is the leading cause of kidney failure, nontraumatic lower-limb amputations, and new cases of blindness among adults in the U.S. The total direct and indirect costs associated with diabetes were $327 billion in 2017. We urge you to provide adequate resources for the Division of Diabetes Translation which funds critical diabetes prevention, surveillance and control programs.

Obesity prevalence in the U.S. remains high. More than 42 percent of adults are obese and 18.5 percent of children ages of 2 to 19 are obese. Obesity, diet and inactivity are cross-cutting risk factors that contribute significantly to heart disease, cancer, stroke and diabetes. The Division of Nutrition, Physical Activity and Obesity funds programs to encourage the consumption of fruits and vegetables, encourage sufficient exercise and develop other habits of healthy nutrition and physical activity and must be adequately funded.

Arthritis is the most common cause of disability in the U.S., striking more than 54 million Americans of all ages, races and ethnicities. CDC's Arthritis Program helps address this growing public health challenge and works to improve the quality of life for individuals affected by arthritis and we urge you to support adequate funding for the program.

CDC provides national leadership in helping control the HIV epidemic by working with community, state, national, and international partners in surveillance, research, prevention and evaluation activities. CDC estimates that about 1.1 million Americans are living with HIV with 14 percent undiagnosed. Prevention of HIV transmission is the best defense against the AIDS epidemic. Sexually transmitted diseases continue to be a significant public health problem in the U.S. Nearly 20 million new infections occur each year. STDs, including HIV, cost the U.S. healthcare system almost $16 billion annually.

The National Center for Health Statistics collects data on chronic disease prevalence, health disparities, emergency room use, teen pregnancy, infant mortality and causes of death. The health data collected through the Behavioral Risk Factor Surveillance System, Youth Risk Behavior Survey, Youth Tobacco Survey, National Vital Statistics System, and National Health and Nutrition Examination Survey must be adequately funded.

CDC's REACH program helps communities address serious disparities in infant mortality, breast and cervical cancer, cardiovascular disease, diabetes, HIV/AIDS and immunizations by supporting community-based interventions and we urge the committee to provide continued funding for these important activities.

CDC oversees immunization programs for children, adolescents and adults, and is a global partner in the ongoing effort to eradicate polio worldwide. Childhood immunizations provide one of the best returns on investment of any public health program. For every dollar spent on childhood vaccines to prevent thirteen diseases, more than $10 is saved in direct and indirect costs. Over the past 20 years, CDC estimates childhood immunizations have prevented 732,000 deaths and 322 million illnesses. We urge you to provide adequate funding for the Section 317 Immunization program and other efforts to prevent vaccine-preventable disease.

Birth defects affect one in 33 babies and are a leading cause of infant death in the U.S. Children with birth defects that survive often experience lifelong physical and mental disabilities. Approximately one in six U.S. children is living with at least one developmental disability and one in four adults live with a disability. The National Center on Birth Defects and Developmental Disabilities conducts programs to prevent birth defects and developmental disabilities and promote the health of people living with disabilities and blood disorders.

CDC's National Center for Environmental Health funds programs to control asthma, protect from threats associated with natural disasters and climate change, reduce, monitor and track exposure to lead and other environmental health hazards. Increased funding for CDC's environmental health prevention activities within NCEH will help reduce illness, disease, injury and even death.

In order to meet the many ongoing public health challenges facing the nation, including those outlined above, we urge you to support, at a minimum, our fiscal year 2021 request of at least $8.3 billion for CDC's programs.

[This statement was submitted by Don Hoppert, Director, Government Relations, American Public Health Association.]

PREPARED STATEMENT OF THE CENTER FOR STUDIES IN DEMOGRAPHY AND ECOLOGY, UNIVERSITY OF WASHINGTON

I am writing on behalf of the hundreds of research scientists at the University of Washington who rely on high quality demographic and vital statistics data for understanding and explaining the state of our nation's and communities' health and wellbeing. In this time of pandemic crisis, we are all made aware of the incredible and important need for high quality vital statistics records. That recognition should increase the legislative priorities for re-investing in our nation's capacities to collect and curate high quality vital statistics records. The Friends of NCHS has submitted a recommendation statement and we support that statement. Please accept this statement of testimony for the Labor-HHS-Education bill.

We recommend funding level of at least $189 million for the National Center for Health Statistics (NCHS) (an increase of $14.6 million and realignment of $14 million in ongoing transfers), which would restore NCHS's budget its inflation-adjusted fiscal year 2010 funding level, giving it the funding it needs to continue to produce its essential existing surveys and reports without interruption while being able to invest in desperately needed innovation.

The investment in transforming NCHS capacity to capitalize on survey methodologies, big data and computing will also catalyze scientific and public health insights across the nation from small localities to major universities. Becoming a gold-standard producer of health statistics is a relatively small investment for an extraordinary return on public investment.

[This statement was submitted by Sara Curran, Director, Center for Studies in Demography & Ecology, University of Washington.]

PREPARED STATEMENT OF THE CHILD CARE ACCESS MEANS PARENTS IN SCHOOLS

Dear Chairmen and Ranking Members,

As organizations committed to promoting the postsecondary success of college students with children, we are writing to express our strong support for increasing funding for the Child Care Access Means Parents in Schools (CCAMPIS) program to $200 million—the amount needed to provide child care support to approximately 2.5 percent of Pell-eligible student parents of children ages 0–5. The CCAMPIS program provides vital support for the participation and success of low-income parents in postsecondary education through the provision of subsidized child care, which is widely recognized as one of the most important supports for parenting college students. The COVID–19 crisis has put into stark relief the challenges student parents—many of whom are also working parents—face balancing child care, academics, one job or several jobs, and precarious finances, even before the pandemic. Quadrupling CCAMPIS funding to $200 million in the Labor-HHS–ED appropriations bill would ensure that tens of thousands more parenting college students receive the child care assistance they need to continue their educational journeys and be successful in college.

Roughly 4 million college students are parents of dependent children, representing more than one in five undergraduates in the United States. Many of these student parents are balancing college and parenting without the support of a spouse or partner: 1.7 million women in college are single mothers. Student parents, and particularly those who are single, face acute financial, work, caregiving demands that can complicate their ability to persist to graduation. Student parents are more likely than other students to live in poverty, to have no resources to devote to college costs, and to incur substantial student debt—due in large part to the high cost of child care. Student parents also spend significant time providing care, with 21 percent of community college students spending more than 20 hours per week caring for dependents, according to the 2019 Community College Survey of Student Engagement.

Access to affordable child care is one of the most important supports that can help student parents succeed in college. Data from one community college show, for example, that usage of the campus child care center led to a 21 percent increase in degree attainment over the rate for student parents who did not access the center. New research shows, however, that students often do not have access to affordable care—according to a recent survey of roughly 23,000 student parents, 70 percent of respondents report that their child care arrangement is unaffordable. Without affordable child care, student parents are often forced to make tough decisions about their educational pursuit: in 2019, 28 percent of community college students reported that they are likely or very likely to leave school due to their caregiving responsibilities.

Unfortunately, campus-based child care has been declining in recent years, most dramatically at community colleges where the largest share of student parents are enrolled. Exacerbating this decline is the fact that, in light of the economic fallout caused by COVID–19, the country may lose as many as 4.5 million child care slots. The need for student parent access to affordable child care has never been greater than it will be as campuses begin to re-open.

The CCAMPIS program is the only Federal program dedicated solely to providing child care assistance for students in postsecondary settings. Other available child care assistance, such as subsidies provided through the Child Care Development Block Grant, can be hard for student parents to access due to restrictive eligibility rules such as work requirements and degree limitations. CCAMPIS has no work requirements and it helps meet students' need for low-cost child care, enabling them to persist in and complete postsecondary credentials, which are critical to their families' economic well-being and are associated with a range of multigenerational benefits. Increasing the program's funding to serve a larger percentage of Pell-eligible students with young children would allow the program to reach tens of thousands more students, greatly improving their chances of postsecondary success.

For these reasons, we express our strong support for increasing funding for the Child Care Access Means Parents in Schools (CCAMPIS) program to $200 million in the fiscal year 2021 Labor-H appropriations bill.

Sincerely,

All Our Kin
America Forward
Augustus F. Hawkins Foundation
BCC EARLY CHILDHOOD CENTER
Center for Law and Social Policy (CLASP)
Charles Stewart Mott Community College
City University of New York
Clearinghouse on Women's Issues
Early Learning Campus, Inc
Every Child Matters
Feminist Majority Foundation
First Focus Campaign for Children
Florence Darlington Technical College
Georgia Budget and Policy Institute
Healthy Teen Network
Helen Gordon CDC, Portland State University
Higher Learning Advocates
Institute for Childhood Preparedness
Institute for Women's Policy Research (IWPR)
Jobs for the Future (JFF)
Los Angeles Valley College Family Resource Center
Mesa Community College
Monroe Community College (SUNY)
National Alliance for Partnerships in Equity (NAPE)
National Indian Child Care Association
National Organization for Women
National Skills Coalition
National Women's Law Center
New America Education Policy Program
One Family
Oregon State University, Family Resource Center
Ray Ellison Family Center
Save the Children Action Network
Society of Women Engineers
Southern Illinois University Edwardsville
St. Louis Community College
Student Veterans of America
The Graduate! Network, Inc
The Hope Center for College, Community, and Justice
The National Child Care Association (NCCA)
The National Early Childhood Program Accreditation (NECPA)
uAspire
Univ. of Hawaii Bridge to Hope
University of Delaware
University of Missouri St. Louis
University of New Mexico Children's Campus
Veterans Education Success
Women Employed
World Education, Inc.
Young Invincibles

PREPARED STATEMENT OF THE CHILDREN'S HOSPITAL ASSOCIATION

The Children's Hospital Association (CHA) advances child health through innovation in the quality, cost and delivery of care. Representing more than 220 institutions, CHA is the voice of children's hospitals nationally. As organizations dedicated to protecting and advancing the health of America's children, we urge the Subcommittee to continue advancing children's health by funding CHGME at $465 million.

A robust pediatric workforce is essential to ensuring that no child lacks access to high-quality medical care. The CHGME program supports this goal by providing funding for the training of pediatric providers at independent children's teaching hospitals, much as Medicare supports training in teaching hospitals that serve primarily adults. CHGME benefits all children, supporting the training of doctors who go on to care for children living in every state—in cities, rural communities, suburbs and everywhere in between. As the only providers of the most complex pediatric cancer, cardiac, trauma and care for chronically and acutely ill infants and children, pediatricians are the primary provider for millions of children in need.

The CHGME program represents our nation's most significant investment in strengthening the pediatric workforce. CHGME was created in 1999 with bipartisan support when Congress recognized that a dedicated source of funding for training the next generation of pediatricians and pediatric specialists in children's hospitals was crucial. Because we treat children—mostly covered through Medicaid and the Children's Health Insurance Program—children's hospitals were effectively left out of the Federal GME system of support provided through Medicare prior to the establishment of CHGME.

Since the establishment of the program, CHGME funding has enabled children's hospitals to dramatically increase training overall and in particular grow the supply of pediatric specialists—the area of greatest shortage in children's healthcare. Today, only 1 percent of all hospitals in the United States—58 children's hospitals—receive CHGME. Yet, these institutions train approximately half of the nation's pediatricians—more than 7,000 FTEs annually—including 44 percent of all general pediatricians and 57 percent of all pediatric specialists.

Between 2000 and 2015, CHGME-supported hospitals collectively increased the number of residents trained by 113 percent. Today, in the majority of pediatric subspecialist fields tracked by the American Medical Association, more than 65 percent of residents are trained at CHGME hospitals. In some fields, such as pediatric rehabilitation medicine, virtually all physicians receive their training at CHGME hospitals.[1]

Unfortunately, multiple indicators suggest a crisis is looming for children's access to care. Despite progress, we are at risk of falling behind on children's health. The current level of support provided for training kids' doctors through CHGME is declining against levels provided per trainee in the Medicare Graduate Medical Education (Medicare GME) program. In fiscal year 2020, CHGME was funded at $340 million. At that level, the average CHGME payment per full-time equivalent (FTE) resident equates to approximately $73,000. By comparison, Medicare GME payments to general acute care hospitals are approximately $142,000 per resident. This shortfall continues to grow. Without additional investments, CHGME funding will decline to 45 percent of Medicare GME by 2023. By increasing CHGME funding by approximately $125 million annually for 3 years, parity between CHGME and Medicare GME can be achieved—ensuring a strong pediatric workforce pipeline for future generations. A funding level of $465 million for fiscal year 2021 is the first step to ensuring the investment in training physicians for adults is comparable.

Even with CHGME, serious pediatric workforce shortages persist nationwide—most acutely among pediatric subspecialties. The most recent survey data available from children's hospitals shows the following wait times for scheduling appointments due to shortages:

—Genetics—average wait time of 20 weeks
—Developmental Pediatrics—average wait time of 19 weeks
—Pain Management/Palliative Care—average wait time of 12 weeks
—Child and Adolescent Psychiatry—average wait time of 10 weeks

Beyond these shortages, children's hospitals also currently incur significant additional costs to subsidize their teaching mission—costs as high as $40 million annually above what they receive from CHGME. This growing funding gap isn't sustainable, as it is being made up through the clinical operations of our children's hospitals, hospitals with the nation's highest Medicaid payer burden. Medicaid reimbursement levels in many states remain well below those of private insurance and other government programs, particularly as state Medicaid programs have been scaled back significantly in recent years. Without strengthening CHGME, hospitals will be at risk of cutting training experiences and patient care services.

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[1] "Percentage of Pediatric Specialists Trained at CHGME Recipient Hospitals," Children's Hospital Association fact sheet, April 2018.

Increased funding for pediatric workforce training programs is even more important as we actively respond to the emergence of COVID–19 within our communities. Residency and fellowship programs are being impacted tremendously during this time due to a shift in healthcare services and the need to provide healthcare in a time of crisis. Many residents are seeing their programs suspended or are being asked to provide services in different capacities. They are being asked to balance the needs of their training requirements while providing care during a pandemic. Additionally, they are adapting to new training platforms and policies to ensure patient safety.

The healthcare needs of the pediatric population are also increasing overall. The number of children with complex medical conditions is growing at a faster rate than the overall child population, requiring an increasing number of specialty care providers.[2] Strengthening funding for CHGME will help children and their families, including those with rare and complex conditions.

The CHGME program is critical to facing these shortages, protecting gains in pediatric health and ensuring access to care for children. Now is the time to take a step forward in pediatric medicine—particularly during this time of emergency—to ensure our children have access to the healthcare services they need.

Children's hospitals thank you for your past support for this critical program and your leadership in protecting children's health. We respectfully request that the Subcommittee continue its history of bipartisan support for children's health and fund CHGME at $465 million in the fiscal year 2021 Labor-HHS appropriations bill.

PREPARED STATEMENT OF THE CHRISTOPHER & DANA REEVE FOUNDATION

Thank you for this opportunity to submit testimony in support of an appropriation of $9,700,000 for the Paralysis Resource Center (PRC) within the Administration for Community Living (ACL) at the Department of Health and Human Services (HHS).

I am proud to speak on behalf of my daughter, Ellie, who is of the 1 in 50 Americans living with paralysis, who rely on programs like the Paralysis Resource Center to live independent and empowered lives. The Reeve Foundation has operated the Paralysis Resource Center for 18 years, competing in a rigorous, competitive bidding process every 3 years for renewal of this grant. For fiscal year 2021, we request funding of $9.7 million for the Paralysis Resource Center. Of this total, we request that the Committee direct no less than $8.7 million to the National Paralysis Resource Center. These requests are in line with the final appropriation for fiscal year 2020, and with the Administration's fiscal year 2021 Budget Request.

When Christopher Reeve was paralyzed from the neck down due to a spinal cord injury in 1995, his family found themselves in total darkness as to what to do next. There was no phone number to call for guidance or help. There were no experts reaching out to connect them to the right rehabilitation facilities, or to discuss how they could support his return home and ongoing well-being. There was certainly no promise that an individual living with that level spinal cord injury could lead a full and active life as a father and husband. Yet, instead of accepting that life with paralysis would be full of limitations, he dreamed of a brighter future.

That was the genesis of the Christopher & Dana Reeve Foundation: Christopher's dream to elevate the needs and rights of the 5.4 million Americans living with paralysis. But he was far from alone. The real drive behind the Paralysis Resource Center came from his wife, Dana. As a caregiver herself, she knew that paralyzed individuals and caregivers around the country need a centralized place to call for resources and expertise.

Just twenty-four hours after my daughter, Ellie, sustained a spinal cord injury, I contacted the Paralysis Resource Center. The same day I was told my daughter would probably never walk again; I was offered a lifeline. I believe that call turned the nose of the Titanic away from the iceberg before it hit us. It altered the course of desperation and isolation of what we were dealing with and gave us real hope. I was assured that Ellie would drive again, work again and enjoy her life-and that the Foundation would hold my hand the entire way.

Since the PRC opened its doors in 2002, it has served as a free, comprehensive, national source of informational support for people living with paralysis and their caregivers. Its work is deeply aligned with ACL's mission to empower people living with disabilities and older adults to live independently and participate in their communities throughout their lives. The PRC is the only program of its kind that di-

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[2] 2014 report, "Summary of Available Evidence and Methodology for Determining Potential Medicaid Savings from Improving Care Coordination for Medically Complex Children," prepared for Children's Hospital Association by Dobson DaVanzo & Associates, p. vi.

rectly serves individuals living with spinal cord injury, MS, ALS, stroke, spina bifida, cerebral palsy and other forms of paralysis. The services and programs described below would not be possible without the ongoing support of this Subcommittee.

The PRC's Core Programs

Information Specialists.—One of the PRC's most essential functions is the team of certified, trained Information Specialists (IS) who provide personalized support on how to navigate the challenges of life with paralysis. This team of experts, many living with paralysis themselves, are often the first port of call for individuals who are newly injured or diagnosed. This is especially critical as we face the current COVID–19 public health emergency. The IS team is providing up-to-date information on how best to care and protect oneself during this exceptionally difficult and uncertain time for the world.

To date, our Information Specialists have provided direct counseling to over 111,000 people. We have distributed 210,000 copies of our Paralysis Resource Guide, which is a staple in hospitals and rehabilitation facilities across the country.

Peer & Family Support Program.—A second pillar of the PRC is our Peer & Family Support Program. This program is born of the idea that the best source of knowledge is experience: and that peer-to-peer connections empower not only the newly-paralyzed individual, but also the mentor. Through the PRC, more than 423 peer mentors have been trained and certified in 41 states and Washington, DC. These individuals have mentored 12,450 peers, including 3,624 caregivers.

Quality of Life Grants Program.—Our third pillar, the Quality of Life Grants Program, operates at the community level to fund nonprofit initiatives in all 50 states. Since 1999, the Quality of Life Grants Program has directed over $28 million dollars to assist 3,150 projects. This program has increased employment trainings and accessible transportation; established adaptive sports programs and camps for children; improved access to buildings, playgrounds and universities; helped individuals learn how to manage their financial well-being, and provided support services for veterans. Critically, these programs use the public attention that comes from receiving PRC funding—often fairly small grants—to raise additional funds in their community, creating a powerful return on investment.

Military & Veterans Program; Multicultural Outreach Program.—The PRC has a comprehensive Military and Veterans Program, which provides dedicated resources to help individuals navigate military and civilian benefits and programs as they reintegrate into their communities. The PRC also facilitates a Multicultural Outreach Program that is designed to engage and support underserved populations like ethnic minorities, older adults, low income earners, and LGBTQ individuals.

ChristopherReeve.org.—One of the most challenging aspects about living with paralysis is combating feelings of isolation and exclusion, especially for those who are unable to leave their homes due to physical and societal barriers. The Reeve Foundation's website, ChristopherReeve.org, provides a vibrant online community and resource hub that attracts close to two million visitors per year.

The Value of Integrated Services

There are many examples in which an individual living with paralysis has not only participated in one program of the PRC, but has benefitted from a suite of our free services. When Sterling Thomas, a college student from Oklahoma, sustained a spinal cord injury in 2012, his family was at a loss as to how to emotionally and physically support their son. They turned to the Reeve Foundation's website to understand Sterling's prognosis and prepare for his future needs. They referred to the Paralysis Resource Guide as a critical tool for managing his health, and connected with an Information Specialist who provided guidance to further improve Sterling's quality of life. Once Sterling and his father felt confident in their path forward, they became certified peer mentors through the Peer and Family Support Program to help other families in the Oklahoma area navigate life after paralysis. And, I am excited to report that the Sterling Thomas "Push-Push-Pray Foundation" received a Quality of Life grant. Sterling's is just one of many stories of how the PRC serves as a lifeline to help families from the moment of injury or diagnosis through the many chapters of living with paralysis-providing a continuum of care made possible by the depth and breadth of the PRC's offerings.

The Importance of Federal Funding

I would like to close my remarks by emphasizing why Federal funding for this program is so important. Simply put: neither the Reeve Foundation, nor any organization competing to run the PRC, could provide this type of centralized resource alone. Because many individuals, including my daughter, are required to attend rehabilitation clinics and/or draw on other resources from out of state, nationwide expertise is required. To get the benefit of investing in a centralized hub of information, we need to promote and deliver these services at scale. Federal funds are essential for this valuable, life-changing resource to work.

Federal funding for the PRC is also a good investment. Our resources help people adapt their homes and gain the tools they need to return to their communities, and eventually to work. The programs funded by the PRC make people less dependent on healthcare providers, so they can reduce their medical costs-saving dollars for Medicaid and Medicare. Our Military and Veterans Programs provide an essential continuum of support for returning heroes as they transition out of the VA system. Our national model and household name allows us to leverage a small team to have maximum impact. The PRC is smart Federal funding at work.

Christopher Reeve once said, “Hope is like a lighthouse,” helping individuals who are lost in the darkness find their way. But like a lighthouse, hope must be built on solid foundations. The resources, support and community created by the PRC are the foundation for hope for millions of individuals affected by paralysis around the country. I thank you for your ongoing support and urge you to protect the Paralysis Resource Center so that individuals nationwide can achieve greater quality of life, health and independence. Thank you.

[This statement was submitted by Jay P. Shephard, Chairman, Board of Directors, Christopher & Dana Reeve Foundation.]

PREPARED STATEMENT OF THE COALITION FOR CLINICAL AND TRANSLATIONAL SCIENCE

FISCAL YEAR 2021 APPROPRIATIONS RECOMMENDATIONS

- —CCTS joins the broader medical research community in asking Congress to provide the National Institutes of Health (NIH) with at least a $3 billion funding increase for fiscal year 2021, to bring total agency funding up to a minimum of $44.7 billion annually.
  - —Please provide the Clinical and Translational Science Awards (CTSA) program at the National Center for Advancing Translational Sciences (NCATS) with at least a $30 million increase in dedicated line-item funding for fiscal year 2021 to bring total support for the program up to a minimum of $608 million in annual dedicated funding.
  - —Please provide the Cures Acceleration Network (CAN) at NCATS with $100 million in dedicated funding for fiscal year 2020, to bolster total support for the program and to ensure that adequate resources are available to ensure notable progress.
  - —Please provide the Institutional Development Awards (IDeA) program and the Research Centers in Minority Institutions (RCMI) program at NIH with meaningful funding increases for fiscal year 2021 ($25 million and $12 million respectively, consistent with fiscal year 2020 increases).
- —CCTS joins the broader medical research community in asking Congress to provide the Agency for Healthcare Research and Quality (AHRQ) with a $131 million increase for fiscal year 2020 to bring total funding up to $471 million annually.
  - —Please continue to support research training and career development activities at NIH and AHRQ to ensure that the next generation of clinical and translational researchers is well-prepared.
- —CCTS joins the broader public health community in requesting $8.3 billion for the Centers for Disease Control and Prevention (CDC).

Chairman Blunt, Ranking Member Murray, and distinguished members of the Subcommittee, thank you for considering the views of the clinical and translational research community as work on fiscal year 2021 appropriations. Moreover, thank you for providing NIH with a significant $2.6 billion funding increase for fiscal year 2020, and for protecting line-item funding for the CTSA program, which provides critical infrastructure support to meritorious institutions across the country and serves as a major catalyst for advancing the full spectrum of medical research at NIH. As you consider fiscal year 2021 funding, the community would like to highlight the critical role that clinical research infrastructure, the CTSA program, and the full spectrum of medical research play in quickly translating scientific advancements into therapies, diagnostic tools, and public health information to properly address COVID–19 or any other health challenge.

ABOUT THE COALITION FOR CLINICAL AND TRANSLATIONAL SCIENCE

The Association for Clinical and Translational Science, the Clinical Research Forum, the CTSA PIs, and the related stakeholder community work together through the Coalition for Clinical and Translational Science (CCTS) to speak out with a unified voice on behalf of the clinical and translational research community. CCTS is a nationwide, grassroots network of dedicated individuals who seek to educate Congress and the administration about the value and importance of clinical and translational research, and research training and career development activities. Our goals are to ensure that the full spectrum of medical research is adequately funded, the next generation of researchers is well-prepared, and the regulatory and public policy environment facilitates ongoing expansion and advancement of the field of clinical and translational science.

ABOUT THE CTSA PROGRAM AND THE FULL SPECTRUM OF MEDICAL RESEARCH

The CTSA Program was established to disseminate medical and population health interventions to patients and populations more quickly, and to enable research teams, including scientists, patient advocacy organizations and community members, to tackle system-wide scientific and operational problems in clinical and translational research that no one team can overcome in isolation. The CTSA program honors the promise of the Cures Act by improving research infrastructure and accelerating the rate at which breakthroughs in basic science are translated to innovations with a tangible benefit to patients.

The goals of the CTSA program include; (1) train and cultivate the translational science workforce, (2) engage patients and communities in every phase of the translational process, (3) promote the integration of special and underserved populations in translational research across the human lifespan, (4) innovate processes to increase the quality and efficiency of translational research, particularly of multisite trials, (5) advance the use of cutting-edge informatics.

The CTSA Program supports a national network of "hubs" at academic research centers across the country that work collaboratively to improve the translational research process to get more treatments to more patients more quickly. The hubs collaborate locally and regionally to catalyze innovation in research training, tools, and processes. Approximately 60 medical research institutions across the nation currently receive CTSA program funding, and these hubs work together to speed the translation of research discovery into improved patient care and public health. Resources appropriated to these hubs allow the network to expand to include additional sites, advance science, and directly invest in the health workforce of the communities where they are located.

The full spectrum of translational science takes the fruits of basic and pre-clinical research and translates them into effective clinical care and public health measures, with a focus on having impact on health. In order to maximize efficiency and patient-centeredness, this research must be done collaboratively and in a systematic way. This team-science approach focuses on outcomes and patient/health system benefits, rather than the advancement of science for the sake of science. There are numerous examples of the success of this approach, including the community's annual awards for the "Top 10" projects, which can be viewed here. In fact, the project studying culturally competent healthcare delivery using community barber shops in Los Angeles, was highlighted in NCATS' fiscal year 2020 budget request.

Finally, the appropriations committees have included meaningful committee recommendations in the past that have facilitated meaningful advancements for the full spectrum of medical research, the CTSA program, and career development for early stage investigators and we hope similar recommendations will be provided for fiscal year 2021.

A FEW RECENT EXAMPLES OF CTSA PROGRAM EFFORTS TO ADDRESS COVID–19

University of Alabama at Birmingham

The UAB CTSA has joined with the Pitt CTSA and NIAID to perform a very large serologic surveillance study for antibodies to SARS–CoV2. This effort has had >400,000 expressions of interest by respondents and we are developing the sampling strategy now. This effort went from the first concept call to going live with all approvals in 3 weeks and a day.

The UAB CTSA and its Partner Network have also embarked on a large scale whole genome sequencing study of severe COVID–19 disease in the special populations we serve in the Deep South to understand the disparities in clinical outcome and help identify factors which will allow earlier and more effective intervention with immunomodulatory agents.

Working with our CCTS Partner HudsonAlpha, we are developing an innovative molecular diagnosis platform based on multiplexed next generation sequencing to enable high throughput diagnosis at a community and population scale. Further, supporting work with a biotechnology company in Maryland, we are developing a nasally delivered vaccine to protect against respiratory acquisition of viral infection.

Finally, using the CTSA platform to stand up clinical trials, nimbly and effectively, and working with the CTSA consortium's Trial Innovation Network, UAB has initiated clinical trials studying the efficacy of convalescent plasma (in partnership with Johns Hopkins), blockade of interleukin-1 and multiple other studies.

Vanderbilt University

The Vanderbilt Institute for Clinical and Translational Research made the early decision not to pursue studies that did not have any control, and instead chose to focus on randomized clinical trials that could provide strong evidence to the U.S. and the world about which treatments meet the gold standard for being effective against COVID–19. As a direct result of funding through the CTSA program, Vanderbilt was positioned to redeploy its clinical research workforce to start up no fewer than ten clinical trials in less than 7 weeks. In one example, Vanderbilt partnered with the NHLBI-funded PETAL Network to start up the multi-site ORCHID trial of hydroxy-chloroquine. The protocol was developed, received regulatory approval and funding, and enrolled its first patient all in under 14 days. This speed in response was possible only because of the common tools and processes that have been built by the CTSA Program. REDCap, for example, is a database system developed by Vanderbilt and deployed at thousands of institutions across the globe at no cost because of support from NIH and the CTSA Program. REDCap has been used by state health departments to track the pandemic, and is being used by researchers to collect data for hundreds of clinical trials and studies of COVID–19.

An important feature of research institutions enabled by the CTSA Program is the ability to be nimble. Traditional clinical trials can take a year or more to enroll patients and produce evidence that will change practice. The statisticians at Vanderbilt University Medical Center, with partners across the country, are pioneering ways of monitoring the studies and analyzing data more quickly, so that as soon as meaningful information is available it can be used to decide about releasing effective drugs, studying new drugs, or stopping studies of drugs that do not appear to be effective. The CTSA Program has invested in biostatistics and data science as a foundation of learning from data in healthcare and clinical trials.

Vanderbilt is also redirecting other research efforts that have utility in COVID–19. For example, every year, more than 300,000 babies in the U.S will be born prematurely and cared for in neonatal intensive care units (NICUs). Monitoring vital signs in these babies has not changed much in 50 years, relying on stiff electrodes glued to the skin using strong adhesives coupled to long wires tethered to boxes on the wall. For tiny neonates, these wires prevent skin-to-skin contact and bonding, frustrate basic nursing care, and often lead to serious skin injury; 90 percent of NICU babies will have scars from the very same medical equipment keeping them alive. The multidisciplinary research team of engineers, neonatologists, nurses, and dermatologists have developed a low-cost, skin-like, wireless sensors capable of ICU-grade monitoring. No-touch technologies like this are essential in a pandemic such as the COVID–19 outbreak, and would not be possible without the ongoing and sustained investment in clinical and translational research infrastructure.

Tufts University

The Tufts Clinical and Translational Science Institute (CTSI) is funding a study to assess the effectiveness of a known therapy, called infliximab therapy, to reduce the cytokine storm that causes severe COVID–19 disease, thereby reducing the need to use a ventilator and, most importantly, preventing deaths. Clinical data strongly support the rationale for investigating the efficacy and safety of anti-TNFa therapy in patients at risk for rapid cardiorespiratory decompensation and early mortality from severe COVID–19.

Rapid testing for COVID–19 is essential for keeping people safe and reopening our economy. Toward these goals, Tufts CTSI is funding the development of a point-of care test, essentially a "lab on a chip," that can diagnose both influenza and COVID–19 simultaneously on a large scale so that health providers and the public have the information they need in real time. Moreover, a CTSI-faculty member at the Tufts CTSI partner MIT Institute for Medical Engineering and Science, who worked with a team of MIT colleagues to quickly design an alternative face shield. This new design was made from inexpensive, easily accessible materials, which allowed them to move immediately to mass production. They partnered with a manufacturer in Massachusetts to start production in record time, which has since expanded internationally. They donated the first 100,000 face shields.

The University of Utah

The Utah Center for Clinical and Translational Science and its community affiliate partner, Intermountain Healthcare—have initiated companion trials looking at the impact of hydroxychloroquine on the duration of infectivity (viral shedding) and household acquisition of COVID–19. This study will create a biobank of samples from COVID–19 patients to help better understand the virus and potential treatments. We have collaborated actively with rural and frontier communities in Utah on this study to ensure that all Utahans are able to participate in this and all COVID–19-related research. The Utah Trial Innovation Center and the Vanderbilt Recruitment Innovation Center jointly provided a comprehensive consultation.

The Utah Data Science Service, a collaboration with University of Utah Health, has created a COVID–19 dashboard that is helping the hospital track the impact of this epidemic, understand resource pressures, and plan to safely reopen. It has also helped inform conversations in our State government regarding racial, ethnic, and sociodemographic disparities in the impact of COVID–19. Further, the biomedical informatics core, in collaboration with the University of Buenos Aires is undertaking work to model variations in the Angiotensin Converting Enzyme receptor-a major point of entry for SARS–CoV–2 into cells to cause infection and disease.

[This statement was submitted by Harry P. Selker, MD, MSPH, Chairman, Clinical Research Forum.]

PREPARED STATEMENT OF THE COALITION FOR HEALTH FUNDING

The Coalition for Health Funding—an alliance of over 93 national health organizations representing more than 100 million patients and consumers, health providers, professionals and researchers—welcomes the opportunity to submit this statement for the record about the importance of health funding in the Labor-HHS-Education bill. As a coalition, our member organizations speak with one voice before Congress and the administration in support of a robustly funded Federal health program with the shared goal of improved health and well-being for all. Each member organization has their own funding priorities within the Department of Health and Human Services (HHS), but we are all united in our support of strong, sustained, predictable funding for all Federal agencies and programs across the public health continuum. The Coalition strongly believes that Congress must support a strong 302(b) allocation for the L–HHS appropriations bill to ensure we are working across the spectrum to protect, promote, and improve the health of all Americans.

As this committee and Congress have demonstrated in the past, with strong bipartisan support, HHS agencies have different roles in addressing our nation's mounting health demands. Our priorities, while different are all interconnected, and the public health continuum is only as strong as its weakest link. For example, investment in medical research at the National Institutes of Health (NIH) is important, however scientific research and development alone does not help treat Americans in need. The Food and Drug Administration (FDA) is necessary to provide reasonable guidance and lead innovation in clinical trials, safeguard patients, ensure medical efficacy, and approve new treatments. The Centers for Disease Control and Prevention (CDC), Health Resources and Services Administration (HRSA), Substance Abuse and Mental Health Services Administration (SAMHSA), and Indian Health Service work to ensure we have qualified health professionals who can move discoveries from the discovery pipeline to public health delivery, while supporting Americans who are awaiting new cures, and prevent them from getting sick in the first place. Also, the Agency for Healthcare Research and Quality (AHRQ) provides evidence and communicates what treatments work for patients helping, health professionals deliver the right treatment to right patient at the right time. And finally, the Administration for Community Living works to support those who are aging and those who have disabilities—as well as their caregivers—so that they can live avoid unnecessary costs and live improved lives.

Despite the importance of these agencies and their programs in protecting Americans' lives, Federal spending for public health and health research represents has not kept pace with ever increasing demands. We thank the Committee for supporting increases in the past. We are concerned that the trends over time that have challenged discretionary health spending and leave these critical needs woefully underfunded. The bill has never received a proportional funding increase from previous bipartisan budget deals, and as a result has lost almost $16 billion in purchasing power over the last decade; it would require a 302(b) allocation of $199 billion to return to the fiscal year 2010 level in inflation-adjusted dollars. In fiscal year 2020 health spending was $184.9 billion in discretionary funding, an increase of $4.9 billion over the 2019 enacted level and $43 billion over the President's 2020 budget request. To support robust funding, the 302(b) allocation for the Labor-HHS-Education Subcommittee must be raised to adequately support these important public health funding needs. Most recently, for fiscal year 2020 non-defense discretionary funding received just a 2.8 percent increase in funding when overall non-defense discretionary funding increased by 4.1 percent, leaving important services and activities underfunded by billions of dollars. The Coalition for Health Funding urges appropriators to ensure that the Labor, Health and Human Services, Education, and Related Agencies appropriations bill receives an increase for the 302(b) allocation in fiscal year 2021 that allows these programs to move past the 2010 inflation adjusted amount and into a future of stronger funding.

Addressing research into chronic disease and acute health events that cost American lives, pandemic response, disaster recovery, shoring up our healthcare delivery infrastructure needs, and support for first responders are just some of the challenges on the horizon that complicate the subcommittee's work in fiscal year 2021 that are of great concern to the Coalition for Health Funding. The Coalition strongly believes that COVID–19 pandemic is demonstrating the dire price we are paying for neglecting the public health infrastructure and healthcare preparedness. For instance, Public Health Emergency Preparedness Cooperative Agreement (PHEP) funding has decreased from $939 million in fiscal year 2003 to $675 million in fiscal year 2020 and ASPR's Hospital Preparedness Program (HPP) has been cut from $515 million in fiscal year 2003 to $275 million in fiscal year 2020. These programs are vital to the core infrastructure needed at the Federal, state, and local levels to ensure we are prepared for not only pandemics but other events such as natural disasters, measles outbreaks, and the list goes on and on.

Finally, the Coalition voices our strong advocacy for the Committee and Congress to work together to avoid continuing resolutions (CRs) in appropriations process. The Coalition is deeply concerned that automatic CRs would harm public health and other domestic programs funded through the annual appropriations bills. When the Federal budget process breaks down, and CRs are the norm, it creates dysfunction and disruption across the entire public health continuum. New initiatives, innovations, and hires are put on hold. Procurement cycles lapse. Opportunities are lost and ultimately the American people are hurt. Automatic CRs would only exacerbate this uncertainty and remove the incentives for Congress to complete the appropriations process in a timely manner, we fear automatic CRs would ultimately lead to cuts in health funding, whether the automatic CR would freeze funding at the current year's levels, or require a percentage of cuts.

We hope in your ongoing deliberations on fiscal 2021 and beyond you will recognize the importance of raising the spending caps and consider the costs-both real costs and opportunity costs-of spending cuts, and the value of all public health and health research programs in improving the lives of American families. We look forward to working with the subcommittee in these endeavors, and hope you will turn to the Coalition for Health Funding as a resource in the future.

[This statement was submitted by Angela M. Ostrom, J.D., Executive Director, Coalition for Health Funding.]

PREPARED STATEMENT OF THE COLLEGE ON PROBLEMS OF DRUG DEPENDENCE

Thank you for the opportunity to submit testimony in support of the National Institute on Drug Abuse. The College on Problems of Drug Dependence (CPDD), a membership organization with over 1000 members, has been in existence since 1929. It is the longest standing group of scholars in the U.S. addressing problems of drug dependence and abuse. CPDD serves as an interface among governmental, industrial and academic communities maintaining liaisons with regulatory and research agencies as well as educational, treatment, and prevention facilities in the drug abuse field.

In the fiscal year 2021 Labor-HHS Appropriations bill, we request that the subcommittee provide at least $3 billion above the fiscal year 2020 level for the National Institutes of Health (NIH), and within that amount a proportionate increase for the National Institute on Drug Abuse (NIDA) using the Institute's conferenced level of $1,462,016,000 as NIDA's base budget for Fiscal 2021. In addition, within the NIH total, we request at least $500 million for targeted research on opioid misuse and addiction, development of opioid alternatives, pain management, and addiction treatment, of which at least $250 million is allocated to NIDA and included in its base budget for Fiscal 2021.

We also respectfully request the inclusion of the following NIDA specific report language.

Opioid Initiative. The Committee continues to be extremely concerned about the epidemic of prescription opioids, heroin, and illicit synthetic opioid use, addiction and overdose in the U.S. Approximately 174 people die each day in this country from drug overdose (over 100 of those are directly from opioids), making it one of the most common causes of non-disease-related deaths for adolescents and young adults. This crisis has been exacerbated by the availability of illicit fentanyl and its analogs in many communities. The Committee appreciates the important role that research plays in the various Federal initiatives aimed at this crisis. To combat this crisis, the bill includes at least $250,000,000 for research related to preventing and treating opioid misuse and addiction. With additional funding for NIDA targeted at addressing the opioid epidemic, the Institute's opioid specific allocation should be targeted for the following areas: development of safe and effective medications and new formulations and combinations to treat opioid use disorders and to prevent and reverse overdose; conduct demonstration studies to create a comprehensive care model in communities nationwide to prevent opioid misuse, expand treatment capacity, enhance access to overdose reversal medications, and enhance prescriber practice; test interventions in justice system settings to expand the uptake of medication assisted treatment and methods to scale up these interventions for population-based impact; and develop evidence-based strategies to integrate screening and treatment for opioid use disorders in emergency department and primary care settings.

Methamphetamines and Other Stimulants. The Committee is concerned that, according to the latest data released by the Centers for Disease Control and Prevention, the number of deaths from the drug categories that include methamphetamine and cocaine more than doubled from 2015–2018, leading some to refer to stimulant overdoses as the “fourth wave” of the current drug addiction crisis in America following the rise of opioid-related deaths involving prescription opioids, heroin, and fentanyl-related substances. The Secretary has also stated that methamphetamine is highly addictive and there are no FDA-approved treatments for methamphetamine and other stimulant use. The Committee continues to support NIDA's efforts to address the opioid crisis, has provided continued funding for the HEAL Initiative, and supports NIDA's efforts to combat the growing problem of methamphetamine and other stimulant use and related deaths.

Barriers to Research. The Committee is concerned that restrictions associated with Schedule I of the Controlled Substance Act effectively limit the amount and type of research that can be conducted on certain Schedule I drugs, especially opioids, marijuana or its component chemicals and new synthetic drugs and analogs. At a time when we need as much information as possible about these drugs to find antidotes for their harmful effects, we should be lowering regulatory and other barriers to conducting this research. The Committee directs NIDA to provide a short report on the barriers to research that result from the classification of drugs and compounds as Schedule I substances including the challenges researchers face as a result of limited access sources of marijuana including dispensary products.

Raising Awareness and Engaging the Medical Community in Drug Abuse and Addiction Prevention and Treatment. Education is a critical component of any effort to curb drug use and addiction, and it must target every segment of society, including healthcare providers (doctors, nurses, dentists, and pharmacists), patients, and families. Medical professionals must be in the forefront of efforts to curb the opioid crisis. The Committee continues to be pleased with the NIDAMED initiative, targeting physicians-in-training, including medical students and resident physicians in primary care specialties (e.g., internal medicine, family practice, and pediatrics). NIDA should continue its efforts in this space, providing physicians and other medical professionals with the tools and skills needed to incorporate substance use and misuse screening and treatment into their clinical practices.

Marijuana Research. The Committee is concerned that marijuana public policies in the states (medical marijuana, recreational use, etc.) are being changed without the benefit of scientific research to help guide those decisions. NIDA is encouraged to continue supporting a full range of research on the health effects of marijuana and its components, including research to understand how marijuana policies affect public health.

Electronic Cigarettes. The Committee understands that electronic cigarettes (e-cigarettes) and other vaporizing equipment are increasingly popular among adolescents, and requests that NIDA fund research on the use and consequences of these devices. The Committee also supports the Population Assessment of Tobacco and Health (PATH) Study, a collaboration between NIDA and the U.S. Food and Drug Administration (FDA) Center for Tobacco Products to help scientists learn how and why people start using tobacco products, quit using them, and start using them again after they have quit, as well as how different tobacco products affect health outcomes over time.

In addition, we request the following report language within the Office of the Director account:

The HEALthy Brain and Child Development (BCD) Study. The Committee recognizes and supports the NIH HEALthy Brain and Child Development Study, which will establish a large cohort of pregnant women from regions of the country significantly affected by the opioid crisis and follow them and their children for at least 10 years. This knowledge will be critical to help predict and prevent some of the known impacts of pre- and postnatal exposure to drugs or adverse environments, including risk for future substance use, mental disorders, and other behavioral and developmental problems. The Committee recognizes that the BCD Study is supported in part by the NIH HEAL Initiative?, and encourages other NIH Institutes, such as NICHD, NIMH, NHLBI, NCI, NIAAA, NIMH, NINR, as well as the Office of the Director to support this important study.

Drug abuse is costly to Americans; it ruins lives, while tearing at the fabric of our society and taking a financial toll on our resources. Over the past three decades, NIDA-supported research has revolutionized our understanding of addiction as a chronic, often-relapsing brain disease -this new knowledge has helped to correctly emphasize the fact that drug addiction is a serious public health issue that demands strategic solutions.

NIDA supports a comprehensive research portfolio that spans the continuum of basic neuroscience, behavior and genetics research through medications development and applied health services research and epidemiology. While supporting research on the positive effects of evidence-based prevention and treatment approaches, NIDA also recognizes the need to keep pace with emerging problems. We have seen encouraging trends in strategies to address these problems, but areas of continuing significant concern include the recent increase in lethalities due to heroin and synthetic fentanyl, as well as continued abuse of prescription opioids. Our knowledge of how drugs work in the brain, their health consequences, how to treat people already addicted, and what constitutes effective prevention strategies has increased dramatically due to research. However, since the number of individuals who are affected is still rising, we need to continue the work until this disease is both prevented and eliminated from society.

We understand that the fiscal year 2021 budget cycle will involve setting priorities and accepting compromise, however, in the current climate we believe a focus on substance abuse and addiction deserves to be prioritized accordingly. Thank you for your support for the National Institute on Drug Abuse.

PREPARED STATEMENT OF THE CONGRESSIONAL FIRE SERVICES INSTITUTE

Dear Chairman Blunt and Ranking Member Murray,

On behalf of the nation's fire and emergency services, we write to urge your support for a vital program addressing the health and safety of our nation's firefighters. As you consider the fiscal year 2021 Labor, Health and Human Services, Education, and Related Agencies Appropriations bill, we urge you to fully fund the National Firefighter Registry at the authorized level of $2.5 million. We very much appreciate the program being funded at this level in fiscal year 2020 and we ask that it be maintained this year.

During the 115th Congress, both the House and Senate unanimously approved the Firefighter Cancer Registry Act (Public Law 115–194). The bipartisan legislation created a specialized national registry to provide researchers and epidemiologists with the tools and resources needed to improve research collection activities related to the monitoring of cancer incidence among firefighters.

Studies have indicated a strong link between firefighting and an increased risk of several major cancers. However, certain studies examining cancer risks among firefighters have been limited by the availability of important data and relatively small sample sizes that have an underrepresentation of women, minorities, and volunteer firefighters. As a result, public health researchers are unable to fully examine and understand the broader epidemiological cancer trends among firefighters. The National Firefighter Registry is an important resource to better understand the link between firefighting and cancer, potentially leading to better prevention and safety protocols.

Thank you for your consideration, and your continued leadership and support for America's fire and emergency services.

Sincerely,

Congressional Fire Services Institute
International Association of Arson Investigators
International Association of Fire Chiefs
International Association of Fire Fighters
International Fire Service Training Association
International Society of Fire Service Instructors
National Fallen Firefighters Foundation
National Fire Protection Association
National Volunteer Fire Council

[This statement was submitted by Michaela Campbell, Director of Government Affairs, Congressional Fire Services Institute.]

PREPARED STATEMENT OF THE CONSORTIUM OF SOCIAL SCIENCE ASSOCIATIONS

On behalf of the Consortium of Social Science Associations (COSSA), I offer this written testimony for inclusion in the official committee record. For fiscal year 2021, COSSA urges the Committee to appropriate:

—$44.7 billion for the National Institutes of Health;
—$8.3 billion for the Centers for Disease Control and Prevention, including $189 million for the National Center for Health Statistics;
—$471 million for the Agency for Healthcare Research and Quality;
—$658.3 million for the Bureau of Labor Statistics;
—$670 million for the Institute of Education Sciences; and
—$106.1 million for the Department of Education's International Education and Foreign Language programs.

First, allow me to thank the Committee for its long-standing, bipartisan support for scientific research. Strong, sustained funding for all U.S. science agencies is essential if we are to make progress toward improving the health and economic competitiveness of the nation. The need for increased investment in science has become even more pronounced in light of the ongoing COVID–19 emergency. It is important to note that the enclosed requests are for baseline budgets for fiscal year 2021 and, without supplemental funding, will not be sufficient in making the agencies and programs whole once the pandemic subsides and Federal agencies return to regular activity.

NATIONAL INSTITUTES OF HEALTH

COSSA joins the more than 330 organizations in support of $44.7 billion for the National Institutes of Health (NIH) in fiscal year 2021. COSSA appreciates the Subcommittee's leadership and its long-standing bipartisan support of NIH, especially during difficult budgetary times. However, recent public health events continue to underscore the need for additional investment. This funding level is important for NIH's baseline, but as previously stated, will not be enough to solve the present COVID–19 emergency and prepare for future public health crises.

To be truly transformative, NIH will need to continue to embrace research from a wide range of scientific disciplines, including the social and behavioral sciences. The Office of Behavioral and Social Sciences Research (OBSSR), housed within the Office of the NIH Director, coordinates basic, clinical, and translational research in the behavioral and social sciences in support of the NIH mission, and co-funds highly rated grants in the behavioral and social sciences in partnership with individual institutes and centers. Unfortunately, OBSSR's budget has been held roughly flat for several years despite the sizable increases to the NIH budget. Knowledge about contagion and social influences on health are needed now more than ever. In addition, understanding behavioral influences on health is needed to battle the leading causes of morbidity and mortality, namely, obesity, heart disease, cancer, AIDS, diabetes, age-related illnesses, accidents, substance abuse, and mental illness. We urge Congress to emphasize support for OBSSR and encourage NIH to increase the Office's budget in fiscal year 2021.

CENTERS FOR DISEASE CONTROL AND PREVENTION

COSSA urges the Subcommittee to appropriate $8.3 billion for the Centers for Disease Control and Prevention (CDC), including $189 million for CDC's National Center for Health Statistics (NCHS). Social and behavioral science research plays a crucial role in helping the CDC carry out this mission by informing the CDC's behavioral surveillance systems, public health interventions, and health promotion and communication programs that help protect Americans and people around the world from disease. As the Department of Health and Human Services' principal statistical agency, NCHS produces data on all aspects of our healthcare system, including opioid and prescription drug use, maternal and infant mortality, chronic disease prevalence, healthcare disparities, emergency room use, health insurance coverage, teen pregnancy, and causes of death. As a result of the rising costs of conducting surveys and years of flat or near-flat funding, NCHS has had to focus nearly all of its resources on continuing to produce the high-quality data that communities across the country rely on to understand their health. Additional funding would allow NCHS to respond to rising costs, declining response rates, and an ever-more complex healthcare system and capitalize on opportunities surrounding advances in statistical methodology, big data, and computing to produce better information more quickly and efficiently, while reducing the reporting burden on local data providers.

Agency for Healthcare Research and Quality

COSSA urges the Subcommittee to appropriate $471 million for the Agency for Healthcare Research and Quality (AHRQ), which would allow AHRQ to rebuild portfolios terminated as a result of years cuts and expand its research and training portfolio to address our nation's pressing and evolving healthcare challenges. AHRQ funds research on improving the quality, safety, efficiency, and effectiveness of America's healthcare system. It is the only agency in the Federal government with the expertise and explicit mission to fund research on improving healthcare at the provider level (i.e., in hospitals, nursing homes, and other medical facilities). Its work is complementary—not duplicative—of other HHS agencies and requires robust support, especially in these trying times.

BUREAU OF LABOR STATISTICS

COSSA urges the Subcommittee to appropriate $658.3 million for the Bureau of Labor Statistics (BLS) for its core programs. BLS produces economic data that are essential for evidence-based decisionmaking by businesses and financial markets, Federal and local officials, and households faced with spending and career choices. The BLS, like every Federal statistical agency, must modernize in order to produce the gold standard data on jobs, wages, skill needs, inflation, productivity and more that our businesses, researchers, and policymakers rely on so heavily. The requested funding level would allow BLS to continue to support evidence-based policymaking, smart program evaluation, and confident business investment.

INSTITUTE OF EDUCATION SCIENCES

COSSA requests $670 million for the Institute of Education Sciences (IES) in fiscal year 2021. Within the Department of Education, IES supports research and data to improve our understanding of education at all levels, from early childhood and elementary and secondary education, through higher education. Research further examines special education, rural education, teacher effectiveness, education technology, student achievement, reading and math interventions, and many other areas. IES-supported research has improved the quality of education research, led to the development of early interventions for improving child outcomes, generated and validated assessment measures for use with children, and led to the establishment of the What Works Clearinghouse for education research, highlighting interventions that work and identifying those that do not. With increasing demand for evidence-based practices in education, adequate funding for IES is essential to support studies that increase knowledge of the factors that influence teaching and learning and apply those findings to improve educational outcomes.

INTERNATIONAL EDUCATION AND FOREIGN LANGUAGE PROGRAMS

The Department of Education's International Education and Foreign Language programs play a major role in developing a steady supply of graduates with deep expertise and high-quality research on foreign languages and cultures, international markets, world regions, and global issues. COSSA urges a total appropriation of $106.1 million ($95.7 million for Title VI and $10.4 million for Fulbright-Hays), which would help make up for lost investment and purchasing power over many years of flat-funding. In addition to broadening opportunities for students in international and foreign language studies, such support would also strengthen the nation's human resource capabilities in strategic areas of the world that impact our national security and global economic competitiveness.

Thank you for the opportunity to present this testimony on behalf of the social and behavioral science research community.

[This statement was submitted by Wendy Naus, Executive Director, Consortium of Social Science Associations.]

PREPARED STATEMENT OF THE CORPS NETWORK

Dear Chairwoman DeLauro, Chairman Blunt, Ranking Member Cole, and Ranking Member Murray,

On behalf of The Corps Network, our 131 member Corps, and the 25,000 Corpsmembers they annually engage, thank you for your hard work in fiscal year 2020 and for the opportunity to share our priorities in fiscal year 2021.

As far back as the 1930s, Conservation Corps have been helping the Federal land management agencies complete important and necessary projects in a high quality and cost-effective manner. The Civilian Conservation Corps (CCC) enrolled approximately 3 million young men from 1933–1942; built more than 125,000 miles of roads, 47,000 bridges, 318,000 dams, and 3,000 fire towers; planted nearly 3 billion trees; and developed more than 3 million acres for public use in 854 state and 94 national parks. The CCC was disbanded in 1942.

Today's 21st Century Conservation Service Corps provide Corpsmembers with opportunities for hands-on job experience, to earn certifications, and skills development in leadership, problem-solving and teamwork. By partnering with businesses, schools and training organizations, Corps help address local workforce needs and create pathways to employment while continuing to undertake priority projects at all levels of government.

We respectfully request that you support these fiscal year 2021 funding levels for programs that support Corps across the country and generate significant return on investment for our communities and people:

—Corporation for National and Community Service—AmeriCorps—$545,000,000
—Corporation for National and Community Service—VISTA—$131,000,000
—Corporation for National and Community Service—NCCC—$42,000,000
—Corporation for National and Community Service—State Service Commissions—$21,000,000
—Corporation for National and Community Service—National Service Trust—$276,000,000
—Department of Labor—Job Corps—US Forest Service—$1,868,655,000
—Department of Labor—YouthBuild—$127,500,000
—Department of Labor—Adult and Youth Training Grants (WIOA)—$2,929,323,600
—Department of Health and Human Services—Community Services Block Grant—$798,000,000

Corporation for National and Community Service

While there are many critical priorities under your jurisdiction, CNCS programs like AmeriCorps meet some of the most vital public needs in rural and urban communities around the country, leverage significant additional private funding and resources through locally-based organizations, and save the government money in the long run. A recent study put the return on investment in AmeriCorps at 4:1. Especially in a difficult fiscal environment, an investment of taxpayer resources in a proven, local partnership-based effort like this makes sense.

AmeriCorps invests in local, cost-effective, public-private partnerships like Corps that generate significant private matching funds. In fact, AmeriCorps programs generate more private resources than the Federal investment, making this an important partnership to attract additional support for important local needs and more effectively using taxpayer resources. Corps utilize AmeriCorps to help make local, state, and Federal Government more efficient and effective by "putting service to work" on a variety of cross-jurisdictional projects and leveraging limited government funds.

Last year alone, Corps engaged over 25,000 youth and veterans in conservation-related service in all 50 states and DC, Puerto Rico, and American Samoa. For example, in fiscal year 2019 Corps built, improved, or maintained 13,317 miles of multi-use trails and waterways; restored 1.4 million acres of wildlife and fish habitat; cleared 66,929 acres of invasive species; removed 19,405 acres of hazardous fuels; increased access to and utilization of 7,914 recreational facilities; responded to 223 wildfires and other natural disasters; preserved 336 historic structures, and planted almost 1.1 million trees. Further, they leveraged an additional 107,000 volunteers who completed 537,879 service hours valuing over $13.6 million dollars.

Corps and AmeriCorps State and National Grants

Corps have enrolled AmeriCorps members from the beginning: during the first full year of AmeriCorps in 1994, 53 Corps received AmeriCorps grants. Today, Corps receive AmeriCorps State & National grants that are competitively awarded. The AmeriCorps competitive grants category includes grants to organizations operating in one state only (state) and organizations operating in more than one state (multi).

Corps also receive funding through their Governor-appointed State Service Commissions—the state partners of the Corporation for National and Community Service (CNCS).

Education Award Program (EAP)

In the last 5 years, roughly 14,700 Corpsmembers have enrolled in The Corps Network (TCN) Education Award Program. EAP members work on Environmental Stewardship projects in hundreds of communities across more than 40 states and DC. Project partners include U.S. Forest Service, National Park Service, Bureau of Land Management, U.S. Fish & Wildlife Service, as well as state and local partners.

Opportunity Youth Service Initiative (OYSI)

Since 2015, over 3,500 Corpsmembers have enrolled into TCN's Opportunity Youth Service Initiative (OYSI) Program. The OYSI Program is designed to engage youth from disadvantaged backgrounds (e.g. economically disadvantaged, unemployed, past court involvement, physical or learning disability) in education and conservation service. During their term of service, Corpsmembers develop job skills, earn certifications, complete their high school requirements, and receive assistance in transition to postsecondary education or the workforce.

Transportation and Infrastructure Program (TIP)

The Transportation Infrastructure Program (TIP) supports AmeriCorps members completing public lands and transportation infrastructure projects in multiple communities across 13 states. Since 2019, 156 Corpsmembers have enrolled in the TIP.

AmeriCorps Disaster Response Teams (A–DRT)

AmeriCorps Disaster Response Teams (A–DRT) are a nationally deployable asset that engage in critical activities in all phases of the disaster cycle. The Corporation for National and Community Service's Disaster Services Unit administers the A–DRT AmeriCorps program, serving as the coordinating entity for all deployments and ensuring appropriate integration into the Incident Command Structure (ICS). Corpsmembers receive technical training, have the ability to travel with their own gear and equipment, and are a cost-effective solution to meeting important recovery needs.

AmeriCorps National Civilian Community Corps (NCCC)

AmeriCorps National Civilian Community Corps (NCCC) is a member of The Corps Network. AmeriCorps NCCC is a full-time, residential, team-based program for young adults ages 18–24. Members develop leadership skills, gain life experience, and strengthen communities by completing service projects. Many NCCC members will start off in NCCC and transition to a Corps, or vice-versa. NCCC crews are also critical to disaster response and recovery, and help support other Corps projects. Corps coordinate with regional NCCC offices on work plans.

Department of Labor Programs Supporting Corps

—Job Corps (US Forest Service)—The US Forest Service operates JCCCC's focused on conservation careers and education. They offer a proven pathway for disconnected youth to gain education and conservation job skills and to get back on track. Several Centers administer Advanced Fire Management Training Programs. While working on prescribed burns and other non-suppression activities, these students earn Public Land Corps non-competitive hiring eligibility and gain valuable experience in wildland fire.

—Department of Labor Adult & Youth Training Grants (WIOA)—Congress updated the Workforce Investment Act (WIA) to prioritize serving disconnected youth, achieving long-term outcomes, and enhancing work-based learning, career pathway, and service opportunities. Corps provide these critical workforce services in communities across the U.S.

—YouthBuild—Corps are a statutorily eligible applicant for YouthBuild grants and manage a significant number throughout the country. YouthBuild enrolls low-income young people who work toward their GED/high school diploma while learning construction skills by building housing for low-income people.

—Community Services Block Grant—Corps can be administered by Community Action Agencies. They also often partner with States and Community Action Agencies to carry out projects funded by this grant.

As you can see, CNCS and DOL support many important initiatives that engage a diverse population of youth serving in Corps including veterans, Native youth and individuals with disabilities. Through your support, we can provide more service opportunities for our youth and veterans to reengage in education, hard work, and their communities and get on a productive path for America's continued growth and prosperity.

Thank you for the opportunity to provide written testimony for the record. We again respectfully urge your support for CNCS fiscal year 2021 and increased funding for these critical programs for thousands of communities and every state around the country. Thank you for your time and consideration of this testimony.

Sincerely.

[This statement was submitted by Mary Ellen Sprenkel, President & CEO, The Corps Network.]

PREPARED STATEMENT OF THE COUNCIL OF ACADEMIC FAMILY MEDICINE

The member organizations of the Council of Academic Family Medicine (CAFM) are pleased to submit testimony on behalf of programs under the jurisdiction of the Health Resources and Services Administration (HRSA) and the Agency for Healthcare Research and Quality (AHRQ). CAFM collectively includes family medicine medical school and residency faculty, community preceptors, residency program directors, medical school department chairs, research scientists, and others involved in family medicine education. We urge the Committee to appropriate at least $60 million for the Primary Care Training and Enhancement program, authorized under Title VII, Section 747 of the Public Health Service Act HRSA. In addition, we recommend the Committee fund the AHRQ at a level of at least $471 million and $5 million dedicated to AHRQ's Center for Primary Care Research.

More than 44,000 primary care physicians will be needed by 2035, and current primary care production rates will be unable to meet the demand, according to the authors of a recent article in Annals of Family Medicine (Petterson, et al Mar/Apr 2015). The primary care training and enhancement programs and AHRQ research enhance our nation's workforce and health infrastructure, improving primary care services that produce better health outcomes and reduce healthcare costs.

Primary Care Training and Enhancement—Title VII

The Primary Care Training and Enhancement Program (Title VII, Section 747 of the Public Health Service Act) has a long history of funding training of primary care physicians. As experimentation with new or different models of care continues, departments of family medicine and family medicine residency programs will rely further on Title VII, Section 747, grants to help develop curricula and research training methods for transforming practice delivery. Future training needs include: training in new clinical environments that include integrated care with other health professionals (e.g. behavioral health, care coordination, nursing, oral health); development and implementation of curricula to give trainees the skills necessary to build and work in inter-professional teams that include diverse professions; and development and implementation of curricula to develop leaders and teachers in practice transformation. Moreover, new competencies are required for our developing health system.

The Advisory Committee on Training in Primary Care Medicine and Dentistry December 2014 report states that "[r]esources currently available through Title VII, Part C, sections 747 and 748 have decreased significantly over the past 10 years, and are currently inadequate to support the [needed] system changes." [1] In order to address some of these challenges, the Advisory Committee recommended that Congress increase funding levels for training under the primary care training health professions program to meet the pent-up demand caused by reduced and stagnant funding levels. We are pleased that Congress increased spending for primary care training and enhancement in fiscal year 2018 and continued such funding. We are hopeful that the Committee will realize the need for continued and increased funding to allow for a more extensive support across the nation for schools and residency programs whose trainees are on the forefront of addressing challenges in primary care.

Primary care health professions training grants under Title VII are vital to the continued development of a workforce designed to care for the most vulnerable populations and meet the needs of the 21st century. We urge your continued down payment for this program and an increase in funding levels to $60 million in fiscal year 2021 to allow for a robust competitive funding cycle.

This funding level will help continue important Title VII programs such as The Preparing Primary Care Trainees to Transform Health Care Systems program at the Kirksville College of Osteopathic Medicine in Missouri. This program uses grant

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[1] http://www.hrsa.gov/advisorycommittees/bhpradvisory/actpcmd/Reports/eleventhreport.pdf.

funding to create enhanced primary care didactics, contextual clinical learning activities and assessments and leadership tracks to prepare students and facility for practice in changing and diverse health systems.

Agency for Health Care Research and Quality (AHRQ)

Primary care clinical research is a core function of AHRQ. Primary care research includes: translating science into patient care, better organizing healthcare to meet patient and population needs, evaluating innovations to provide the best healthcare to patients, and engaging patients, communities, and practices to improve health. AHRQ has proved to be uniquely positioned to support best practice primary care research and to help disseminate the research nationwide. However, reduced levels of AHRQ funding in the past have exacerbated disparities in funding primary care research.

AHRQ is in a unique position to further primary care clinical research as well as the implementation science to identify how to deploy new knowledge into the hands of primary care providers and systems in communities. However, more funding is needed to accomplish these goals. For this reason, we are supporting additional overall funding increases for fiscal year 2021 to the level of $471 million as well as specific funding for the Center for Primary Care Research of $5 million to help coordinate and direct primary care research funding at AHRQ. We hope additional funding will continue and expand the following goals: (1) development of clinical primary care research and researchers (2) real world application of evidence, (3) the process of practice and health system transformation, (4) how high functioning primary care systems and practices should look, (5) how primary care practices serving rural and other underserved populations adapt and survive, and (6) how health extension systems serve as connectors of research institutions with practices and communities.

AHRQ research is used by practices and universities across the nation. This funding level will help continue important programs such as the one at University of Washington. The University of Washington used funding from AHRQ to develop a system to incorporate Patient-Reported Outcomes (PRO) into clinical assessments and decisionmaking leading to improved patient-provider communication, patient satisfaction, and treatment monitoring. The project employs systems engineering methods, human-centered design, and mixed-research methods to develop more effective integration of PRO data into patient care activities through health information technology.

Highlighting the success of AHRQ's patient safety initiatives, a 2014[2] report showed hospital care to be much safer in 2013 compared to 2010. The report noted a decline of 17 percent in hospital-acquired conditions, in harm to 1.3 million individuals, as well as 50,000 lives saved, and $12 billion in reduced health spending during that period. AHRQ supports this research that is essential to create a robust system for our nation that delivers quality of care while reducing the rising cost of care.

In AHRQ's recent report, "Potentially Preventable Readmissions: Conceptual Framework to Rethink the Role of Primary Care," AHRQ rethinks primary care as an "integrator" able to work alongside sub-specialty physicians and hospitals to provide more comprehensive care. Most hospital readmissions occur within the 14-day window that a patient is supposed to follow up with their primary care doctor. By involving the primary care team during hospitalization and in the subsequent 14-day window, hospital readmissions can be significantly reduced. However, to accomplish this goal, AHRQ needs increased funding.

CAFM is grateful Congress included report language in fiscal year 2020 stating that Congress "supports primary care clinical research and dissemination as a core function of AHRQ." As we look to the future, this core function can only be expanded by increasing the funding of the agency as a whole, and supporting specific funding for the Center for Primary Care Research at AHRQ to provide a true coordinating center for primary care research at AHRQ.

Enhanced Funding for COVID–19 Recovery

COVID–19 has created both short and longer-term primary care needs. The following items merit funding to help our research and training infrastructures adjust to COVID related primary care needs.

AHRQ Funding $130 Million

—$80 million—for telehealth questions and general broad-based study on training needs (workforce).

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[2] Publication # 15–0011–EF.

—$50 million—on questions of deferred primary care, practice changes and training and supervision, physical and emotional burden on providers, patients, community; analyses regarding reduction—what services found aren't really necessary, but used for billing purposes, special needs for rural and underserved areas.

Title VII Section 747 Funding $125 Million

—Funding for both residencies and departments—faculty retention, public health competencies, recruit and retain students into primary care, develop new curriculum in this regard; other curriculum related to pandemic, and address segmented primary care workforce in an effort to reduce delivery system division and increase full scope primary care providers.

In conclusion, we support increased funding for AHRQ at the level of $471million for fiscal year 2021 which would support important primary care and health services research efforts. We also support $5 million in new funding for the Center for Primary Care Research.

CAFM looks forward to working with the Subcommittee to protect HRSA primary care programs and AHRQ—both entities which enhance our nation's primary care workforce and infrastructure.

[This statement was submitted by Deborah S. Clements, MD, FAAFP, Chair, Council of Academic Family Medicine.]

PREPARED STATEMENT OF THE COUNCIL OF STATE AND TERRITORIAL EPIDEMIOLOGISTS

Chairman Blunt, Ranking Member Murray, and members of the subcommittee, I am Janet Hamilton, Executive Director at the Council of State and Territorial Epidemiologists (CSTE). CSTE is organization of 56 member states and territories representing applied public health epidemiology and serves as the professional home for over 2,000 applied public health epidemiologists nationwide. As the subcommittee works on the fiscal year 2021 Labor, Health and Human Services, Education, and Related Agencies appropriations bill, we respectfully request that you appropriate at least $100 million to the Centers for Disease Control and Prevention's (CDC) Public Health Scientific Services for the Data Modernization Initiative that will transform public health and save lives.

As part of a multi-billion dollar investment over the next decade, sustained annual funding of at least $100 million will allow CDC and public health departments to move from sluggish, manual, paper-based data collection to seamless, automated, interoperable, and secure data systems that yield critical health information in real-time. This funding would also modernize the public health workforce by training, recruiting, and retaining skilled data scientists. Data systems require adept staff to use them, maintain them, interpret the data, and develop and deploy actionable public health interventions to save lives.

The COVID–19 pandemic has acutely highlighted that public health threats are persistent and consistently evolving here at home and overseas. Effective prevention and efficient, timely, responses rely on the integrated network of governmental public health agencies at the Federal, state, local, tribal, and territorial levels working with healthcare providers and the public. Each day, this network saves lives by monitoring the health of the population and detecting, investigating, and responding to health threats.

Unfortunately, the nation's public health data systems are antiquated, rely on obsolete information sharing methods and are in dire need of security upgrades. Lack of interoperability, reporting consistency, and data standards leads to errors in quality, completeness, timeliness, and communication. Sluggish, manual processes—paper records, phone calls, spreadsheets, and faxes requiring manual data entry—still in widespread use have important consequences, most notably delayed detection and response to public health treats of all types: chronic, emerging, and urgent.

COVID–19 has highlighted significant gaps in today's public health infrastructure:

—Lack of seamless, interoperable data sharing across public health partners

  —Data on COVID–19 cases are managed electronically at the state/local public health department, but cannot be seamlessly shared with CDC. Data are often re-keyed to report critical details from states to the CDC; manual efforts are time consuming; data may not be submitted for days despite it being stored in an electronic system.

  - —Data collection and transmission for persons under investigation is manual: pen and paper, Excel spreadsheets, phone calls to healthcare providers and laboratories and from state/local public health to CDC.
- —No process to order COVID–19 laboratory tests electronically
  - —The process for submitting specimens for testing is entirely paper-based requiring multiple phone calls to assign person under investigation numbers, and complete paperwork for laboratory submission;
  - —All test results are returned via manual processes—phone calls and faxes-and must be manually entered by staff.
- —No electronic case reporting to share data between healthcare and public health
  - —Healthcare providers already have basic clinical data of COVID–19 patients (symptoms, pregnancy status, hospitalization, ICU status) stored and collected in electronic health records but are submitting paper forms and are unable to rapidly share these data or submit electronic case reports to public health; data must be hand entered into databases. Delays occur, and providers are often too busy to manually submit these critical data for days or at all.
- —Emergency departments do not participate in public health syndromic surveillance systems
  - —Approximately 30 percent of all emergency department visits are not submitted to CDC's National Syndromic Surveillance Program; urgent care data are almost entirely absent.
  - —Early detection of COVID–19 through patients presenting at emergency departments was missed.
- —Paper filing of death certificates
  - —Some states still file death certificates on paper requiring them to be manually requested and processed by the health department;
  - —There is no link between medical examiners/coroner's data systems to the public health department.

These gaps lead to slow, cumbersome data exchanges resulting in sluggish efforts to respond effectively with the speed and intensity the COVID–19 pandemic demands.

Public health professionals, providers, policymakers, and the public will all agree that we need a 21st Century public health surveillance system to protect health. In fiscal year 2020, Congress made an important initial down payment of $50 million in new funds to launch the Data Modernization Initiative. CSTE and our partners in this effort—APHL, NAPHSIS, and HIMSS—represent a diverse group of patients, consumers, public health professionals, healthcare providers, and health systems. We encourage you to continue to prioritize the Data Modernization Initiative at CDC and public health departments. Public health data systems have fallen behind over the past decade because crosscutting resources have not been available, and we must not allow this initial $50 million investment become obsolete. We must build upon the improvements made and continue to provide adequate resources for public health to implement advance technologies and train the next generation of data scientists.

In your ongoing deliberations on fiscal year 2021 and beyond, CSTE hopes you will consider the Data Modernization Initiative. Data and workforce are the lifeblood of public health action. This effort must continue to be funded with new money, rather than supplant with already underfunded public health programs. A robust, sustained commitment to transform today's public health data system will ultimately improve Americans' health. We look forward to working with the subcommittee in these endeavors and hope you will turn to the CSTE as a resource in the future.

[This statement was submitted by Janet Hamilton, Executive Director, Council of State and Territorial Epidemiologists.]

PREPARED STATEMENT OF THE COUNCIL ON SOCIAL WORK EDUCATION AND NATIONAL ASSOCIATION OF SOCIAL WORK

Dear Chairman Blunt and Ranking Member Murray,

On behalf of the Council on Social Work Education (CSWE) and the National Association of Social Work (NASW), thank you for your continued support of the social work profession and social work education. CSWE is a nonprofit national association representing over 800 accredited baccalaureate and master's degree social work programs, as well as individual social work educators, practitioners, and agencies dedicated to advancing quality social work education. NASW represents the social work profession, supporting the professional growth and development of its 120,000 members by creating and maintaining professional standards, and advancing sound social policies. We appreciate your efforts and leadership on issues that impact social work, social work education, and the wellbeing of individuals, families, and communities and social and economic justice.

We encourage you to consider the following appropriations requests that will support social work in the fiscal year 2021 appropriations process. Federal funding helps strengthen the pipeline of social workers, addresses the needs of vulnerable and at-risk populations, and supports students, including those from disadvantaged backgrounds. Social worker practice in a diversity of fields including child advocacy, geriatrics, school social work, healthcare and other fields. As policymakers continue to focus on the social determinants of health, support for social workers, who are the workforce at the center of addressing these social factors, will be critical.

Our organizations strongly support efforts to boost critical funding at the Department of Health and Human Services for behavioral health initiatives, including the Community Mental Health Services Block Grant, the National Child Traumatic Stress Network, the Centers for Disease Control and Prevention, Substance Abuse and Mental Health Services Administration, and Health Resources and Services Administration programs.

Below are the funding CSWE and NASW request for critical programs in fiscal year 2021. We respectfully ask for your support of these requests during the fiscal year 2021 appropriations process.

HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

—$790 million for the HRSA Title VII: These programs improve access to and quality of care for vulnerable populations. Public health threats continue to impact patients across the country, such as substance use disorder epidemics. Titles VII programs are essential to addressing the health challenges of today and the future.

—$30 million for the Mental Health and Substance Use Disorder Workforce Training Demonstration Program: CSWE and NASW support funding for interprofessional training, including social workers, Nurse Practitioners, Physician Assistants, and health service psychologists. It is vital that the Demonstration supports the training of all eligible providers, including social workers, to ensure that mental and substance use disorder services in underserved community-based settings integrate primary care and mental and substance use disorders services.

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

—$757.5 million for Community Mental Health Services Block Grant

—$2.3 billion for Substance Abuse Prevention and Treatment Block Grant

—$38.5 billion in emergency funding to organizations that primarily treat individuals with behavior health concerns and/or Substance Use Disorders and use evidence-based practices, with a significant portion of these emergency funds set aside for organizations enrolled in Medicaid as a result of the COVID–19 epidemic.

DEPARTMENT OF EDUCATION

—$7,000 in fiscal year 2021 for the maximum individual Pell Grant. The Pell Grant Program is the foundation of financial aid for low-income students. Unfortunately, the purchasing power of the Pell Grant has continuously declined since the program's inception in the 1970s, shouldering students with a growing share of the cost of college.

—Support for Public Service Loan Forgiveness (PSLF) Programs.

NATIONAL INSTITUTES OF HEALTH (NIH)

—$44.7 billion for the National Institutes of Health.

Sincerely.

[This statement was submitted by Darla Spence Coffey, PhD, MSW, President and Chief Executive Officer, Council on Social Work Education and Angelo McClain, PhD, LICSW, Chief Executive Officer, National Association of Social Workers.]

PREPARED STATEMENT OF THE COUNCIL ON SOCIAL WORK EDUCATION

Dear Chairman Blunt and Ranking Member Murray,

On behalf of the Council on Social Work Education (CSWE), thank you for your continued support for social work and social work education. CSWE is a nonprofit national association representing over 800 accredited baccalaureate and master's degree social work programs, as well as individual social work educators, practitioners, and agencies dedicated to advancing quality social work education. We appreciate your efforts and leadership on issues that impact social work, social work education, and the wellbeing of individuals, families, and communities and social and economic justice.

We encourage you to consider the following appropriations requests that will support social work programs and social work students in the fiscal year 2021 appropriations process. Pressing societal challenges like the opioid crisis and other substance-use issues, growing mental and behavioral health needs, workforce shortages, and rising higher education costs, are just some of the challenges facing social work students and practitioners. Your support of these appropriations requests will help meet these challenges.

Federal funding helps strengthen the pipeline of social workers, addresses the needs of vulnerable and at-risk populations, and supports students, including those from disadvantaged backgrounds. Social work students go on to work in a diversity of fields including child advocacy, geriatrics, school social work, healthcare and other fields. As policymakers continue to focus on the social determinants of health, support for social workers, who are the workforce at the center of addressing these social factors, will be critical. CSWE's fiscal year 2021 requests (as detailed below) illustrate support for important programs that address vital health workforce needs, provide invaluable student aid, address the social determinants of health, and promote important health-care research.

Below is the funding CSWE supports for critical programs in fiscal year 2021. We respectfully ask for your support of these requests during the fiscal year 2021 appropriations process.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

—$116.280 million for HRSA's Behavioral Health Workforce Education and Training (BHWET) program. CSWE was pleased to see continuous investments for the BHWET program in the fiscal year 2020 Labor-HHS-ED appropriations bill. BHWET supports the recruitment and education of behavioral health-care providers, which is critical as the nation continues to combat the opioid crisis and substance use disorders. The number of training programs supported by BHWET has grown tremendously over the past several years, particularly amongst social workers. According to a June 2018 HRSA study, out of the 4,618 behavioral health professionals participating in the BHWET program, 3,523 included new social workers.[1] In 2018, a new four-year competition awarded social work programs over $17 million a year to help develop and expand the behavioral health workforce serving populations across the lifespan, including in rural and medically underserved areas. As the nation's demand for well-equipped behavioral health-care providers continues to grow, we hope you will support $116,280,000 million for BHWET in fiscal year 2021.

—$58.675 million for Scholarships for Disadvantaged Students. This program helps ensure that the United States has the pipeline of health professionals to meet health needs of underserved individuals and communities. Furthermore, this program provides much needed opportunities for students from disadvantaged backgrounds.

—$51 million for the Geriatrics Workforce Enhancement Program (GWEP). GWEP supports training and educating health professionals, including social workers, as well as direct care workers, and family caregivers in the care of older adults. It is the only Federal program that focuses on developing a health-care workforce that maximizes patient and family engagement while improving

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[1] Closing Behavioral Health Workforce Gaps: A HRSA Program Expanding Direct Mental Health Service Access in Underserved Areas; American Journal of Preventive Medicine.

health outcomes for older adults. GWEPs are successfully integrating and equipping a primary care workforce and family caregivers with the knowledge and skills to care for older adults and build community networks to address gaps in healthcare for seniors.

—$10 million for continued support of a demonstration program to strengthen the mental and substance disorders workforce.

—$25 million for continued support of the Loan Repayment Program for Substance Use Disorder Treatment Workforce.

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

—$15.70 million for the Minority Fellowship Program (MFP). For more than 45 years, MFP has been increasing the number of professionals preparing for leadership roles in mental health and substance use fields and working to reduce health disparities and improve behavioral health-care outcomes for racial and ethnic populations. CSWE appreciates increased investments in the MFP in fiscal year 2020, particularly focused on addiction medicine to address the opioid crisis. CSWE urges the committee to include $15.70 million for the MFP in fiscal year 2021.

DEPARTMENT OF EDUCATION

—$7,000 in fiscal year 2021 for the maximum individual Pell Grant. Pell Grants are critical to ensuring access and affordability in higher education. CSWE also supports increasing the amount of Pell funding that is supported by mandatory spending. Student aid programs, particularly grant programs, represent important investments and help students avoid crushing debt burdens when they graduate.

—Support for Public Service Loan Forgiveness (PSLF) Programs. PSLF is an integral program to ensuring a pipeline of professionals in public service serving in high-needs areas. CSWE encourages Congress to continue support for this vital program and programs like the Temporary Expanded Public Service Loan Forgiveness (TEPSLF), which assists public service workers who were enrolled in ineligible loan repayment programs. In addition to continuing support for PSLF, CSWE asks Congress to continue oversight of how the Department of Education is implementing the program.

—$35 million in fiscal year 2021 for The Graduate Assistance in Areas of National Need (GAANN) program. The Graduate Assistance in Areas of National Need (GAANN) program provides fellowships through institutions of higher education to assist graduate students with financial need pursue a degree in a field designated as an area of national need as determined by the Secretary. Since 2012, an academic area related to health professions has been designated once. It is estimated that more than 18 percent of the U.S. adult population has suffered from any mental illness. Mental health is clearly an area of national need.

NATIONAL INSTITUTES OF HEALTH

—$44.7 billion for the National Institutes of Health (NIH). CSWE appreciate the continued support from Congress and the increased funding for NIH. To build on the advances in research, CSWE hopes you will support continued investments in biomedical and health-related research that incorporates the social and behavioral science research necessary to better understand and address the needs of high-risk populations including children, minority, and geriatric populations.

Sincerely.

[This statement was submitted by Darla Spence Coffey, PhD, MSW, President and Chief Executive Officer, Council on Social Work Education.]

PREPARED STATEMENT OF THE CREUTZFELDT-JAKOB DISEASE FOUNDATION

Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee:

On behalf of the Creutzfeldt-Jakob Disease (CJD) Foundation, we appreciate the opportunity to submit this testimony in strong support for funding of the crucial prion disease work being undertaken by the Centers for Disease Control and Prevention in partnership with public health agencies around the country and the National Prion Disease Pathology Surveillance Center (NPDPSC).

The CJD Foundation is a patient advocacy organization for those affected by Prion Diseases. We work closely with families, physicians, researchers, and public health officials to ensure that all possible efforts are taken to prevent acquired forms of the disease. Given the importance of prion surveillance to public health, we are extremely disappointed to see that the President's budget proposal would eliminate the $6 million appropriation to the Centers for Disease Control and Prevention (CDC) for prion disease. Indeed, the growing threat posed by Chronic Wasting Disease (CWD), a widespread prion disease of deer and elk, has placed additional strains on the CDC's limited prion disease resources and warrants a budgetary increase. As such, we are requesting that the budget for prion disease surveillance be restored and increased to $7 million to appropriately deal with emerging prion disease threats occurring within our borders.

OVERVIEW

Creutzfeldt-Jakob Disease (CJD), is a 100 percent fatal, degenerative brain disease that causes rapidly progressive dementia, memory loss, visual disturbances, motor skill impairments, and involuntary movements. Patients most often progress from initial symptoms to death in less than a year. CJD, caused by "prion" proteins, is transmissible and presently has no treatment or cure. Approximately 1 in 6,000 individuals die from this disease; however, the number of unreported and undiagnosed cases remains unclear.

CJD/Prion Disease surveillance receives modest support through the Centers for Disease Control and Prevention (CDC), Center for Emerging and Zoonotic Diseases. The Administration's budget has proposed eliminating Prion Disease Surveillance in fiscal year 2021. We need your support to strengthen and continue the coordination of prion disease surveillance and to protect the safety of the American public and the nation's food supply.

VARIANT CJD AND BOVINE SPONGIFORM ENCEPHALOPATHY

One form of Prion Disease in humans, variant CJD (vCJD), is known to be caused by ingesting beef contaminated with Bovine Spongiform Encephalopathy (BSE), more commonly known as "mad cow" disease. The most recent U.S. case of variant CJD was announced in 2013 and confirmed by the National Prion Disease Pathology Surveillance Center (NPDPSC) in 2014.

Limited BSE testing by the USDA adds another layer to the already deepening concerns regarding possible risks to humans. In recent years, the USDA has decreased random testing for BSE from 40,000 to 25,000 tests per year (12,719 tests in 6 months, or 1 test per 3,302 live cows). Hence, surveillance of BSE in this country is largely dependent on demonstrating the lack of transmission to humans through human disease surveillance. The vCJD case identified by NPDPSC in 2014 exemplifies the persistent risk for vCJD acquired in unsuspected geographic locations and highlights the need for continuing prion surveillance and awareness to prevent further dissemination of vCJD.

CHRONIC WASTING DISEASE

Most recently, emerging laboratory data show that a prion disease of deer and elk called Chronic Wasting Disease (CWD) could potentially transmit to humans and other mammals, posing a new threat to public health. Human surveillance through brain tissue examination is the only way to definitely diagnose human prion diseases, determine their origin, and determine whether the spread of CWD found in elk and deer in 26 states in the U.S. and in 3 Canadian provinces has become a human risk. A study in progress has shown that CWD was transmitted to macaques (primates that are genetically similar to humans) by feeding them contaminated deer meat.

Unlike the BSE outbreak in cattle, CWD prions are highly infectious and are transmitted via direct contact and through contamination of the environment, including soil and plants. Additionally, multiple lines of experimental evidence indicate that sheep and cows are susceptible to CWD. Since CWD has been proven to cross the species barriers, this opens up the possibility of oral transmission to humans as well, either directly by eating contaminated venison or indirectly through infected domestic animals.

Additional concerns include widespread and long-term prion contamination of the environment given that prions can persist for decades and the vector of this illness (e.g., deer) are free ranging animals that are difficult to impossible to cull. Continued prion disease surveillance, particularly through examination of human brain tissue, is imperative to evaluate whether CWD has or can spread to humans. If transmissible to humans, the possibility of transmission between individuals via blood transfusions must also be investigated as transmission through blood is known to occur in vCJD. Hence now is NOT the time to remove funding for prion disease surveillance, rather it should be increased to appropriately deal with these emerging threats.

The NPDPSC, funded by the CDC and located at Case Western Reserve University in Cleveland, Ohio, is our line of defense against the possibility of an undetected U.S. human prion disease epidemic as experienced in the United Kingdom.

We ask for Congressional support in increasing the National Prion Disease Pathology Surveillance Center's (NPDPSC) appropriation for fiscal year 2021 by $1 million, for a total of $7 million. This would allow the NPDPSC to meet increasing autopsy costs and continue to develop more efficient detection methods while providing an acceptable level of human prion disease surveillance. Reduction of funding to the NPDPSC would eliminate an important safety net to U.S. public health, making the U.S. the only industrialized country lacking prion disease surveillance, which in turn would jeopardize the export of U.S. beef. The increase in funding would allow the NPDPSC to expand its scope to address the growth in Chronic Wasting Disease (CWD) among deer and elk and explore whether CWD could spread to humans.

NATIONAL PRION DISEASE PATHOLOGY SURVEILLANCE CENTER

The NPDPSC is funded entirely by the CDC from funds allocated by Congress. The CDC traditionally keeps approximately half of the appropriation for CDC and state public health activities, and half goes to the NPDPSC; however, this is changing as more states require CDC support due to the increasing incidence of CWD in new locations.

Increasing the 2020 appropriation from $6.0M to $7.0M will allow the NPDPSC to persist and continue to develop more efficient detection methods while providing an acceptable level of prion surveillance. Acceptable national prion surveillance would not be possible at a lower level of funding. The requested $1.0M addition to the appropriation (total of $7.0M) would enable the NPDPSC to increase surveillance, tissue collection, diagnostics and diagnostic test development of prion disease cases from CWD endemic states to determine whether CWD is transmissible to humans and if so, to what extent this poses a threat to public health (e.g., transmission risks from human to human).

The National Prion Disease Pathology Surveillance Center is the only organization in the U.S. that monitors human prion diseases and is able to determine whether a patient acquired the disease through the consumption of prion contaminated beef ("mad cow" disease) or meat from elk and deer affected by chronic wasting disease (CWD).

The NPDPSC also monitors all cases in which a prion disease might have been acquired by infected blood transfusion, from the use of contaminated surgical instruments or from contaminated human growth hormone. Because standard hospital sterilization procedures do not completely inactivate prions that transmit the disease, these incidents put a number of patients under unnecessary risk and required costly replacement of contaminated surgical equipment.

The NPDPSC also plays a decisive role in resolving suspected cases or clusters of cases of food-acquired prion disease that are often magnified by the media, stirring intense public alarm. To date, the NPDPSC has examined over 7,208 suspected cases of prion disease and has definitely confirmed the presence and type of prion disease in more than 4,399 cases.

The NPDPSC represents the primary line of defense in safeguarding U.S. public health against prion diseases because the U.S.—unlike other BSE affected countries such as the United Kingdom, the European Union, and Japan—does not have a sufficiently robust animal prion surveillance system.

The NPDPSC's work offers assurances, to countries that import (or are considering importing) meat from the U.S., that the U.S is free of indigenous human cases of "mad cow" disease. In recent years, South Korean and Chinese health officials resumed importation of U.S. beef to their country after a visit to the NPDPSC provided assurances regarding rigorous human prion surveillance.

Thank you for the opportunity to submit this testimony.

[This statement was submitted by Deborah R. Yobs, President/Executive Director, CJD Foundation.]

PREPARED STATEMENT OF THE CURE ALZHEIMER'S FUND

Chairman Blunt, Ranking Member Murray, and members of the Senate Labor, Health & Human Services, Education, and Related Agencies Appropriations Subcommittee, I am Tim Armour, President and CEO of Cure Alzheimer's Fund. I want to thank Congress for past funding for Alzheimer's disease research at the National Institutes of Health (NIH), and to submit this written testimony to respectfully request at least an additional $354 million in fiscal year 2021 above the final enacted amount for fiscal year 2020 for Alzheimer's disease research at the NIH.

Additionally, Cure Alzheimer's Fund respectfully requests at least $500 million in total appropriations for the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative. The BRAIN Initiative is poised to play an important imaging role in the early detection and diagnosis of Alzheimer's disease.

Cure Alzheimer's Fund is a national nonprofit, based in Massachusetts, that funds research with the highest probability of preventing, slowing or reversing Alzheimer's disease. Since its founding 15 years ago, Cure Alzheimer's Fund has invested more than $107 million in research through more than 460 grants. Cure Alzheimer's Fund has supported research ideas that have become more widely accepted such as the role of the innate immune system, a better understanding of protein expression and subtle changes in the brain at various stages of the disease, and the better understanding of a lymphatic/drainage system in the brain.

A sustained Federal investment, as the one established by this Subcommittee in recent years, allows Cure Alzheimer's Fund to support initial research that can then be supported by larger grants from the NIH. Continued investment in NIH presents opportunities for new ideas and researchers to be able to secure funding necessary for continued progress in unlocking the secrets of Alzheimer's disease. As we learn more about the disease, new researchers, both young investigators and established researchers from other disciplines, are entering the field. Continued, robust investment in Alzheimer's disease research will allow these additional researchers to be able to pursue important new understandings of the pathology and development of Alzheimer's disease.

This Subcommittee has demonstrated its commitment to Alzheimer's disease research at NIH through recent sustained increases in the NIH budget. And for this commitment, Cure Alzheimer's Fund expresses its thanks and appreciation.

The sustained support from this Subcommittee allows for organizations such as Cure Alzheimer's Fund to focus on early-stage research knowing that researchers will be able to seek NIH funding at a scale larger than Cure Alzheimer's Fund offers for individual projects. The "hand-off" from Cure Alzheimer's Fund to NIH is an important part of the process to getting therapeutic interventions tested, validated, and ultimately into the clinic to change the course of the disease for the millions of Americans and individuals around the world who are afflicted.

As Dr. Francis Collins, Director of the NIH, mentioned at the House LHHSE Subcommittee NIH hearing on March 4, 2020, one of the most promising areas of Alzheimer's disease research is the role of the innate immune system in the development of Alzheimer's disease. Cure Alzheimer's Fund is at the forefront of this research.

As far back as 2010, Cure Alzheimer's Fund has supported research into the beta-amyloid protein and its role in fighting infection. At that time, I stated that this type of creative research does not often receive Federal funding. However, NIH sees the importance of this research and has convened meetings (September 23–24, 2019) around the topic of infection and viruses in the development of Alzheimer's disease. This would not have happened without early investment in research and the availability of larger-scale research funding made possible by this Subcommittee.

https://curealz.org/news-and-events/abeta-may-have-beneficial-function-as-part-of-the-innate-immune-system/.

https://www.nia.nih.gov/about/naca/january-2020-directors-status-report.

Research has shown that the pathology of Alzheimer's disease begins long before symptoms appear. Because of this, it is very important to be able to determine what happens at each stage in Alzheimer's disease development. Research into protein expression and epigenetics is providing insight into the subtle changes in the brain that could be early markers for the development of Alzheimer's disease. The Cure Alzheimer's Fund CIRCUITS program is a multi-laboratory consortium that brings together researchers and institutions from various fields for a better understanding of the development of Alzheimer's disease and the changes it causes in the brain.

https://curealz.org/news-and-events/circuits-a-consortium-approach-to-understanding-the-epigenetics-of-alzheimers/.

Researchers and scientists are still learning new things about the brain. In the past, I have highlighted the work of Jonathan Kipnis and the role of the brain lymphatic system, but knowing it is an important area of concern for the Subcommittee, I want to mention it again.

Dr. Kipnis' work showed that the brain lymphatic system acts as a type of drain in the brain to be able to remove debris. Continued research in this area shows that this brain lymphatic system may also be a way to have therapies enter the brain and pass through the blood-brain barrier. We are also learning that this brain lymphatic system works better when people are asleep, which has implications for the research being done on circadian rhythms and their impact on a number of health conditions.

https://curealz.org/news-and-events/a-new-discovery-the-brain-has-a-drain-to-remove-debris/.

https://curealz.org/research/foundational-genetics/berg-brain-entry-and-exit-consortium-human-3d-neurovascular-interaction-and-meningeal-lymphatics-models-with-application-to-alzheimers-disease/.

The understanding that Alzheimer's disease pathology begins long before symptoms appear, discoveries of brain systems, and a better understanding of subtle changes in the brain at the onset of Alzheimer's disease pathology benefit not only investment at NIH, but also investment in the BRAIN Initiative.

As we learn more about the brain, we will learn more about neurodegenerative conditions including Alzheimer's disease. Better imaging tools will allow for researchers to be able to detect changes in the brain. An improved "brain map" will allow researchers to be better able to see changes in the brain and be able to compare brains, since every human brain is different. Additionally, better assessment tools such as non-radiological tracers and improved cognitive assessments will improve early detection and diagnosis of Alzheimer's disease.

https://curealz.org/research/immune-system-structures/neuroimmune-molecular-imaging-redefining-the-landscape-of-opportunities-in-alzheimers-disease-2/.

https://directorsblog.nih.gov/2019/10/08/multiplex-rainbow-technology-offers-new-view-of-the-brain/.

Progress is being made in the fight against Alzheimer's disease, and this progress is the direct result of partnerships between private organizations and NIH. There are many exciting and important discoveries happening right now in Alzheimer's disease research. Discoveries that will need access to sustained Federal investment to be able to move from the laboratory to the marketplace. Now is not the time turn away from the important commitment this Subcommittee has demonstrated.

Thank you for your continued support of Alzheimer's disease research, and for the opportunity to submit this written testimony and to respectfully request at least an additional $354 million above the final enacted level in fiscal year 2020 for fiscal year 2021 for Alzheimer's disease research at NIH, and at least $500 million in total appropriations for the BRAIN Initiative. Cure Alzheimer's Fund has worked closely with the Subcommittee in the past and looks forward to being your partner as we work toward Alzheimer's disease research having the necessary resources to end this awful disease.

[This statement was submitted by Timothy Armour, President and CEO, Cure Alzheimer's Fund.]

Prepared Statement of the Deadliest Cancers Coalition

The Deadliest Cancers Coalition is a collaboration of national nonprofit organizations focused on addressing issues related to our nation's most lethal cancers. We appreciate the opportunity to submit this statement in support of strengthening the Federal investment in deadliest cancers research conducted and supported by the National Institutes of Health (NIH) and the National Cancer Institute (NCI).

Deadliest cancers are defined by the Recalcitrant Cancer Research Act (aka RCRA and Public Law 112–239) as those with a five-year relative survival rate below 50 percent. While any cancer with a survival rate below 50 percent is considered part of this group, it is notable that the definition currently includes seven site-specific cancers: brain, esophageal, liver, lung, ovarian, pancreatic, and stomach as well as mesothelioma.

We deeply appreciate Congress' continued strong leadership in support of cancer research through the steady increases you have provided to the NIH and NCI over the last 5 years. We are also grateful for the new dedicated fiscal year 2020 funding Congress provided to address a significant decline in the success rate for research project grant (RPG) applications at NCI. For fiscal year 2021, the Deadliest Cancers Coalition respectfully requests at least $44.7 billion for NIH, a $3 billion increase over the fiscal year 2020 level. For NCI, we request $6.9 billion, which is the amount proposed by NCI in its fiscal year 2021 professional judgment budget and would provide an increase for the NCI which is proportional to our overall request for NIH.

A recent report showed that the $30.82 billion that NIH awarded for research grants in fiscal year 2019 supported 475,905 jobs and $81.22 billion in national economic activity. Medical research funding is going to continue to be essential, not just to the patients who are counting on the treatments and early detection tools that will be developed as a result, but also as part of a plan to reboot the economy after the pandemic.

At the start of this year, the media highlighted reports that the U.S. cancer death rate declined by 29 percent from 1991 to 2017, including a 2.2 percent drop from 2016 to 2017, the largest single-year drop in cancer mortality ever reported. While this achievement is worthy of celebration, and is directly attributable to NIH and NCI supported research, it masks the fact that we still have few if any screening or early detection tools or treatments for those who have been diagnosed with one of the deadliest cancers.

In fact, the deadliest cancers offer a powerful example of the need for continuing the path of sustained and robust increases for the NIH and NCI. While the overall five-year relative survival rate for all cancers combined has risen from 50 percent when the War on Cancer was first declared in 1971 to 67 percent today, we have seen relatively little success in improving survival for the deadliest cancers. Multiple myeloma is one of the few "success" stories among this group as the five-year survival rate was 34 percent when the coalition was founded in 2008 and is now 54 percent. As the table below demonstrates, the prognosis for those with one of the deadliest cancers is far below the current average.

FIVE YEAR SURVIVAL RATES FOR THE DEADLIEST CANCERS COMPARED TO THE OVERALL CANCER SURVIVAL RATE

(2008–2020)

	Est. 2020 5-Year Survival Rates	Est. 2008 5-Year Survival Rate
Brain	34%	35%
Esophageal	20%	16%
Liver	18%	11%
Lung	19%	15%
Myeloma *	54%	34%
Ovarian	48%	45%
Pancreas	10%	5%
Stomach	32%	24%
ALL CANCERS	67%	66%

* Myeloma "graduated" out of the deadliest cancers in 2016 when its survival rate reached 50 percent.

Congress passed the RCRA to encourage the NCI to identify specific areas of research that could speed progress in the deadliest cancers as well as opportunities for the public and private sectors to work together to achieve these goals. Specifically, it required that the NCI develop a long-term strategic plan for addressing recalcitrant cancers beginning with pancreatic adenocarcinoma and small-cell lung cancer. The statute requires that the NCI provide regular updates on the implementation of these "scientific frameworks" through the annual Congressional Justifications and requires a report to Congress due later this year that evaluates the effectiveness of the frameworks that were created.

The NCI has made progress in implementing the statute, particularly with respect to pancreatic adenocarcinoma and small-cell lung cancer, and has also begun a scientific-framework-like process for glioblastomas. In late 2018, NCI signaled its intention to also begin discussions on other cancers, however, it is unclear whether those discussions are leading to the NCI-led meetings with the broader scientific community necessary for progress. There is still much that needs to be done for all of these cancers. It is therefore vital that Congress continue to shine a light on all recalcitrant cancers so that they do not slip back into the shadows.

The Deadliest Cancers Coalition deeply appreciates the inclusion of report language focusing on these cancers in years past, including the fiscal year 2020 language that directed NCI to develop a scientific framework using the process outlined in the RCRA for stomach and esophageal cancers. The fiscal year 2020 language also urged the Institute to continue to support research with an emphasis on developing screening and early detection tools and more effective treatments for all recalcitrant cancers. The NCI's response in the fiscal year 2021 Significant Items shows that while they are certainly supporting a range of research projects that support advancements in some of the deadliest cancers, there is no information on how they are addressing Congress' instructions to begin a scientific framework process for stomach and esophageal cancers.

We are therefore requesting that the Subcommittee include language in the fiscal year 2021 LHHS Appropriations bill that holds NCI accountable to the fiscal year

2020 language and to the goals and ideals of the RCRA. Specifically, in addition to ensuring that NCI moves forward with plans for stomach and esophageal cancers, it is critical that NCI also specifies how it will continue the goals of the RCRA to develop and implement strategic plans for the full range of recalcitrant cancers.

The 2012 legislation was first introduced by Senator Whitehouse and Representatives Anna Eshoo and Leonard Lance because it was clear that just following "standard procedure" with respect to the recalcitrant cancers was not working and that there needed to be a specific focus on determining research priorities for these diseases. That need has not diminished. The Deadliest Cancers Coalition has submitted report language to Subcommittee that we believe will meet these goals and assist our members in their conversations and collaboration with NCI on working together to improve survival.

The Deadliest Cancers Coalition was founded because we believe that every patient diagnosed with cancer should have at least a 50 percent chance at survival. Unfortunately, in 2020, nearly half of all cancer-related deaths will be due to one of the deadliest cancers—a statistic that is largely unchanged since we were founded. We clearly still have a long road ahead of us to see more cancers "graduate" out of being considered a recalcitrant cancer. We therefore urge the Subcommittee to continue its leadership to ensure that NIH receives $44.7 billion for fiscal year 2021 and $6.9 billion for the NCI and that you continue to hold the Institute accountable to making progress on the deadliest cancers through report language in the fiscal year 2021 bill.

[This statement was submitted by Megan Gordon Don, Executive Director, Deadliest Cancers Coalition.]

PREPARED STATEMENT OF THE DISABILITY ADVOCACY ALLIANCE

Disability Advocacy Alliance (DAA) is a 501(c)(3) organization that works to protect the rights of individuals with intellectual and developmental disabilities (I/DD) in Ohio. We support a full continuum of residential and employment options, including Intermediate Care Facilities for Individuals with Intellectual Disability (ICFs) and Home and Community Based Services (HCBS). We disagree with the notion that community is defined by the arbitrary label of a Medicaid funding source. Rather, DAA families know that community is defined by the loving homes and relationships our family members build with their family, friends, and caregivers. DAA writes in support of legislative and report language submitted by VOR that:

—Prohibits the use of appropriations for a Protection & Advocacy (P&A) System to bring a lawsuit against an ICF/IID, unless the affected individuals and their legal guardians have been provided reasonable notice of the lawsuit.

—Prohibit states from using MFP funds or its resulting Federal Assistance Matching Percentage (FMAP) to override beneficiary choice and be used by a state to finance and abet the closure of an ICF/IID and the transfer of its residents, or to financially incentivize private providers to close or reduce the number of beds in their ICF/IID facilities.

FEDERAL LAW SUPPORTS RESIDENTIAL CHOICE FOR I/DD BENEFICIARIES

The foundational U.S. Supreme Court *Olmstead* decision makes individual need and choice paramount:

> "But we recognize, as well, the States' need to maintain a range of facilities for the care and treatment of persons with diverse mental disabilities, and the States' obligation to administer services with an even hand." (*Olmstead v. L.C.* 527 U.S. 581, 597)
>
> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle and benefit from community settings...nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it. (*Olmstead*, 601–602)
>
> "Each disabled person is entitled to treatment in the most integrated setting possible for that person recognizing that, on a case-by-case basis, that setting may be in an institution." (*Olmstead*, 605)

Medicaid law gives beneficiaries the right to choose between an institutional or community setting. 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C.§ 1396n(c)(2)(C)

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) recognizes that individuals with I/DD and their families are the primary decision-makers regarding services.

> "Individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive, including regarding choosing where the individuals live from available options, and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families." DD Act, 42 U.S.C. § 15001(c)(3)(2000).

PROTECTION & ADVOCACY SYSTEMS

The DD Act requires that states receiving Federal financial assistance under the Act have in place a Protection & Advocacy (P&A) System to protect and advocate the rights of individuals with (I/DD). 42 USC § 10543. P&As are funded by the U.S. Department of HHS through its agency, the Administration on Community Living (ACL). P&As protect the rights of individuals who access community services, but they attack the rights of individuals with severe I/DD who need and choose intensive care in intermediate care facilities for individuals with intellectual disability (ICFs/IID). P&As advocate for ICF/IID closures regardless of the interests of the Medicaid beneficiaries they are charged to protect. A favorite tool of P&As is the class action lawsuit. States are often wary of becoming involved in costly litigation, and so many will settle a class action before providing a proper defense. Often, simply the threat of litigation is enough to cause states to implement policies to limit ICFs/IID and restrict access to them.

Ohio families have spent 4 years fighting a P&A class action, *Ball v. Kasich* (2:16-cv-282) (2016) that was brought by Disability Rights Ohio (DRO) against Ohio's ICF/IID program. DRO threatened litigation in Fall 2014. Just the threat of litigation caused the State to close two state ICFs/IID and institute policies to force downsizings and closures of private ICFs/IID. Families objected strongly, filing over 21,000 hardcopy petition signatures with the state legislature. Despite this express support for the ICF/IID program, the P&A still filed suit against the State even though its goals and priorities are to take into consideration the comments of its constituents. 42 USC § 15043(a)(2)(D)(i) & (ii). Widespread ICF/IID closures were only prevented by the intervention of a group of ICF/IID families into the lawsuit. The judge recognized the importance of families' efforts when he allowed their intervention. In his Order of July 25, 2017, the judge stated that the rights of individuals who want to remain in their ICF/IID homes or who may need an ICF/IID in the future were not protected until the families filed their Motion to Intervene.

A P&A action in Illinois, *Ligas v. Maram* (1:05-cv-04331) (2005), was opposed just as vociferously by ICF/IID families when an overwhelming number of families objected to the class settlement, causing the judge to overturn the settlement, order the intervention of ICF/IID families, and allow families to be part of negotiations for a new settlement. As with *Ball* in Ohio, families' intervention in *Ligas* was crucial to protecting the rights of ICF/IID residents.

In a third P&A case from Utah, *Christensen v. Miner* (2:18-cv-00037) (2018), the state of Utah did not even offer a defense to the class action. The State began settling the class action almost immediately upon its filing. By the time ICF/IID families were aware of the lawsuit and understood its affects, it was too late to mount a defense. Families sent hundreds of letters to the Court objecting to the settlement, but the settlement was approved with the requirement that Utah's ICF/IID bed census would be reduced by 30 percent, to 465 total beds from 650.

These examples show the importance of VOR's language request so that families are notified of litigation from the start so that they can act to protect the rights of their disabled loved ones.

MONEY FOLLOWS THE PERSON

MFP (Money Follows the Person) is a program of the U.S. Department of HHS' Centers for Medicaid & Medicaid Services (CMS). It was enacted to rebalance states' Medicaid service systems toward community settings, but for I/DD systems, this goal was realized long ago. Today, MFP has become a favorite tool of P&As and other anti-ICF/IID groups like the ARC to close institutional settings. In December 2019, the CEO of the ARC stated, "We applaud elected officials who understand the value of MFP, core to our mission to advance community living and close all institutions."[1] Such activity, however, goes against a statutory goal of the MFP program, "to enable Medicaid-eligible individuals to receive support for appropriate and nec-

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[1] https://thearc.org/huge-victory-for-community-living-for-people-with-disabilities-agreement-in-congress-to-commit-to-money-follows-the-person-program/.

essary long-term services in the settings of their choice."[2] (Emphasis added.) The following examples exhibit how MFP is used to override beneficiary choice:

Ohio used MFP to help fund transitions of residents from two state run ICFs/IID. The State moved to close the facilities in response to threats of litigation from the P&A. MFP and the enhanced FMAP were also used by the State to give financial incentives to private providers[3] to close and reduce their ICF/IID facilities.

New York announced that it would undertake sweeping ICF/IID closures of both state run and private ICFs/IID reducing system capacity by over 6,000 ICF/IID beds. Only 150 state run ICFs beds and 456 private ICFs beds will be open after completion of the New York's MFP plan.[4] With such mass closings, beneficiary choice can not be protected.

Texas used MFP funds to incentivize private ICF/IID providers to engage in what they termed "voluntary closures" of their ICF/IID facilities. The state of Texas provided this mock example in "The Texas Money Follows the Person Demonstration Operational Protocol,"

> "Management of ABC Place invited all residents and their family members/LARs to a meeting on November 14, 2007 to discuss the possibility of closing ABC Place and what the impact would be for the residents. (See footnote 5.)
>
> "Ms. Johnson indicated at that time that she was most comfortable with Jim residing in a large community ICF/IID and was very angry about the closure."[5]

The fact that the state of Texas proposed this particular mock example in preparing for its MFP implementation shows that Texas likely anticipated angry reactions of ICF guardians to the news of facility closures.

Wisconsin used MFP to implement its "ICF restructuring Initiative." 28 ICFs were closed with 936 individuals losing their ICF homes. Only 135 ICF/IID residents remained.[6] Again, with such mass closings, beneficiary choice cannot be respected.

VOR's language request will ensure that MFP is used as it was intended, to aid transitions initiated at the choice of beneficiaries.

CONCLUSION

If beneficiary choice is followed, Medicaid participants with I/DD will lead happier and safer lives, as individuals and their families will always be the most motivated to protect health and welfare. While the advent of community services has helped a large portion of the I/DD community, there will always be a portion of the I/DD community with severe and profound needs that require intensive supports (i.e. nursing, therapy, psychological services, medical oversight). For individuals with complex needs, these services are most practically, economically, and safely provided in large congregate settings like ICFs/IID where sharing of resources across patients can take place. Families understand all of this instinctively as they know better than anyone what is involved in the care of their loved ones, physically, emotionally, and socially. Expanding community services should never come at the expense of the health and safety of America's most fragile citizens. Ensuring that appropriations for P&A and MFP programs are used in ways that honor statutory requirements to respect beneficiary choice will protect lives.

PREPARED STATEMENT OF THE DISABILITY RIGHTS EDUCATION & DEFENSE FUND

Dear Chairman Blunt, Ranking Member Murray and Committee Members,

The Disability Rights Education & Defense Fund (DREDF) appreciates the opportunity to submit this testimony regarding necessary funding for the Parent Training and Information Centers (PTIs) and Community Parent Resource Centers (CPRCs) under the Individuals with Disabilities Education Act. Thank you for the leadership you have provided in beginning to address the needs of students and families during the COVID–19 pandemic. It is more important than ever for this Committee to continue its role of providing leadership to address the needs of students with disabilities and their families.

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[2] Public Law 109–171 § 6071(a)(2).

[3] https://www.ohca.org/uploads/news/The__Future__of__the__ICF–IID__Program__White__Paper.pdf, page 4–5.

[4] Links on NY Office for People with Developmental Disabilities website no longer available, but documentation available upon request.

[5] https://hhs.texas.gov/sites/default/files/documents/laws-regulations/reports-presentations/2018/mfp-operational-protocol-amendment-5.pdf, page 41 & page 42.

[6] https://www.dhs.wisconsin.gov/publications/p01054-16.pdf, page 3 of attachment to cover letter.

As you develop the fiscal year 2021 Labor, Health and Human Services, Education, and Related Agencies Appropriations bill, we request that you provide $30 million to the Parent Information Centers program at the U.S. Department of Education. This request is a slight increase over fiscal year 2020 to support improved services to parents, and is in line with cost of living increases.

We also urge you to provide an emergency, one-time investment of $27.411 million for the PTI program to support children with disabilities and their families as they navigate ensuring access to education during this difficult time. We would further urge that this funding be provided proportionally to each current grantee and that funds be permitted to be expended through the end of September 2021. Additional support is needed as the temporary closure of school buildings, and requirements for social distancing as schools reopen can be traumatic and disruptive to receiving crucial services for children with disabilities and their families.

DREDF was founded in 1979 as a unique alliance of adults with disabilities and parents of children with disabilities. DREDF advances the civil and human rights of people with disabilities through legal advocacy, training, education, and public policy and legislative development. One-third of our work aims to protect and advance the rights of students with disabilities, and promoting their integration into mainstream society.

DREDF operates one of nearly 100 PTIs and CPRCs funded under the PTI program nationwide. DREDF's successful PTI has served three Bay Area counties for 32 years, supporting the role of parents in the education of children with disabilities and working with foster families and county agencies and local and state organizations focused on child welfare. DREDF's Education Advocates (who are also parents of children with disabilities) are in daily contact with California families in the disproportionately low-income and of—color communities in Alameda and Contra Costa counties. They work closely with DREDF's senior and litigation staffs, providing a marginalized community with much-needed access to skilled advocates and attorneys. PTI services are needed now more than ever. A parent recently commented on DREDFs services, "I can't imagine what the quality of our lives would be like without the knowledge I gained from participating in DREDF's workshops for parents and the community."

The current COVID–19 crisis as well as resulting school closures and transition to digital or other curriculum-based learning has presented a challenge for all students. These challenges have been compounded for children with disabilities who may rely on hands-on assistance from teachers or aides which can be difficult to replicate outside of classrooms, particularly amidst social distancing and stay at home order requirements. These disruptions to students' classroom-based learning experiences as well as the very real stress children and families are experiencing during the pandemic itself can be particularly traumatic for some children. PTIs need additional resources to help parents navigate the closure and eventual reopening of school buildings, compensatory services to make up for lost instructional time, and social distancing policies that will likely impact supports and services and equal access to education for their children.

Thank you again for the opportunity to submit comments to the Senate Committee on Appropriations Subcommittee on Labor, Health and Human Services, and Education and Related Agencies for this important topic. We would be happy to address any questions or concerns about the above.

Respectfully.

[This statement was submitted by Susan Henderson, Executive Director, Disability Rights Education & Defense Fund.]

PREPARED STATEMENT OF DUKE HEALTH

Duke Health (the conceptual integration of the Duke University Health System, the schools of Medicine and Nursing, the Private Diagnostic Clinic as the independent, multi-specialty physician practice, and other health and health research centers across Duke University) would like to express appreciation for Federal support provided to academic health centers across the United States, especially in this unprecedented time of the COVID–19 public health emergency. COVID–19 has illustrated how vital the investments from this Subcommittee are for securing a healthcare infrastructure in the United States that can research and develop new vaccines and therapeutics, and provide high-quality care to patients at all times.

Duke Health is committed to conducting innovative basic and clinical research, rapidly translating breakthrough discoveries to patient care and population health, providing a unique educational experience to future clinical and scientific leaders, improving the health of populations, and actively seeking policy and intervention-based solutions to complex global health challenges. Underlying these ambitions is a belief that Duke Health is a destination for outstanding people and a dedication to continually explore new ways to help people grow, collaborate, and succeed.

Reflecting Duke Health's mission of "Advancing Health Together," this written testimony outlines Duke Health's biomedical research and healthcare priorities that represent sound investments in vital programs at HHS that make a difference in the lives of patients across the United States. Thank you for this opportunity to submit written testimony.

NATIONAL INSTITUTES OF HEALTH (NIH)

Duke Health is grateful for Congress' robust investments in NIH, which has kept the United States on the cutting edge of new biomedical advances. For fiscal year 2021, Duke Health respectfully requests at least $44.7 billion for the NIH. This funding would allow for meaningful growth above inflation in the base budget and aid efforts to expand NIH's capacity to support promising science in all disciplines in addition to special initiatives. Labs across the country that were conducting groundbreaking biomedical research have paused due to COVID–19, losing ground on every other disease. As these labs restart, additional resources from NIH will be vital to support the biomedical infrastructure in the United States and to continue biomedical advances. Thoughtful consideration must be given to how this subcommittee can help meet the biomedical research needs for labs and workforce as a result of COVID–19.

At Duke, NIH funding plays a critical role in the advancement of research and clinical care. NIH has supported vital research at the Duke Clinical Research Institute, the world's largest academic research organization working to improve patient care through innovative clinical research; the Duke Human Vaccine Institute, a national and international leader in the fight against major infectious diseases; and the Duke Cancer Institute, a top comprehensive cancer center in peer-reviewed research support.

Duke Health asks the Subcommittee to not include language that would limit the use of nonhuman primates in research that could cripple the search for treatments and cures for many human diseases, especially therapeutics and vaccines for COVID–19.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

The CDC serves as the command center for the nation's public health defense system against emerging and reemerging infectious diseases. Now, more than ever, investments in the nation's public health infrastructure are vital. Duke Health urges the Subcommittee to provide $8.3 billion for the CDC in fiscal year 2021. From aiding in the surveillance, detection and prevention of the Zika virus to playing a lead role in the control of Ebola in West Africa and the current COVID–19 public health emergency, CDC is the world's expert resource and response center, coordinating communications, and serving as the laboratory reference center.

Among its many programs, the Prevention Epicenters Program is a unique research program in which CDC's Division of Healthcare Quality Promotion collaborates with academic investigators to conduct innovative infection control and prevention research. The Duke-UNC Epicenter has considerable experience and research expertise in hospital epidemiology, infection control, antimicrobial stewardship, epidemiologic studies of multidrug-resistant organisms, disinfection, and sterilization. In addition, the Duke Infection Control Outreach Network (DICON) and Duke Antimicrobial Stewardship Outreach Network (DASON) engage over 60 community hospitals in the United States.

Duke Health is grateful for the $2 million increase in fiscal year 2020 for the CDC's Agency for Toxic Substances and Disease Registry. Although this program does not fall under the jurisdiction of this Subcommittee, Duke Health continues to support a robust investment in its activities at the CDC, which are closely linked with the vital activities at the Superfund Research Center at Duke University. This Center receives its funding from the National Institute of Environmental Health Sciences Superfund Research Program at NIH.

HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

Duke Health appreciates the Subcommittee's continued investment in Title VII health professions and training programs and Title VIII Nursing Workforce Development programs at HRSA. These programs ensure a well-trained pipeline of health professionals to meet the increasing health needs facing the United States. For fiscal year 2021, Duke Health respectfully requests that the Subcommittee provide $512 million for Title VII and VIII programs overall, including $278 million to be allocated for Title VIII Nursing Development Workforce Programs. Title VII and Title VIII are the only Federal programs that support education/training opportunities for an array of aspiring and practicing health professionals, both facilitating career opportunities and bringing healthcare services to rural and underserved communities.

Duke Health urges the Subcommittee to provide $23 million in fiscal year 2021 for the National Cord Blood Inventory (NCBI) at HRSA. This program is charged with building a genetically and ethnically diverse inventory of at least 150,000 new units of high-quality umbilical cord blood for transplantation. These cord blood units (CBUs), as well as other units in the inventories of participating cord blood banks, are made available to physicians and patients for blood stem cell transplants through the C.W. Bill Young Cell Transplantation Program. Cord blood banks participating in the NCBI Program, including the Carolinas Cord Blood Bank in the Duke University School of Medicine, also make cord blood units available for preclinical and clinical research focusing on cord blood stem cell biology and the use of cord blood stem cells for human transplantation and cellular therapies.

Blood stem cell transplantation is potentially a curative therapy for many individuals with leukemia and other life-threatening blood and genetic disorders. Each year, nearly 18,000 people in the U.S. are diagnosed with illnesses for which blood stem cell transplantation from a matched donor is their best treatment option. Often, the first-choice donor is a sibling, but only 30 percent of people have a fully tissue-matched brother or sister. For the other 70 percent, a search for a matched unrelated adult donor or a matched umbilical cord blood unit must be performed. The success of cord blood stem cell therapies in treating diseases and alleviating suffering makes an urgent and compelling case for funding this program.

Duke Health respectfully requests the Subcommittee provide $30 million for the C.W. Bill Young Cell Transplantation Program through the National Cord Blood Inventory (NCBI) at HRSA in fiscal year 2021. The Carolinas Cord Blood Bank (CCCB) at Duke is a member bank of the National Cord Blood Inventory of the C.W. Bill Young Cell Transplantation Program. The goal of this program is to increase the number of transplants for recipients suitably matched to biologically unrelated donors of bone marrow and umbilical cord blood. The CCBB is one of the largest cord blood banks in the world. Cord blood units that are banked at CCBB are listed on the National Marrow Donor Program (NMDP) Be the Match(r) Registry, an accumulated listing of donated cord blood units from participating banks that are available to provide donors for patients needing a hematopoietic stem cell transplant to treat cancer or certain genetic diseases.

Thousands of mothers have donated their cord blood to the CCBB. Banked units are comprised of African-American, Hispanic-American, Asian-American, and Caucasian samples. This diversity helps patients of all racial and ethnic backgrounds find suitable matches for transplantation. The CCBB has distributed cord blood units for transplantation to several thousand patients since 1999. Cord blood recipients of CCBB units include children and adult patients facing life-threatening illnesses who need a "stem cell" transplant from an unrelated donor to provide them with healthy blood cells. Many of these patients have been affected by leukemia, lymphoma, severe aplastic anemia, or other fatal diseases of the blood or immune system, or certain inherited metabolic diseases. In addition to life-saving transplants, the CCBB also provides cord blood units for research. These units are made available to investigators for critical research in the area of cord blood and stem cell biology. The impact of funding has far reaching impacts, and Duke Health urges the Subcommittee to support this request.

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY (AHRQ)

Duke Health urges the Subcommittee to provide $471 million for the Agency for Healthcare Research and Quality in fiscal year 2021. This funding level is consistent with the fiscal year 2010 level adjusted for inflation and would allow AHRQ to rebuild portfolios terminated as a result of years of past cuts and expand its research and training portfolio to address our nation's pressing and evolving healthcare challenges. As the agency that provides funding for health systems research, AHRQ is vital to improving health, safety and health outcomes for patients. AHRQ is forward thinking, addressing issues such as data analytics, and is providing important resources for healthcare professionals during COVID–19.

Patients with sickle cell disease (SCD), an inherited red blood cell disorder, often have intense pain that brings them to hospital emergency departments (EDs) for immediate treatment. Their care can be fragmented, with frequent hospitalizations and specialist care, infrequent follow-up with primary care doctors, and repeat ED visits. Funding from AHRQ supports activities at the Duke University School of

Nursing to improve the care of these patients in the ED department, particularly through the development and use of evidence-based decision support tools. In addition, AHRQ funding supports the Duke Center for Healthcare Safety and Quality, which works to develop and support quality and safety related roles and committees, training, tools, research, strategies, data and other resources through an interdisciplinary team.

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION (SAMHSA)

Duke Health appreciates investments in the National Child Traumatic Stress Network (NCTSN) grant program at SAMHSA, especially efforts to provide additional funding for this program during COVID–19. For fiscal year 2021 Duke Health urges the Subcommittee to provide $73.9 million for NCTSN.

NCTSN, which is coordinated by the UCLA-Duke University National Center for Child Traumatic Stress, increases access to services for children and families who experience or witness traumatic events. This unique network of frontline providers, family members, researchers, and national partners is committed to changing the course of children's lives by improving their care and moving scientific gains quickly into practice across the U.S. In recent years, estimates from the NCTSN Collaborative Change Project (CoCap) have indicated that each quarter about 35,000 individuals—children, adolescents and their families—directly benefited from services through this Network. Since its inception, the NCTSN has trained more than one million professionals in trauma-informed interventions. Hundreds of thousands more are benefiting from the other community services, website resources, educational products, community programs, and more. Over 10,000 local and state partnerships have been established by NCTSN members in their work to integrate trauma-informed services into all child-serving systems, including child protective services, health and mental health programs, child welfare, education, residential care, juvenile justice, courts, and programs serving military and veteran families.

OFFICE OF THE ASSISTANT SECRETARY FOR PREPAREDNESS AND RESPONSE (ASPR)

Duke Health requests that the Subcommittee provide $11.5 million, full authorized funding, for the Military and Civilian Partnership for the Trauma Readiness Grant Program for fiscal year 2021 within ASPR. Originally known as MISSION ZERO, this critical program would provide funding to ensure trauma care readiness by integrating military trauma care providers into civilian trauma centers. These partnerships allow military trauma care providers to gain exposure to treating critically injured patients in communities and keep their skills sharp to increase readiness for deployment. Additionally, they allow civilian trauma care providers to gain insight into best practices from the battlefield that can be integrated into civilian care. Fully funding this program will help to improve the nation's response to public health and medical emergencies.

Prepared Statement of the Dystonia Medical Research Foundation

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2020

- —Provide $44.7 billion for the National Institutes of Health (NIH) and proportional increases across its Institutes and Centers
- —Continue dystonia research supported by NIH through the National Institute on Neurological Disorders and Stroke (NINDS), the National Institute on Deafness and other Communication Disorders (NIDCD), and the National Eye Institute (NEI).

Dystonia is a neurological movement disorder that causes muscles to contract and spasm involuntarily. It affects men, women and children. Dystonia can be generalized, affecting all major muscle groups, and resulting in twisting, repetitive movements and abnormal postures or focal, affecting a specific part of the body such as legs, arms, hands, neck, face, mouth, eyelids and vocal cords. Currently, it is estimated that at least 300,000 individuals in North America suffer from dystonia, making it more common than Huntington's, muscular dystrophy, and ALS. There is no known cure for dystonia.

DYSTONIA RESEARCH AT THE NATIONAL INSTITUTES OF HEALTH

The Dystonia Medical Research Foundation urges the Subcommittee to continue its support for natural history studies on dystonia that will advance the pace of clinical and translational research to find better treatments and a cure. In addition, we encourage Congress to continue supporting NINDS, NIDCD, and NEI in conducting and expanding critical research on dystonia.

Currently, dystonia research at NIH is supported by the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute on Deafness and Other Communication Disorders (NIDCD), and the National Eye Institute (NEI).

The majority of dystonia research at NIH is supported by NINDS. NINDS has utilized a number of funding mechanisms in recent years to study the causes and mechanisms of dystonia. These grants cover a wide range of research including the genetics and genomics of dystonia, the development of animal models of primary and secondary dystonia, molecular and cellular studies in inherited forms of dystonia, epidemiology studies, and brain imaging. Earlier this year, NINDS released a summary of our 2018 meeting that focused on defining emerging opportunities in dystonia research.

Key findings include (1) noting that the heterogeneity of dystonia poses challenges to research and therapy development. (2) There is more to be learned from genetic subtypes, along clinical, etiology, and pathophysiology axes. (3) In order to facilitate key advancements in research technology, there needs to be more collaboration. (4) New research priorities should include the generation and integration of high-quality phenotypic and genotypic data. (5) reproducing key features in cellular and animal models, both of basic cellular mechanisms and phenotypes, leveraging new research technologies. (6) Collaboration is necessary both for collection of large data sets and integration of different research methods.

It is of great significance that a number of dystonia patient advocacy group, led by the Dystonia Medical Research Foundation, actively took part in the meeting and are working to ensure that Congress continues to support robust NIH funding.

NIDCD and NEI also support research on dystonia. NIDCD has funded many studies on brainstem systems and their role in spasmodic dysphonia, or laryngeal dystonia. Spasmodic dysphonia is a form of focal dystonia which involves involuntary spasms of the vocal cords causing interruptions of speech and affecting voice quality. NEI focuses some of its resources on the study of blepharospasm. Blepharospasm is an abnormal, involuntary blinking of the eyelids which can render a patient legally blind due to a patient's inability to open their eyelids. We were pleased to see that Congress has encouraged both NIDCD and NEI to expand their research into both spasmodic dysphonia and blepharospasm.

We thank the committee for the increase for NIH in fiscal year 2020. We know firsthand that this will further NIH's ability to fund meaningful research that benefits our patients.

PATIENT PERSPECTIVES

My dystonia first presented when I was about 8 years old and my parents took me to many, many doctors. My foot and leg would turn in when I tried to walk—making walking very difficult. The kids at school would tease me and called me names like "mental foot". When I couldn't explain it, they teased me more. Finally, at the age of 12 the diagnosis of dystonia was made. I have the genetic form of dystonia—DYT1 dystonia that is generalized and commonly affects children between the ages of 8 to 15. For me, dystonia spread from my left foot to both legs, my arms and my back. When I walked, my back would arch and put a lot of pressure on the bottom of my spine which was pretty painful. My legs were very tight. My right foot started to turn in and that put pressure on my ankle when I walked. My right arm was very tight, so when I had to write it was painful. I decided to pursue Deep Brain Stimulation for my dystonia when it became too painful to walk with my son to the park that was around the corner from our house. The results have been life-changing. My wife and sons now have a husband and father who, despite having dystonia, is physically able to be active and a part of their lives. It isn't a cure but a treatment that really worked for me.

BLEPHAROSPASM

I drive through Atlanta's brutal traffic when suddenly, my eyes clamp shut. I pry my left eye open with thumb and forefinger, steer with my right hand. My eyes open for a few seconds, then close with no warning. What is happening? Over the next few months, these spasms progress from eyes to lower face, neck and shoulders. A year later I am diagnosed with Dystonia, a debilitating, little-known disease. A healthy 49-year-old mother of three, I now fight constant pain; can no longer work, drive or perform basic activities. Even walking our dog is a dangerous fall risk.

SPASMODIC DYSPHONIA

Spasmodic dysphonia (SD), a focal form of dystonia, is a neurological voice disorder that involves "spasms" of the vocal cords causing interruptions of speech and affecting voice quality. My voice sounds strained or strangled with breaks where no sound is produced. When untreated, it is difficult for others to understand me. I receive injections of botulinum toxin into my vocal cords every 3 months for temporary relief of symptoms. This has worked well for me for over a decade. At the start of this year, my insurance coverage changed when my husband's company changed providers. As a result, I had to undergo an extensive review process and change methods for obtaining my medicine. The review lasted for four weeks. Multiple times during this time period, my doctor and I were told that I had been denied coverage. We had to make numerous phone calls to encourage the company and specialty pharmacy to review my case again and again. These phone calls were extremely difficult as my voice deteriorated from the delay in treatment. The automated phone systems were the worst, but the representatives also had trouble understanding my broken voice and I had to repeat my information over and over. Finally, the company determined my treatment is medically necessary and has approved it for 1 year. After a seven week delay, I am scheduled for my injection and am looking forward to a period of spasm-free speaking.

DMRF was founded in 1976. Since its inception, the goals of DMRF have remained to advance research for more effective treatments of dystonia and ultimately find a cure; to promote awareness and education; and support the needs and wellbeing of affected individuals and their families.

Thank you for the opportunity to present the views of the dystonia community, we look forward to providing any additional information.

[This statement was submitted by Janet Hieshetter, Executive Director, Dystonia Medical Research Foundation.]

PREPARED STATEMENT OF THE EDUCATION TRUST

On behalf of The Education Trust, an organization dedicated to closing longstanding gaps in opportunity and achievement separating students from low-income backgrounds and students of color from their peers, thank you for the opportunity to present testimony on the fiscal year 2021 Labor, Health and Human Services, Education and Related Agencies (L–HHS–ED) Appropriations bill. We request that the L–HHS–ED bill receive its proportional share of the discretionary increase in the fiscal year 2021 budget caps to ensure that essential education programs have the resources they need.

It is important to acknowledge that this year's appropriations process is operating during an unforeseen and unprecedented crisis. The Education Trust has articulated our views on what must be done in separate, uncapped stimulus packages to provide for our nation's students and protect our public education systems in face of the ongoing massive challenges posed by the coronavirus pandemic. During this pandemic, we call on Congress to take swift action to:

—Double the Pell Grant and make it non-taxable in the face of widespread job loss, uncertainty about college enrollment, and structural racial and financial inequities in college access and attainment;

—Appropriate at least $250 billion for states to help combat coronavirus-related declines in financial support for public P–12 and higher education systems, accompanied by maintenance of effort provisions that ensure state investments do not decline past recent levels;

—Invest at least $6 billion in expanding broadband access to both K–12 and college students who are increasingly likely to be remote learning into academic year 2020–2021;

—Continue to fund and expand the Pandemic EBT program, eliminate barriers for students and families in accessing SNAP benefits, and provide continued flexibility for the Department of Agriculture (USDA) to extend relevant nationwide and state-by-state waivers to ensure that meals can be served to children in whatever form is safe and necessary during the summer and while students cannot return to school;

—Maintain the suspension of student loan payments and interest for all Federal loans, and authorize targeted student loan forgiveness provisions to give relief to millions of borrowers;

—Create a dedicated funding stream to address learning loss and summer slide made available to LEAs for summer school and extended learning opportunities for students and schools with the highest need for summer 2020, academic year 2020–2021, and summer 2021; and

—Create a dedicated funding stream to address the need for increased academic, social-emotional, and physical supports for students, educations, and families during and in the aftermath of the coronavirus crisis.

We look forward to working with staff on these priorities and others in the ongoing stimulus and relief process as the crisis continues to unfold over the coming months.

Regarding the regular appropriations process, while there are many programs under your jurisdiction that are critical to advancing equity, for fiscal year 2021, The Education Trust is focused on the following: strengthening the Pell Grant program by increasing the maximum award $156 to keep pace with inflation, at a minimum; protecting the existing Pell Grant reserve; supporting teachers and school leaders by level funding ESSA's Title II–A ($2.13B), the Teacher and School Leader Incentive Program ($200 million), the Supporting Effective Educator Development Program ($80 million), HEA's Title II's Teacher Quality Partnership grants ($50 million); and restoring funding to the School Leader Recruitment and Support Program ($14.5M). Finally, we request that the Augustus Hawkins Centers, which support enhanced educator preparation for teaching candidates at HBCUs and MSIs, receive $40 million in funding for fiscal year 2021. We are encouraged by the slight increase in funding levels provided by the House Subcommittee on Labor, Health and Human Services, Education and Related Agencies (L–HHS–ED) in the last appropriations cycle for some of these initiatives and urge continued support for these critical programs.

STRENGTHENING THE PELL GRANT PROGRAM

The Pell Grant program is the cornerstone of Federal financial aid. Created in 1972 as the Basic Educational Opportunity Grant, the program benefits over 7 million students annually and continues to serve as the primary Federal effort to open the door to college for students from low-income backgrounds. Over one-third of White students, two-thirds of Black students, and half of Latino students rely on Pell Grants every year.[1] Pell Grant dollars are well-targeted to those in need: 83 percent of Pell recipients come from families with annual incomes at or below $40,000, including 44 percent with annual family incomes at or below $15,000.[2]

Increasing the Maximum Award and Protecting the Pell Reserve

The Pell Grant program's impact is shrinking as the maximum award has failed to keep pace with the rapidly rising cost of college. The purchasing power of the Pell Grant has dropped dramatically since the program's inception. In 1980, the maximum Pell Grant award covered 77 percent of the cost of attendance at a public university. Today, it covers just over 28 percent, the lowest portion in over 40 years. If the maximum award continues to stagnate, the grant will cover just one-fifth of college costs in 10 years.

We very much appreciate previous increases to the maximum award in prior appropriations bills, and we respectfully request that you continue to increase the maximum award amount. For fiscal year 2021, Congress should, at minimum, increase the maximum award by $156 to $6,501 to keep pace with inflation. As indicated above, we also ask Congress to include within the forthcoming coronavirus stimulus package provisions to double the Pell Grant, helping to reverse the downward trend of Pell's purchasing power, ensuring that the maximum Pell award covers at least half of the cost of attendance at a public four-year institution.

Congress should also ensure that the program's reserve funds remain within the program. Students and families already needed help paying for college, and the pandemic will only make the amount of help they need even greater. It remains unclear how the combination of the pandemic and an economic recession will affect net college enrollment. However, current unemployment is the highest it has been since the Great Depression, and this may result in a surge in college enrollment like the one during the previous recession. Cuts to Pell, especially in this context, could quickly put the program in jeopardy and generate unnecessary uncertainty for students. If used for anything, the Pell reserve should be used to improve and expand Pell.

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[1] Congressional Budget Office (CBO), January 2017 baseline projections for the Pell Grant program, http://bit.ly/2mLy0nk, Table 2; and Ed Trust calculation NPSAS:12 using PowerStats.

[2] Analysis of Federal Pell Grant Program Annual Data Report, available at https://www2.ed.gov/finaid/prof/resources/data/pell-data.html.

SUPPORTING TEACHERS AND SCHOOL LEADERS

Research and experience show the powerful impact that teachers and school leaders have on student learning. ESSA's Title II program provides grants to states and districts that can be used to invest in and develop the education profession. These funds can be used to, among other things, address inequities in access to effective teachers and school leaders, provide professional development, and improve teacher recruitment and retention. States and districts can also apply for additional competitive grant dollars for programs targeted at specific, evidence-based strategies for improving teacher and school leader effectiveness and increasing educator diversity. Additionally, HEA's Title II Teacher Quality Partnership grants (TQP), awarded to partnerships of high-need districts and teacher preparation programs at institutions of higher education, can be used to recruit underrepresented populations to the teaching profession. As Ed Trust's work continues to demonstrate the positive impact that diverse teachers and school leaders of color can have on the academic achievement of both students of color and White students, we remain supportive of Federal dollars to increase and bolster the diversity of the educator pipeline.

Maintain funding for ESSA's Title II–A (Supporting Effective Instruction), the Teacher and School Leader Incentive Program (TSLIP), the Supporting Effective Educator Development (SEED) program, and HEA's Title II Teacher Quality Partnership (TQP) grants

Despite the nationwide attention to the need to invest in educators, President Trump's fiscal year 2021 budget request again called for the elimination via block grant of the Title II–A grant, the SEED program, the TSLIP, and HEA's Title II Teacher Quality Partnership grants. We appreciate Congress' prior rejection of similar requests in the fiscal year 2019 omnibus appropriations bill.

At a minimum, in fiscal year 2020, Congress should continue funding Title II–A, TSLIP, SEED, and TQP at fiscal year 2020 levels: $2.13B, $200 million, $80 million, and $50 million, respectively.

Fund the Augustus Hawkins Centers of Excellence Grant Program

Research has shown that students of color benefit tremendously from having teachers of color, particularly one of the same racial background: they are less likely to be chronically absent or suspended from school, more likely to be recommended for gifted and talented programs, and low-income Black students who have a Black teacher for at least 1 year in elementary school are less likely to drop out of high school and more likely to consider college. Despite students of color making up a majority of students in public schools, the diversity gap for teachers of color still exists in every state.

The nationwide impact of HBCUs, MSIs, HSIs, and TCUs on producing teachers of color cannot be overstated. HBCUs, TCUs, and MSIs, collectively, award only 11 percent of the nation's bachelor's degrees in education, yet they produce more than 50 percent of the bachelor's degrees earned in education by Hispanic and Native Hawaiian and Pacific Islander students.[3] HBCUs graduate approximately 50 percent of the nation's African American teachers with bachelor's degrees.[4] HSIs prepare 90 percent of Hispanic teachers, and along with other MSIs, constitute a vital pipeline to maintain diversity among our nation's teachers.[5]

In light of the importance of these institutions and the increased needs they experience as a result of graduating an outsized portion of the nation's teachers of color, we request that the Augustus Hawkins Centers of Excellence Grant program receive funding for the first time since its creation in the bipartisan Higher Education Act of 2008. The program would provide critical funding to these key institutions to provide increased and enhanced clinical experience and increased financial aid to prospective teachers of color, who face higher burdens in college access and affordability than their White peers.

For fiscal year 2021, Congress should fund the Augustus Hawkins Centers of Excellence Grant Program at $40 million.

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[3] Branch Alliance for Educator Diversity, "Homepage," available at https://www.educatordiversity.org/.

[4] Jacqueline Jordan Irvine and Leslie T. Fenwick, "Teachers and Teaching for the New Millennium: The Role of HBCUs," The Journal of Negro Education 80 (3) (2011): 197–208, available at http://www.jstor.org/stable/41341128; National Association for Equal Opportunity in Higher Education: Comments to the Department of Education proposed rule changes for teacher preparation programs available at: http://nafeonation.org/wp-content/uploads/2015/01/NADEC__Teacher__Prep__Regulations__Discussion__Document__2-2-15.pdf.

[5] Hispanic Association of Colleges and Universities, "Teacher Diversity," https://www.hacuadvocates.net/teacherdiversity?1.

Restore Funding for the School Leader Recruitment and Support Program

Landmark research funded by the Wallace Foundation has found "virtually no documented instances of troubled schools being turned around without intervention by a powerful leader," and the School Leader Recruitment and Support Program is the only Federal program specifically focused on investing in evidence-based, locally driven strategies to strengthen school leadership in high-need schools. A recently concluded seven-year study of school districts that created pipelines to develop school leaders saw increasing gains in student achievement over time, showing how a sustained initiative can demonstrate positive effects on student learning.

It is also worth noting that the need to develop strong and diverse school leaders has only been heightened due to the coronavirus pandemic. The school closures taking place across America are disproportionately hurting students from low-income backgrounds and students of color, and they need teachers and leaders who are supported and qualified to tackle the historic learning loss and trauma they are facing. In order to effectively counter those growing problems, funding must be in place to ensure those diverse teachers and leaders get the training they need to stay in the classroom.

During the past decade, we have learned a lot about what works in education leadership—lessons made possible, in part, by Federal investments in the School Leader Program (the previous iteration of the SLRSP). There is still a great deal of work to do, especially when it comes to identifying and efficiently preparing effective turnaround leaders, as well as sustainably supporting them to accelerate academic achievement, close gaps, and maintain improvement over time for all students and in every community. The SLRSP is a key lever for seeding the next generation of effective school leader development programs, promoting equity, advancing ongoing innovation, and sharing cutting-edge lessons on transformational leadership with the broader field.

For fiscal year 2021, Congress should restore funding for the School Leader Recruitment and Support Program to $14.5M, its fiscal year 2017 appropriation level.

Thank you for the opportunity to submit testimony. The Education Trust looks forward to working with Congress to allocate Federal funds in a way that addresses the critical equity gaps that our nation's students from low-income backgrounds and students of color continue to face. We are happy to respond to any questions or concerns that you may have on these topics, and look forward to continuing to work with you on coronavirus response stimulus and relief and through the fiscal year 2021 appropriations process.

[This statement was submitted by John B. King Jr., President and CEO, The Education Trust.]

PREPARED STATEMENT OF THE ENDOCRINE SOCIETY

The Endocrine Society thanks the Subcommittee for the opportunity to submit the following testimony regarding fiscal year 2021 Federal appropriations for biomedical research and public health programs. The Endocrine Society is the world's oldest and largest professional organization of endocrinologists representing approximately 18,000 members worldwide. The Society's membership includes basic and clinical scientists who receive support from the National Institutes of Health (NIH) for research on endocrine diseases that affect millions of Americans, such as diabetes, thyroid disorders, cancer, infertility, aging, obesity and bone disease. Our membership also includes clinicians who depend on new scientific advances to better treat and cure these diseases. Our organization is dedicated to promoting excellence in research, education, and clinical practice in the field of endocrinology.

The Endocrine Society offers the following recommendations for fiscal year 2021:

—At least $44.7 billion for the NIH to support necessary advances in biomedical research to improve health;

—At least $8.2 billion for the CDC to facilitate the translation of these advances to improve public health; and

—$400 million for the Title X program to ensure that women have access to appropriate health services.

The current COVID–19 pandemic is a compelling illustration of why we must sustain funding for the NIH and CDC to protect the public's health. In addition to a strong annual appropriation for these agencies, emergency supplemental funding is required to achieve research goals to understand, treat, and prevent future outbreaks.

ENDOCRINE RESEARCH IMPROVES PUBLIC HEALTH

Sustained investment by the United States Federal Government in biomedical research has dramatically advanced the health and improved the lives of the American people. The United States' NIH-supported scientists represent the vanguard of researchers making fundamental biological discoveries and developing applied therapies that advance our understanding of, and ability to treat human diseases. Their research has led to new medical treatments, saved innumerable lives, reduced human suffering, and launched entire new industries.

Endocrine scientists are a vital component of our nation's biomedical research enterprise and are integral to the healthcare infrastructure in the United States. Endocrine Society members study how hormones contribute to the overall function of the body and how the glands and organs of the endocrine system work together to keep us healthy. The multiple body functions governed by the endocrine system are broad and essential to overall wellbeing: endocrine functions include reproduction, the body's response to stress and injury, sexual development, energy balance and metabolism, and bone and muscle strength. Endocrinologists also study interrelated systems, for example how hormones produced by fat can influence the development of bone disease and susceptibility to infections.

With the emergence of the COVID–19 pandemic, endocrinology has taken on a new role in understanding how endocrine systems and endocrine disease intersect with the virus and infection pathways. The presence of diabetes is a critical risk factor impacting outcomes for patients with COVID–19 and understanding shared pathophysiology and therapeutic implications of treatments for both diseases remains an important area of active research.[1] As we learn more about the virus and implications for patients with endocrine disease, funding for public health agencies is more important than ever.

ENDOCRINE RESEARCH IS SUPPORTED BY NUMEROUS NIH INSTITUTES

Many endocrine diseases and disorders are addressed by the missions of multiple NIH Institutes and Centers (ICs); research on all biological systems and disease states is necessary to advance effective therapies for these diseases. For example:

—Endocrine researchers funded by the National Institute of Aging (NIA) help us understand how hormonal treatment for menopause might improve stress responses in women.[2] Other NIA-funded researchers are investigating how the loss of ovarian hormones due to surgery affects overall aging, physical and cognitive function, and risk for Alzheimer's disease pathophysiology.

—Researchers funded by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) are discovering how hormones influence the gut microbiome, which in turn can influence the development of polycystic ovarian syndrome (PCOS).[3]

—Endocrine oncologists supported by the National Cancer Institute developed a new drug with a unique mechanism that could inhibit the growth of drug-resistant prostate cancer.[4]

—Diabetologists funded by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) are advancing knowledge of how insulin-producing cells develop so that we can apply this knowledge towards regenerative medicine and cell-based approaches to the treatment of diabetes.[5]

—National Institute of Environmental Health Science (NIEHS)-funded researchers are investigating how per-and polyfluoroalkyl substances can disrupt endocrine systems resulting in reproductive and cognitive health effects.[6]

—Neuroendocrine researchers funded by National Institute of Mental Health (NIMH) are discovering how overexposure to glucocorticoids early in life can cause anxiety—and depressive-like behaviors in adults in response to stress, and how these behaviors may differ between males and females.

Moreover, multiple ICs are prepared to use rapidly use emergency supplemental funds to prioritize critical endocrine-related research on COVID–19 such as:

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[1] Daniel J Drucker, Endocrine Reviews, Volume 41, Issue 3, June 2020, bnaa011, https://doi.org/10.1210/endrev/bnaa011.

[2] https://www.endocrine.org/news-room/press-release-archives/2017/treating-menopausal-symptoms-can-protect-against-stress-negative-effects Accessed March 11, 2018.

[3] Torres, PJ, et al., The Journal of Clinical Endocrinology & Metabolism, jc.2017–02153.

[4] https://www.endocrine.org/news-room/press-release-archives/2013/new-medication-treats-drug-resistant-prostate-cancer-in-the-laboratory. Accessed March 11, 2018.

[5] Sharon, N, et al., Cell. 2019 Feb 7;176(4):790–804.e13. doi: 10.1016/j.cell.2018.12.003. Epub 2019 Jan 17.

[6] Vuong, A., et al., Environmental research. 2019 Feb 16; 172 :242–248.

—Helping us understand how endocrine-disrupting chemicals (EDCs) contribute to chronic diseases that are comorbidities for COVID–19.
—Understanding the short and long-term impacts of COVID–19 infection on pregnant women and pediatric patients.
—Understanding how health disparities contribute to COVID–19 disease risk and outcomes.

An effective biomedical research enterprise therefore requires a strong base appropriation for the NIH and sustained support for all ICs in addition to emergency supplemental funding to study COVID–19 and impacts on patients with endocrine disease.

NIH REQUIRES STEADY, SUSTAINABLE FUNDING INCREASES

The Endocrine Society appreciates increases to the NIH budget in recent fiscal years; however, the biomedical research community requires steady, sustainable increases in funding to ensure that the promise of scientific discovery can efficiently be translated into new cures. NIH grant success rates are predicted to remain close to historically low averages, meaning that highly skilled scientists will continue to spend more time writing highly meritorious grants that will not be funded. Young scientists will also continue to be driven out of biomedical research careers due to the lack of funding. We know that when laboratories lose financing; they lose people, ideas, innovations and new patient treatments.[7]

ADEQUATE FUNDING OF CDC PROGRAMS IS NECESSARY TO PROTECT THE PUBLIC'S HEALTH

The CDC plays a critical role in protecting the public's health by applying new knowledge to the promotion of health and prevention of diseases, including diabetes. The Division of Diabetes Translation administers the National Diabetes Prevention Program (National DPP), which addresses the increasing burden of prediabetes and Type 2 Diabetes in the United States. The National DPP creates public and private partnerships to provide evidence-based, cost-effective interventions that prevent diabetes in community-based settings. Through structured lifestyle change programs at local YMCAs or other community centers, individuals with prediabetes can reduce the risk of developing diabetes by 58 percent in those under 60 and by 71 percent in those 60 and older.[8] In addition to supporting public health and prevention activities, CDC's Clinical Standardization Programs in the Center for Environmental Health are critical to improving accurate and reliable testing of hormones, appropriate diagnosis and treatment of disease, and reproduceable public health research. Adequate funding is critically important to ensure that CDC has the capacity to address existing and emerging threats to public health in the United States and around the world.

TITLE X FUNDING PROVIDES NECESSARY SERVICES AND REDUCES HEALTHCARE COSTS

Title X is an important source of funding for ensuring reproductive health benefits including both contraceptive and preventive services to women. In 2015, a study found that Title X-funded health centers prevented 822,000 unintended pregnancies, resulting in savings of $7 billion to Federal and State Governments. Offering affordable access to contraception can have a measurable impact on these costs. For every public dollar invested in contraception, short-term Medicaid expenditures are reduced by $7.09 for the pregnancy, delivery, and early childhood care related to births from unintended pregnancies, resulting in savings of $7 billion to Federal and State Governments.[9]

Title X is the main point of care for low income, under- or un-insured, adults and adolescents for affordable contraception, cancer screenings, sexually transmitted disease testing and treatment, and medically-accurate information on family planning options. However, to provide these services to the over 4 million people who depend on Title X-funded centers, Title X is significantly underfunded.

FISCAL YEAR 2021 FUNDING REQUESTS

In conclusion, to avoid loss of promising research opportunities, allow budgets to keep pace with inflation, support our public health infrastructure, and assure high-

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[7] Teresa K. Woodruff "Budget Woes and Research." The New York Times. September 10, 2013.

[8] The Diabetes Prevention Program (DPP) Research Group Diabetes Care. 2002 Dec;25(12):2165–71.

[9] Frost JJ, et al., Publicly Funded Contraceptive Services at U.S. Clinics, 2015, New York: Guttmacher Institute, 2017.

quality, evidence-based, and patient-centered family planning care while also addressing the COVID–19 pandemic, the Endocrine Society recommends that the Subcommittee provide at least the following funding amounts through the fiscal year 2021 Labor, Health and Human Services, Education, and Related Agencies appropriations bill:

—$44.7 billion for the National Institutes of Health, as well as additional emergency supplemental funds needed to study COVID–19
—$8.2 billion for the Centers for Disease Control and Prevention in addition to emergency supplemental funds
—$400 million for Title X

PREPARED STATEMENT OF THE ENTOMOLOGICAL SOCIETY OF AMERICA

The Entomological Society of America (ESA) respectfully submits this statement for the official record in support of funding for vector-borne diseases (VBD) research at the U.S. Department of Health and Human Services (HHS). ESA requests:

—$44.7 billion in fiscal year 2021 for the National Institutes of Health (NIH), including increased support for VBD research at the National Institute of Allergy and Infectious Diseases (NIAID);
—$8.3 billion for the Centers for Disease Control and Prevention (CDC), including investments in the budgets for VBD, global health, and core infectious diseases; and
—Robust funding for the Institute of Museum and Library Services (IMLS), including $42.7 million for the Office of Museum Services.

ESA urges the subcommittee to support VBD research programs that incorporate the entomological sciences as part of a comprehensive approach to addressing infectious diseases. These efforts can help mitigate the enormous impact that insect carriers of disease have on human health. NIH, the nation's premier medical research agency, advances human health by supporting research on basic human and pathogen biology and by developing prevention and treatment strategies. Cutting-edge research in the biological sciences, including the field of entomology, is essential for addressing societal needs related to environmental and human health. Many species of insects and arachnids, including ticks and mites, are carriers or vectors of an array of infectious diseases that threaten the health and well-being of people worldwide. This threat impacts citizens in every U.S. state and territory, as well as military personnel serving at home and abroad. The mosquitoes that carry and transmit diseases are responsible for more human deaths than all other animal species combined, including other humans.[1] VBD can be particularly challenging to manage due to insect and arachnid mobility and their propensity to develop pesticide resistance. Further, effective preventative treatments, including vaccines, are not available for many VBD.

Within NIH, NIAID conducts and supports fundamental and applied research related to understanding, preventing, and treating infectious diseases. The risk of emerging infectious diseases grows as global travel increases in speed and frequency and as environmental conditions conducive to population growth of vectors, like mosquitoes and ticks, continue to expand globally. Entomological research to understand and characterize the relationships between insect vectors and the diseases they transmit is essential to enable scientists to reliably monitor and predict outbreaks, prevent disease transmission, and rapidly diagnose and treat diseases. For example, NIAID-funded researchers are working to understand how common prevention tools like mosquito repellent work at the molecular level. Although topical mosquito repellents such as DEET are a popular tool for preventing mosquito bites and mosquito-borne diseases like malaria, the mechanism they use to repel mosquitoes is not understood. Using grant funding from NIAID, researchers from Johns Hopkins University have determined that DEET is an effective mosquito repellent because it masks human odors from female mosquitoes.[2] Researchers can use these findings to develop similar safe, low-cost mosquito repellents to prevent mosquito bites, reducing the burden of mosquito-borne diseases.

Given that the contributions of the CDC are vital for the health security of the nation, ESA requests that the committee provide robust support for CDC programs addressing VBD and to continue to support the Centers of Excellence on VBD beyond 2021 with at least $10 million per year. CDC, serving as the nation's leading health protection agency, conducts scientific research and provides health information to prevent and respond to infectious diseases and other global health threats,

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[1] https://www.gatesnotes.com/Health/Most-Lethal-Animal-Mosquito-Week
[2] https://www.sciencedirect.com/science/article/abs/pii/S0960982219311674.

irrespective of whether they arise naturally or via acts of bioterrorism. Within the core infectious diseases budget of CDC, the Division of Vector-Borne Diseases (DVBD) aims to protect the nation from the threat of viruses, bacteria, and parasites transmitted primarily by mosquitoes, ticks, and fleas. DVBD's mission is carried out by a staff of experts in several scientific disciplines, including entomology.

CDC plays a key role in tracking new and emerging diseases, as well as in supporting healthcare professionals in identifying and diagnosing these diseases. From 2016 to 2017, there was a 46 percent increase in reported cases of a group of tick-borne diseases known as Spotted Fever Rickettsiosis (SFR), which includes the notably fatal Rocky Mountain spotted fever (RMSF).[3] Disability and death from RMSF are treatable if the antibiotic doxycycline is administered within the first five days of illness: without treatment, 1 in 5 RMSF cases lead to death.[4] Importantly, SFR, including RMSF, has non-specific symptoms, and fewer than 1 percent of the SFR cases reported in 2016–2017 had sufficient laboratory evidence for diagnosis. In response to this issue, the CDC has created a first-of-its-kind education module that will help healthcare providers recognize the early symptoms of RMSF and distinguish it from other diseases, enabling affected patients to get the life-saving treatment they need as quickly as possible.[5] CDC funding is crucial in the development of this and other educational tools that equip healthcare providers to effectively combat tick-borne diseases.

CDC has also awarded nearly $50 million to five universities to establish regional centers of excellence (COE) that can help effectively address emerging and exotic VBD. The five centers, for which current funding expires in 2021, help generate the necessary research, knowledge, and capacity to enable appropriate and timely local public health action for VBD throughout the United States. The COE model has also required collaboration between the research institutions and the local and regional departments of health, important relationships which haven't generally arisen organically. This is critical given significant regional differences in vector ecology, disease transmission dynamics, and resources.

A notable recent development supported by the Southeastern COE in VBD involves an innovative "attract-and-kill" approach to mosquito control. The strategy takes advantage of the discovery that female mosquitoes are attracted to the common microbial compound geosmin, and can be effectively lured into laying their eggs in traps containing geosmin-scented water.[6] Researchers hope that getting mosquitoes to lay eggs in traps will help to break their ongoing breeding cycle and ultimately curtail mosquito populations.

ESA requests robust funding for IMLS, including no less than $42.7 million for the Office of Museum Services in fiscal year 2021. The services and funding provided by IMLS are critical in several areas—research infrastructure, workforce development and economic impact. The IMLS provides for the expansion of collections capabilities at American museums, which are key for the identification, documentation of locations, and classification of entomological species. Funding provides for the training and education of students and museum professionals. The 21st Century Museum Professionals Program provides opportunities for diverse and underrepresented populations to become museum professionals, expanding participation in an industry with an annual economic contribution of approximately $21 billion. Museums are critical to the public understanding of emerging major scientific issues through exhibits and programs, and in so doing, support science education as an integral part of the nation's educational infrastructure. Finally, they make significant long-term contributions to economic development in their local communities.

ESA thanks the committee for the opportunity to provide input on these important priorities. ESA, headquartered in Annapolis, Maryland, is the largest organization in the world serving the professional and scientific needs of entomologists and individuals in related disciplines. As the largest and one of the oldest insect science organizations in the world, ESA has over 7,000 members affiliated with educational institutions, health agencies, private industry, and government. Members are researchers, teachers, extension service personnel, administrators, marketing representatives, research technicians, consultants, students, pest management professionals, and hobbyists. For more information about the Entomological Society of America, please see http://www.entsoc.org/.

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[3] https://www.ncbi.nlm.nih.gov/pubmed/?term=30969821.

[4] https://www.cdc.gov/media/releases/2019/p0513-rocky-mountain-spotted-fever-training.html.

[5] https://www.cdc.gov/rmsf/resources/module.html.

[6] https://www.cell.com/current-biology/fulltext/S0960-9822(19)31441-1.

[This statement was submitted by Robert K.D. Peterson, PhD, Science Policy Committee Chair and Past President, Entomological Society of America.]

PREPARED STATEMENT OF THE EPILEPSY FOUNDATION

Dear Chairman Blunt and Ranking Member Murray:

The Epilepsy Foundation appreciates the opportunity to submit written testimony as the Subcommittee begins its work on the fiscal year 2021 Labor, Health and Human Services (HHS), Education and Related Agencies appropriations bill. The Epilepsy Foundation respectfully requests that the following funding levels be included in the final fiscal year 2021 Labor, HHS, Education and Related Agencies bill: $11.5 million for the Centers for Disease Control and Prevention (CDC)'s National Center for Chronic Disease Prevention and Health Promotion's Epilepsy program; $44.7 billion for the National Institutes of Health (NIH); $5 million for the National Neurological Conditions Surveillance System at the CDC; $10 million for the Lifespan Respite Care Program; and $8.8 billion for the Health Resources & Services Administration's (HRSA) discretionary budget authority. Our written testimony focuses on the incredible value and impact of CDC's Epilepsy program.

The Epilepsy Foundation is the leading national voluntary health organization that speaks on behalf of the approximately 3.4 million living with epilepsy and seizures. We foster the wellbeing of children and adults affected by seizures through research programs, educational activities, advocacy, and direct services. Epilepsy is a medical condition characterized by seizures, which are sudden surges of electrical activity in the brain, that affects a variety of mental and physical functions.

The Institute of Medicine's (IOM) report on epilepsy, Epilepsy Across the Spectrum: Promoting Health and Understanding, identifies the Epilepsy Foundation and the CDC leaders in addressing many of its national recommendations. The Epilepsy Foundation, supported by a cooperative agreement with CDC, has made the following progress:

—Provided education and/or direct training on epilepsy to more than 81,531 law enforcement and first responders, 58,543 school nurses and 419,541 students and teachers;
—Delivered evidence-based self-management training to people with epilepsy so that they can take control of their health, better cope with day-to-day challenges and reduce healthcare utilization and healthcare costs;
—Reached underserved populations through:
    —Project ECHO, a tele-mentoring process between an epilepsy specialist and primary care providers, in Ohio, Indiana, West Virginia and Kentucky;
    —An advanced practice provider model with family nurse practitioners and physician assistants;
    —Delivery of signature programs through local Epilepsy Foundation offices;
    —Training community health workers in Texas and Illinois; and
    —Outreach to behavioral health professionals in rural settings.

The Department of Health and Human Services initiative, Healthy People 2020, includes the goal to "increase the proportion of people with epilepsy and uncontrolled seizures who receive appropriate medical care." Continued and increased funding for the CDC epilepsy program is critical to meeting this goal-as it is the only public health program specifically related to epilepsy that offers a national scope and local community programs.

Approximately 1 in 26 Americans will develop epilepsy at some point in their lifetime. There is no "one size fits all" treatment option for epilepsy, and despite available treatments, about a third of people living with epilepsy—approximately 1 million—suffer from uncontrolled or intractable seizures,[1] with many more living with significant side-effects. Among adults with epilepsy, only 50 percent have seen both a primary care physician and a neurologist and epilepsy specialist in the last year; 36 percent have seen a primary care physician only; 8 percent have seen a neurologist or epilepsy specialist only; and 6 percent have seen neither.[2] Thirty-nine percent of those experiencing seizures in the last year have not seen a neurologist.[3] Compared to adults with no history of epilepsy, adults with active epilepsy are more likely to report not being able to afford their prescription drugs (21 percent v. 9 per-

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[1] Patrick Kwan & Martin J. Brodie, Early identification of refractory epilepsy, 342 N ENGL J MED 314–9 (2000). Retrieved from https://www.nejm.org/doi/pdf/10.1056/NEJM200002033420503.

[2] David J. Thurman et al., Health-care access among adults with epilepsy: The U.S. National Health Interview Survey, 2010 and 2013, 55 EPILEPSY BEHAV 184–88 (2015). Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5317396/.

[3] Ibid.

cent) and mental healthcare (8 percent v. 2 percent) when these were needed in the previous year.[4] Nine percent of those with active epilepsy report not being able to obtain needed healthcare because of a lack of transportation.[5]

In fiscal year 2020, $9.5 million was appropriated for the CDC's National Center for Chronic Disease Prevention and Health Promotion's Epilepsy program. The $2 million additional requested funds will help support epidemiologic studies, national dissemination of evidence-based programs to address the access of care barriers described above and expand provider education and public awareness campaigns to reduce stigma. Epilepsy accounts for $19.4 billion in direct costs (medical) and indirect costs (lost or reduced earnings and productivity) each year. To decrease this public health burden and help more people with epilepsy have a high quality of life and access the quality, physician-directed and person-centered healthcare they need, we simply must do more.

The Epilepsy Foundation thanks the Subcommittee for its consideration. If you have any questions, please contact the Epilepsy Foundation's Vice President of Government Relations and Advocacy Laura Weidner at lweidner@efa.org.

Sincerely.

[This statement was submitted by Laura E. Weidner, Esq., Vice President, Government Relations & Advocacy, Epilepsy Foundation.]

PREPARED STATEMENT OF EVERMORE

Chairman Blunt, Ranking Member Murray, and members of the Committee, thank you for the opportunity to provide testimony on the fiscal year 2021 appropriations for key U.S. Department of Health & Human Service Agencies including the Administration for Children and Families (ACF), Centers for Disease Control and Prevention (CDC), Centers for Medicare & Medicaid Services (CMS), Health Resources and Services Administration (HRSA), Indian Health Service (IHS), National Institutes of Health (NIH), Office of Minority Health (OMH), Substance Abuse and Mental Health Services Administration (SAMHSA) and the Social Security Administration (SSA). Your leadership has resulted in major advances in the health and wellbeing of Americans, as well as ensuring that our taxpayer dollars are appropriated to our nation's most pressing health and human needs.

I am submitting this testimony on behalf of Evermore, a nonprofit dedicated to making the world a more livable place for bereaved families by raising awareness, advancing research, and advocating on behalf of bereaved families and the professionals who serve them. The unexpected or untimely death of a loved one is the most common traumatic event Americans experience; many rate it as the worst event of their life.[1] This is not surprising considering suicide, homicide, overdoses, mass casualty events, and now COVID–19. Americans are not only exposed to an alarming number of tragic and often traumatic deaths, but they are encountering a formidable array of barriers to bereavement care that compound their suffering. For too long, access to quality bereavement care has gone unrecognized by lawmakers, lacked funding, and been excluded from Federal health agency priorities. Although bereaved families indeed appreciate Congressional "thoughts and prayers," we desperately need your leadership on this immediate, ongoing, and often invisible public health crisis. Epidemics of suicide, opioid overdose, and others including contagious diseases are so vast that our national life expectancy dropped for the first time in a century. Arguably, we need your leadership more than ever.

Bereavement care is an essential element to any comprehensive public health strategy. Our families require more support, practitioners require more tools and resources, and we must understand more about bereavement. Research not only saves lives, but drives innovation.

Rigorous population-level studies, examining the health behaviors and outcomes of millions of people, have concluded that bereaved parents,[2] siblings,[3] children[4] and spouses[5] are all at risk of premature death as a result of such loss. This is just the tip of the iceberg: bereavement is an underlying driver of the poor health undermining our nation's healthcare and social services systems.

Consider the following:

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[4] Ibid.

[5] Ibid.

[1] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4119479/.

[2] https://www.ncbi.nlm.nih.gov/pubmed/12573371.

[3] https://www.ncbi.nlm.nih.gov/pubmed/28437534.

[4] https://jamanetwork.com/journals/jamapsychiatry/fullarticle/2469106.

[5] https://www.ncbi.nlm.nih.gov/pubmed/16481639.

> Today, ten million American children are bereaved, with two million having lost a parent[6] and a projected eight million having lost a sibling.[7] These uniquely devastating losses alter the lifetime success of these youth. Nearly 90 percent of detained youth have experienced the death of a close loved one and 25 percent subsequently joined a gang.[8] Research studies have found that "bereaved children experience lower self-esteem, reduced resilience, lower grades and more school failures, heightened risk of depression, suicide attempts, suicide, and premature death due to any cause, drug abuse, violent crime involvement, youth delinquency, and a greater number of, and more severe, psychiatric difficulties."[9]

If this does not cause alarm and encourage leadership, what will? These few statistics demonstrate that our nation's Federal health agencies should actively work to stem the individual and societal costs of bereavement. The cost of inaction is incalculable.

Our request, a no-cost appropriation, will achieve three goals: (1) continue LHHS' leadership in advancing America's health, (2) reveal what, if anything, is being done by our Federal health agencies to advance bereavement care and (3) alert leadership that bereavement itself poses great risks to our society and should rank within future priority activities. To that end, our research indicates that some agency policies may be inflicting additional harm, including additional trauma, on the newly bereaved.

In March 2020, we worked with the U.S. House of Representatives to advance appropriations report language that would require key Federal health agencies to report to Congress what activities, if any, they are conducting to advance bereavement care for Americans. This is the first time in history Federal health agencies will be asked to report bereavement-related activities.

In an effort to ensure parity across legislative chambers, our hope is that this subcommittee will adopt the same report language that the House advanced. The House-endorsed report language is as follows:

> "*State of Bereavement Care*.—The Committee is aware of research indicating that individuals and families suffer severe health, social, and economic declines following the death of a loved one—be it a child, sibling, spouse, or parent. The Committee encourages OMH, ACF, CDC, CMS, HRSA, IHS, NIH, SAMHSA, and SSA to examine its involvement in activities to advance bereavement care for families, including documenting and investigating the policies or programs that help or hinder functional coping or adaptive processing and the prevalence and outcome of bereavement events (what relationships are impacted, how the loved one died and their age, risk factors and associated health events or outcomes, and biological or physiological changes in well-being)."

FEDERAL AGENCY RATIONALE AND CONTEXT

Bereavement and its unintended outcomes are inextricably linked to many of our Federal health agencies missions, priorities, and programs. Outlined below is a brief rationale as to why we suggest each of the following Federal agencies; however, we are happy to provide more robust explanations upon request:

ACF.—Given bereavement's alarming prevalence and outcomes among children, understanding how ACF integrates, if at all, bereavement care into their programs is imperative. Facilitating functional coping and adaptive processing among these children following the death of a loved one may help stem or reduce other health and human services expenditures, as well as alter the trajectory, independence, and individual success of these children.

CDC.—CDC's National Center for Health Statistics (NCHS) collects mortality events, but not who survives them or what outcomes survivors' experience. Bereavement itself is an "injurious" event threatening family health, wellbeing, and economic solvency. Scientific evidence finds that bereaved parents, as a result of their loss, experience cardiac events,[10] immune dysfunction,[11] depressive symptoms, poorer well-being, less purpose in life, more health complications, marital disruption,[12]

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[6] https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3471209.

[7] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4302726/.

[8] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4577059/.

[9] Layne, C. M., & Kaplow, J. B. (2020). Assessing bereavement and grief disorders. In E. A. Youngstrom, M. J. Prinstein, E. J. Mash, & R. A. Barkley (Eds.), Assessment of Disorders in Childhood and Adolescence (5th ed., pp. 471–508). New York: Guilford Press.

[10] https://www.ncbi.nlm.nih.gov/pubmed/12270855.

[11] https://psycnet.apa.org/record/1992–05615-001.

[12] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2841012/.

psychiatric hospitalization,[13] a slight increase in cancer incidence[14] as well as premature death for mothers and fathers as early as age 40.[15]

CDC is one the nation's most trusted sources of data and evidence on population and public health. Given the growing evidence base about the profound long-lasting effects of bereavement on individuals and community health, bereavement (as a marker of risk) and quality bereavement care should be a top priority for CDC. The country needs consistent and reliable data on the prevalence and sequelae of bereavement on which to formulate sound policy and practice. These data will also be important as the CDC begins plans for the next decade of Healthy People 2030.

CMS.—As the purveyor of Medicare and Medicaid benefits, it touches the lives of millions of Americans at high-risk of experiencing bereavement. Although bereavement counseling is a required Medicare benefit for up to 1 year of hospice participants, it is not eligible for stand-alone reimbursement. Reimbursement rates are not linked to counseling quality, and researchers have found that there are few, if any, financial incentives for hospice to ensure quality care.[16] These constitute real barriers to bereaved families' ability to function and cope with a death. As the primary funder of hospice benefits, CMS should ensure that the quality of services rendered meet sound professional standards, including incorporating standard quality assurance and improvement practices and a research evidence base. With $1.2 trillion taxpayer investment, it is imperative that we understand CMS benefit coverage, quality, uptake, and reimbursement rationale.

HRSA.—HRSA's core demographics, footprint and the health risk profiles of its participants, make it a prime candidate for helping us to understand bereavement offerings and how their programs help (or hinder) an individuals' ability to cope and productively return to the workforce.

IHS.—Millions of American Indians and Alaska Natives (AI/NA) experience both a higher portion of disease prevalence and a reduced life expectancy, when compared to their fellow Americans. As a result, AI/AN experience death at younger ages, thus compounding their social and health hardships. Requesting current bereavement-related activities will help elucidate to what extent, if any, IHS is facilitating functional coping and adaptive processing among this high-risk population.

NIH.—In 2016, NIH aligned mortality and prevalence data to its spending categories to link its research priorities and our nation's public health needs. Because NIH extracts data from CDC and NCHS (and CDC does not collect those bereaved by mortality events) bereavement does not rank in NIH's 292 top disease conditions or research priorities. However, with a $33 billion budget authority, undoubtedly NIH is conducting useful research as it relates, directly or indirectly, on bereavement care, function, coping, statistics or outcomes. The potency of bereavement as a highly prevalent and impactful stressor capable of altering lifelong developmental trajectories underscores how critical these endeavors are to shaping programs, resources, and driving innovation to meet our pressing public health needs.

OMH.—Black Americans are at higher risk of losing a child, spouse, sibling or parent throughout the lifespan when compared to their white counterparts.[17] As a result of these unique stressors, black Americans face greater adversity and cumulative disadvantage.[18] OMH should play a leadership role in understanding bereavement's implications to advance the wellbeing of minority Americans and reduce gaps in health disparities and inequities.

SAMHSA.—Substance abuse and mental health distress play a central role in an individual's ability to cope, productively contribute to the workforce and maintain stability following the death of a loved one. Although it has made major strides in addressing childhood trauma, today, none of SAMHSA's five hotlines or three directories of services include care for the bereaved. SAMHSA should examine its current offerings and determine how bereavement integrates into their existing priorities and programs.

SSA.—SSA offers programs to the bereaved, but many of them are not being utilized or have not been updated for decades. Consider, only 45 percent of bereaved children access Social Security benefits following the death of a parent, thus leaving them at greater risk of poverty, academic failures and use of other social programs.[19] Further, the lump sum death benefit (LSDB) program offers $255 to be-

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[13] https://www.nejm.org/doi/full/10.1056/NEJMoa033160.

[14] https://acsjournals.onlinelibrary.wiley.com/doi/pdf/10.1002/cncr.10943.

[15] https://www.ncbi.nlm.nih.gov/pubmed/12573371.

[16] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3374048/.

[17] https://www.ncbi.nlm.nih.gov/pubmed/28115712.

[18] https://journals.sagepub.com/doi/abs/10.1177/0022146517739317.

[19] https://papers.ssrn.com/sol3/papers.cfm?abstract__id=3471209.

reaved individuals to help subsidize the high cost of funerals (estimates range from $7,000 to $12,000). LSBD has not been updated since 1954.[20] SSA's programs, data and policies warrant examination.

Thank you for the opportunity to present this testimony on behalf of bereaved Americans.

[This statement was submitted by Joyal Mulheron, Founder & Executive Director, Evermore.]

PREPARED STATEMENT OF THE FAMILIES AND FRIENDS OF CARE FACILITY RESIDENTS

Chairman Blunt, Ranking Member Murray and Committee Members,

Thank you for the opportunity to submit testimony. Thank you for your public service.

INTEREST AND REQUEST OF FF–CFR

I am the mother and guardian of John Farrar Sherman, aged 51, who functions on the level of a young toddler. I submit this testimony in behalf of Arkansas' statewide parent-guardian association, Families & Friends of Care Facility Residents (FF–CFR), a 501 (c)3 organization which was formed by my late husband and other concerned families in 1991 in support of Arkansans with life-long permanent disabilities. Most, but not all, members of FF–CFR have loved ones with disabilities receiving residential treatment services in one of Arkansas' five human development centers which are Medicaid-certified intermediate care facilities (ICFs).

FF–CFR is not requesting Federal funds. Rather, we request relief from the use of funds by Department of Health and Human Services to undermine and eliminate intermediate care facilities (ICFs), the specialized long-term care facilities for persons with cognitive and other developmental disabilities.

FALSE NARRATIVE: NATIONAL TREND TO CLOSE INSTITUTIONS

Our families watch with concern as states consolidate/downsize and close public and private intermediate care facilities (ICFs), the Medicaid certified congregate care programs designed to address the urgent care needs of persons with cognitive and other life-long developmental disabilities. A false narrative is being promoted that all persons with disabilities thrive in small-less-regulated-care programs and also that deinstitutionalization from licensed facilities is a "national trend." We submit that vulnerable persons are dying horrific deaths when they are barred from appropriate care in licensed facilities. We submit that the so-called "national trend" of deinstitutionalization has been: (1) created and encouraged by Department of Health and Human Services programs and policies which destructively promote one needed program ("community" care) over another needed program ("institutional" care); (2) fueled by Federal dollars; and (3) encouraged by insufficient oversight of Federal programs, policies and funds being used to weaken and eliminate the ICF option. Finally, the "national trend" of deinstitutionalization has been promoted by federally funded advocacy organizations and programs which do not represent our family members with disabilities and their peers, individuals living with life-long profound or severe cognitive deficits and other developmental disabilities, most of whom are nonverbal and who are unable to self-advocate.

MORTALITY OF VULNERABLE PERSONS

Do you read stories in the media of horrific deaths of persons unable to care for themselves? I do. And each time I read a story about the awful death of such an at-risk individual, that person is not faceless to me. He or she has a family; they are someone's daughter or son/sister or brother. When I read such stories, I have these thoughts: without me and without my state's specialized residential treatment programs, my son could be the subject of such an article.

Attached hereto are summaries of two stories which were published recently in our statewide paper. See FF–CFR Attachment 1. Through the Internet, one can download the full reports. Here is the reality about me reading the stories: yes, I see my son and his peers in them, but I also know from my years of advocacy work that the two states where these two individuals died their lonely horrible deaths are states which have closed admissions to the ICF program. In the states where these deaths occurred, qualified persons are denied admission to the specialized residen-

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[20] https://fas.org/sgp/crs/misc/R43637.pdf.

tial treatment programs for persons with cognitive and other developmental disabilities.

There is a connection between the work of the LHHS subcommittee, the funding of Department of Health and Human Services programs and grants, and the policies which have led to states closing admissions to ICF programs.

REQUEST

We respectfully request your consideration for report language in the fiscal year 2021 LHHS spending bill barring Federal funds from incentivizing states to close their specialized facilities for persons unable to care for themselves. Suggested Language Attached hereto, FF–CFR Attachment 2.

Respectfully submitted.

[This statement was submitted by Carole L. Sherman, Families & Friends of Care Facility Residents.]

PREPARED STATEMENT OF THE FAMILY PLANNING COALITION

Chairman Blunt, Ranking Member Murray, and Subcommittee Members:

The undersigned organizations collectively represent millions of providers, patients, administrators, researchers, public health professionals, and advocates who support access to high-quality family planning services. Established 50 years ago, the Title X family planning program helps ensure that millions of individuals can obtain high-quality sexual and reproductive healthcare. We are deeply concerned by the administration's continued attacks on the integrity of the Title X program, including the devastating program rule that the Department of Health and Human Services finalized in 2019.[1] Today, more than 1.5 million Title X patients no longer have access to the Title X-funded services at the site they used in 2018 due to the rule.

We urge you to use the fiscal year 2021 Labor, Health and Human Services, Education, and Related Agencies appropriations bill to make a strong statement in support of high-quality, evidence-based, and patient-centered family planning care and against the Title X program rule. We request that you include language to block the rule and to allow existing and former networks to rebuild and begin to reverse the damage caused by the rule. With that language in place, we urge you to appropriate $400 million for the program.

TITLE X IS A CRITICAL SOURCE OF CARE

In 2018, Title X helped close to 4 million people access family planning and related health services at nearly 4,000 health centers.[2] More than half of users identified as people of color.[3] For many individuals, particularly those who have low incomes, are under- or uninsured, or are adolescents, Title X has been their main access point to obtain affordable and confidential contraception, cancer screenings, sexually transmitted disease testing and treatment, complete and medically accurate information about their family planning options, and other basic care. In fact, a study found that in 2016, six in ten women seeking contraceptive services at a Title X health center saw no other healthcare provider that year.[4]

The data show that Title X makes a difference for patients. In 2016, Title X-supported contraceptive services helped patients prevent an estimated 755,000 pregnancies.[5] Title X also supports important health center efforts that are not reimbursable under insurance, including staff training and community-based sexual and reproductive health education programs. Moreover, research has shown that Title X-supported services saved the Federal and state governments approximately $4.4

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[1] Department of Health and Human Services. Final Rule. "Compliance with Statutory Program Integrity Requirements." Federal Register 84 (March 4, 2019): 7714–7791.

[2] Christina Fowler et al, "Family Planning Annual Report: 2018 National Summary," RTI International (August 2019). https://www.hhs.gov/opa/sites/default/files/title-x-fpar-2018-national-summary.pdf.

[3] Id. This calculation includes persons who identify as non-white and persons who identify as white and Hispanic.

[4] Megan Kavanaugh, Mia Zolna, and Kristen Burke, "Use of Health Insurance Among Clients Seeking Contraceptive Services at Title X-Funded Facilities in 2016," Perspectives on Sexual and Reproductive Health 50.3 (September 2018). https://onlinelibrary.wiley.com/doi/full/10.1363/psrh.12061.

[5] Jennifer Frost et al, "Publicly Supported Family Planning in the United States: Likely Need, Availability and Impact, 2016," Guttmacher Institute (October 2019). https://www.guttmacher.org/report/publicly-funded-contraceptive-services-us-clinics-2015.

billion in 2016,[6] and 75 percent of American adults-including 66 percent of Republicans, 75 percent of Independents, and 84 percent of Democrats-support the program.[7]

Title X's key role in the public health safety net has been threatened by the Trump administration's 2019 program rule. Following rule implementation in July 2019, 18 grantees, along with many subrecipients, left the program rather than comply with the onerous, medically unnecessary requirements. In 2018, the approximately 1,000 sites run by those entities served more than 1.5 million patients, including the many patients served by Planned Parenthood. Health centers that remained in the program face the challenge of implementing a misguided rule while attempting to keep their doors open and services available to, and affordable for, patients.

To rectify this situation, we urge Congress to include language in the fiscal year 2021 Labor-HHS bill that blocks implementation of the rule and allows entities that left the program to rejoin it. It is crucial that remaining and previous grantees be able to rebuild their networks and trusted services once the rule is no longer in place. These steps are critical to ensure that people across the country regain access to affordable services at their preferred family planning provider.

TITLE X IS SEVERELY UNDERFUNDED

In addition to the challenges posed by the Title X rule, the program is unable to serve as many patients as need care due to woeful underfunding. In 2016, researchers from the Centers for Disease Control and Prevention, the Office of Population Affairs, and George Washington University estimated that Title X would need $737 million annually to deliver family planning care to all uninsured women with low incomes in the United States.[8] This estimate understates the true need for Title X, as it does not include an estimate of costs for men (who made up 13 percent of patients in the network in 2018),[9] gender non-binary persons, and the insured patients who rely on Title X's confidentiality protections.

The gap between the funds appropriated and the funds needed has only grown in recent years. From 2010 to 2016 the number of women in need of publicly funded family planning services increased by 1.5 million,[10] but Congress cut Title X's funding by $31 million over that period. That decrease unfortunately corresponded to dramatic decreases in patients served at Title X-funded sites, from 5.22 million seen in 2010[11] to just under 4 million seen in 2018.[12]

We are deeply concerned about diminishing access to high-quality family planning services and urge Congress to take an initial step to reverse this devastating trend by appropriating $400 million for Title X in fiscal year 2021. This funding increase, however, must be paired with the language referenced above, and we urge you to prioritize blocking the 2019 rule and creating the pathway for entities to reenter the program.

TITLE X IS MORE IMPORTANT THAN EVER DUE TO COVID–19

The need for the Title X program and network of providers it funds is even more critical as the novel coronavirus affects communities across the country. Family planning and sexual health services are often time-sensitive, and the need for these services does not stop during a pandemic. In fact, recent public opinion polling shows that a majority of U.S. adults (65 percent) think now is a bad time for individuals and couples to try to get pregnant, and only 5 percent of adults would consider it "less essential" for individuals to have access to birth control during the coronavirus pandemic.[13] Now more than ever, the Title X provider network, already

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[6] Rachel Benson Gold, Adam Sonfield, "Title X Family Planning Services: Impactful but at Severe Risk," Guttmacher Institute (October 2019). https://www.guttmacher.org/article/2019/10/title-x-family-planning-services-impactful-severe-risk.

[7] Survey Says: Birth Control Support. The National Campaign to Prevent Teen and Unplanned Pregnancy (2017). https://thenationalcampaign.org/resource/survey-says-january-2017.

[8] Euna August, et al, "Projecting the Unmet Need and Costs for Contraception Services After the Affordable Care Act," American Journal of Public Health (February 2016): 334–341.

[9] Fowler, "FPAR 2018."

[10] Frost, "Publicly Supported Family Planning Services in the United States."

[11] Christina Fowler et al, "Family Planning Annual Report: 2010 National Summary," RTI International (September 2011). https://www.hhs.gov/opa/sites/default/files/fpar-2010-national-summary.pdf.

[12] Fowler, "FPAR 2018."

[13] Morning Consult, on behalf of the National Family Planning & Reproductive Health Association (NFPRHA), conducted a poll using a national sample of 2,200 US adults, between April 30—May 2, 2020. The interviews were conducted online, and the data were weighted to approxi-

struggling in the wake of years of attacks and chronic underfunding, needs the robust support of Congress to continue to provide high-quality family planning and sexual health services.

Furthermore, family planning staffing has been impacted at health centers due in some instances to employees being redeployed to COVID–19 response and because of the individual toll the pandemic has taken on staff, including short-term and long-term absences because employees need to tend to health and family issues. Staffing issues coupled with decreased patient visits and the likelihood that states will need to cut family planning funding in future budgets to help backfill COVID–19 expenditures means that current public funding for safety-net health centers is simply not enough. Access to essential services depends on health centers receiving sufficient funds to remain open and programmatic rules that allow expert providers to offer the best possible care.

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During the fiscal year 2021 appropriations process, Congress has the opportunity to stand against relentless attacks on family planning and support strong public funding for the Title X family planning network. The undersigned organizations urge you to begin the expansion of family planning and related healthcare services with this critical language and meaningful investment in Title X.

If you have any questions or would like additional information, please contact Lauren Weiss at the National Family Planning & Reproductive Health Association at lweiss@nfprha.org.

Thank you for considering these requests.

Sincerely,

Abortion Care Network
ACLU
AIDS Action Baltimore
AIDS Alabama
AIDS Alliance for Women, Infants, Children, Youth & Families
AIDS Foundation of Chicago
AIDS United
Alliance for Justice
American Academy of Pediatrics
American Atheists
American College of Nurse-Midwives
American College of Obstetricians and Gynecologists
American Medical Student Association
American Public Health Association
American Sexual Health Association
American Society for Reproductive Medicine
Association of Nurses in AIDS Care
Association of Schools and Programs of Public Health
Association of Women's Health, Obstetric and Neonatal Nurses
Black AIDS Institute
Black Women's Health Imperative
Cascade AIDS Project
Catholics for Choice
Center for American Progress
Center for Reproductive Rights
Endocrine Society
Equality California
Equality North Carolina
Equity Forward
Girls Inc.
Guttmacher Institute
Hadassah, The Women's Zionist Organization of America, Inc.
Healthy Teen Network
HIV Medicine Association
Human Rights Campaign
If/When/How: Lawyering for Reproductive Justice
In Our Own Voice: National Black Women's Reproductive Justice Agenda
Ipas
Jacobs Institute of Women's Health
Jewish Women International
NARAL Pro-Choice America
NASTAD
National Abortion Federation
National Asian Pacific American Women's Forum (NAPAWF)
National Association of County and City Health Officials
National Coalition of STD Directors
National Council of Jewish Women
National Family Planning & Reproductive Health Association
National Hispanic Medical Association
National Institute for Reproductive Health (NIRH)
National Latina Institute for Reproductive Health
National Medical Association
National Network of Abortion Funds
National Organization for Women
National Partnership for Women & Families
National Women's Health Network
National Women's Law Center
North Carolina AIDS Action Network
Nurses for Sexual and Reproductive Health
Ovarian Cancer Research Alliance
PAI

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mate a target sample of US adults based on age, educational attainment, gender, race, and region. Results from the full survey have a margin of error of +/−2 percent.

People For the American Way
Physicians for Reproductive Health
Planned Parenthood Federation of America
Population Connection Action Fund
Population Institute
Power to Decide
Raising Women's Voices for the Health Care We Need
Religious Coalition for Reproductive Choice
Reproductive Health Access Project
Ryan White Medical Providers Coalition
San Francisco AIDS Foundation
SIECUS: Sex Ed for Social Change
Silver State Equality-Nevada
Society for Adolescent Health and Medicine
Southern AIDS Coalition
The AIDS Institute
The Well Project
Treatment Action Group
Union for Reform Judaism
Women of Reform Judaism

PREPARED STATEMENT OF THE FEDERAL AIDS POLICY PARTNERSHIP'S RESEARCH WORKING GROUP

On behalf of the Federal AIDS Policy Partnership's Research Working Group, we thank Chairman Senator Blunt, Ranking Member Senator Murray, and members of the Committee for the opportunity to submit testimony to the Senate LHHS Subcommittee on fiscal year 2021 Appropriations for the National Institutes of Health (NIH) in regards to protecting, strengthening, and expanding our nation's HIV/AIDS research agenda. The Research Work Group (RWG) of the Federal AIDS Policy Partnership (FAPP) is a coalition of more than 60 national and local HIV/AIDS research advocates, patients, clinicians and scientists from across the country. Our goal is to advance and support U.S. leadership to accelerate progress in the field of HIV/AIDS research. The FAPP RWG urges the subcommittee to recommend a fiscal year 2021 budget request level of at least $44.7 billion for the NIH, and ask that at least $3.502 billion be allocated for HIV research at the NIH in fiscal year 2021.

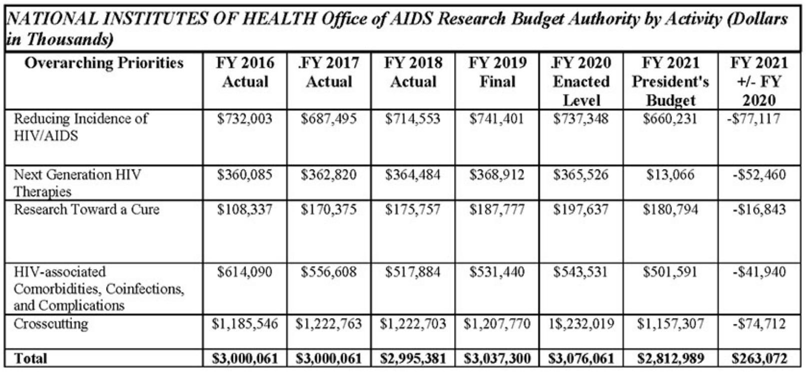
Public investments in health research via NIH have paid enormous dividends in the health and wellbeing of people in the U.S. and around the world, particularly for people living with, or vulnerable to, HIV. NIH funded AIDS research has supported innovative basic science for better drug therapies, and evidence-based behavioral and biomedical prevention interventions which have saved and improved the lives of millions. NIH funding has contributed to over 210 approvals for a range of novel therapeutics between 2010 through 2016, with new anti-infectives for HIV and HCV receiving the second largest fraction of those approvals. Additionally, NIH support was crucial in the development of pre-exposure prophylaxis (PrEP), an HIV prevention tool that is upwards of 99 percent effective in preventing sexual transmission. Now more than ever, NIH-supported HIV research is critical to advancement of possible treatments and a vaccine to counter the rising COVID–19 pandemic.

HIV research advances at the NIH hold the potential to end the AIDS epidemic, as well as update prevention approaches and improve outcomes along the treatment cascade—a cornerstone of the Trump Administration's initiative to End the HIV Epidemic in the U.S. In addition, the average age of people living with HIV in the United States is increasing, so it also remains critically important to make substantial investments in research on co-morbidities and new antiretroviral therapies. This aging population needs to stay healthy and virally suppressed in order to bring community viral load to zero.

Federal support for HIV/AIDS research has cross-benefits for new treatments for other diseases, including cancer, heart disease, Alzheimer's, hepatitis, osteoporosis, and a wide range of autoimmune disorders. Several HIV/AIDS treatments, notably lopinavir/ritonavir, have been researched as treatments for the novel coronavirus (SARS-CoV–2)—saving months of research time and, in the process, potentially countless lives. Coronavirus vaccine research is now ongoing using platforms and technology, such as Ad26, previously developed for use as an HIV vaccine. These cross-disease benefits of HIV research provide tremendous value in the dollars invested and necessary infrastructure to support our nation's response to this emerging public health crisis.

Yet, the Administration's fiscal year 2021 budget proposal ignores these significant contributions made by NIH and the need for a strong HIV/AIDS research agenda in the End the HIV Epidemic initiative with deep cuts in funding made to the Office of AIDS Research (OAR) that places current studies, including for a vaccine and a cure for HIV, in peril. These cuts also have a collateral effect by undermining existing research infrastructure to develop tools needed to counter COVID–19, which were made possible through historical and sustained investments to HIV research.

The fiscal year 2021 President's Budget request for the NIH HIV research program at OAR is $2,812 billion, a decrease of $263 million compared to fiscal year 2020 levels. The proposal includes substantial cuts (see table below) to HIV research into prevention, cure, and HIV aging research. Scientific progress on cure and vaccine research remains steady and iterative, and cutting research funding at this juncture will only lengthen the time horizons or completely impede these studies from realizing the potential of these investments. To truly achieve an end to the HIV epidemic, we need a vaccine and cure alongside our current slate of therapeutics and prevention modalities. To support a science-based agenda for COVID–19, we must continue to strengthen HIV research. In sum, these cuts would do harm to the HIV research agenda, the health of people living with HIV, and the prospect of new tools to combat COVID–19 in which HIV research infrastructure is being relied upon. We urge the subcommittee to reject these cuts.



NATIONAL INSTITUTES OF HEALTH Office of AIDS Research Budget Authority by Activity (Dollars in Thousands)

Overarching Priorities	**FY 2016 Actual**	**.FY 2017 Actual**	**FY 2018 Actual**	**FY 2019 Final**	**.FY 2020 Enacted Level**	**FY 2021 President's Budget**	**FY 2021 +/- FY 2020**
Reducing Incidence of HIV/AIDS	$732,003	$687,495	$714,553	$741,401	$737,348	$660,231	-$77,117
Next Generation HIV Therapies	$360,085	$362,820	$364,484	$368,912	$365,526	$13,066	-$52,460
Research Toward a Cure	$108,337	$170,375	$175,757	$187,777	$197,637	$180,794	-$16,843
HIV-associated Comorbidities, Coinfections, and Complications	$614,090	$556,608	$517,884	$531,440	$543,531	$501,591	-$41,940
Crosscutting	$1,185,546	$1,222,763	$1,222,703	$1,207,770	1$,232,019	$1,157,307	-$74,712
Total	**$3,000,061**	**$3,000,061**	**$2,995,381**	**$3,037,300**	**$3,076,061**	**$2,812,989**	**$263,072**

Furthermore, since 2003, funding for NIH HIV research has failed to keep up with our existing research needs—damaging the success rate of approved grants and leaving very little money to fund promising new research—despite increases to the overall NIH budget. According to the Biomedical Research and Development Price Index (BRDI)—which calculates how much the NIH budget must change each year to maintain purchasing power—between fiscal year 2003 and fiscal year 2017, the NIH budget in constant dollars according to BRDI will have declined by more than a third. The cuts proposed in the President's budget would only further widen the gap.

Investment by the NIH has transformed the HIV epidemic from a terrible, untreatable disease to a chronic condition that can be managed through once-a-day drug regimens. Now is the time to increase investment for the NIH to finish the job and end the HIV epidemic through strategic, science-based interventions. NIH funding of HIV/AIDS research provides an example of innovation at work where investment in basic and translational research, working in partnership with industry and community, can move quickly to develop solutions. NIH investments in HIV/AIDS research add value by seeding ideas later taken up in industry partnerships and creating innovation incubators for important medical advances with significant health impact.

Robust funding for NIH overall enables research universities to pursue scientific opportunity, advance public health, and create jobs and economic growth. NIH funding puts approximately 300,000 scientists to work at research institutions across the country. According to NIH, each of its research grants creates or sustains six to eight jobs and NIH-supported research grants and technology transfers have resulted in the creation of thousands of new independent private sector companies.

The race to find better treatments and a cure for cancer, Alzheimer's, heart disease, HIV/AIDS, and other diseases, and for controlling global epidemics like AIDS, tuberculosis, coronavirus, and malaria, all depend on a robust long-term investment strategy for health research at NIH. There can be no innovation without reliable and adequate research funding. Congress should ensure the nation does not delay vital HIV/AIDS research progress. We must protect HIV/AIDS research funding to sustain research capacity and maintain our worldwide leadership in HIV/AIDS research and innovation.

To that end, we urge the subcommittee to consider a needed increase to the overall fiscal year 2021 budget request level of at least $44.7 billion for the National Institutes of Health (NIH) consistent with the request of the Ad Hoc Group for Medical Research. While this increase gets us closer to meeting the recent Trans-NIH AIDS Research By-Pass Budget Estimate for fiscal year 2020, we ask the committee that at least $3.502 billion be allocated for HIV research at the NIH in fiscal year 2021, an increase of $426 million. We also urge the subcommittee to consider approaches to ensure the HIV research budget receives increases alongside other important and intersecting biomedical research at NIH. The fiscal year 2021 President's Budget request includes reallocation of $6 million in existing Centers for AIDS Research (CFAR) funding to support this initiative. We believe that CFARs are suited well to reach this goal, but funding must be new funding for this initiative to succeed. We urge the subcommittee to direct specific and increased CFAR funding for this purpose.

In conclusion, the RWG calls on Congress to continue the bipartisan Federal commitment towards combating HIV as well as other chronic and life-threatening illnesses by increasing funding for NIH in fiscal year 2021. This is especially critical in a time where science is needed to counter the escalating COVID–19 pandemic. A meaningful commitment towards maintaining the U.S. pre-eminence in HIV research and fostering innovation cannot be met without prioritizing the research investment at NIH that will lead to tomorrow's lifesaving vaccines, treatments, and cures that are needed to end the HIV epidemic here and abroad. Thank you for the opportunity to provide these written comments.

PREPARED STATEMENT OF THE FEDERATION OF AMERICAN SOCIETIES FOR EXPERIMENTAL BIOLOGY

The Federation of American Societies for Experimental Biology (FASEB) respectfully requests a minimum of $44.7 billion in fiscal year 2021 for the National Institutes of Health (NIH).

The NIH is the nation's largest funder of biomedical research, providing competitive grants to support the work of 300,000 scientists at universities, medical centers, independent research institutions, and companies nationwide.

Congress has renewed its commitment to this critical research agency, providing robust, sustained, and predictable budget increases over the last five fiscal years (Figure 1). With these resources, NIH has accelerated progress across all areas of medical science, including regenerative medicine, cancer immunotherapy, and neurological health.[1,2,3] The agency has also expanded its commitment to support more of the best and brightest young scientists, the next generation of our biomedical research enterprise.[4]

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[1] NIH Regenerative Medicine Innovation Project, National Institutes of Health, Bethesda, MD.

[2] NCI's Role in Immunotherapy Research, National Cancer Institute, Bethesda, MD.

[3] The BRAIN Initiative Summary, National Institutes of Health, Bethesda, MD.

[4] NIH Grants and Funding, Next Generation Research Initiative, National Institutes of Health, Bethesda, MD.

FASEB FY 2021 Recommendation: at least $44.7 billion for NIH

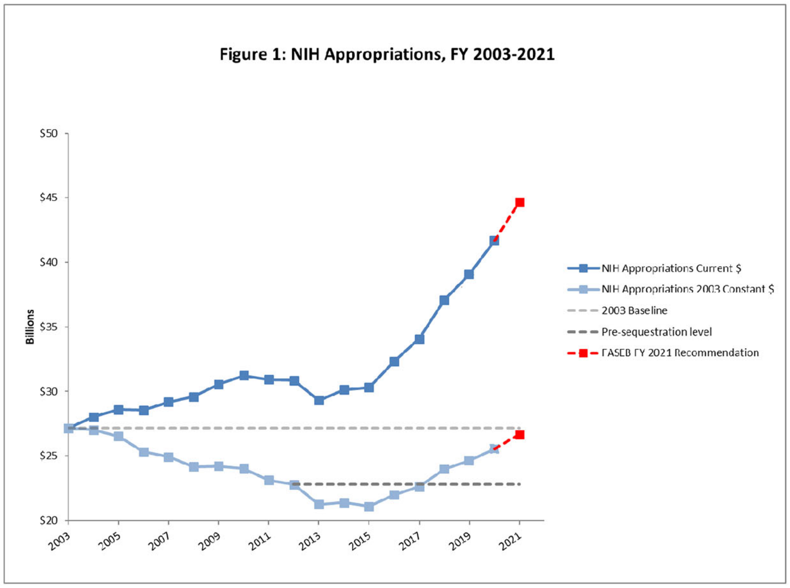

Figure 1: NIH Appropriations, FY 2003-2021

Though the NIH is in a stronger position than it was just a few years ago, Congress must continue to increase biomedical research funding because our nation and the world are confronting daunting public health threats, especially given a changing global climate. More research will be needed to address increased risks posed by infectious diseases and greater exposure to environmental pollutants.[5]

In the U.S., we also must address the needs of an aging population. NIH-supported research is developing therapies and cures for the whole spectrum of age-related disorders.[6]

The great challenges of a changing climate and our aging population will require us to expand our robust investment in biomedical research. A $44.7 billion budget ($3 billion above fiscal year 2020) would allow NIH to continue its commitment to the Next Generation Researchers Initiative; provide $404 million already authorized through the 21st Century Cures Act for key research initiatives; and provide a 3 percent budget increase across NIH Institutes and Centers, allowing them to bolster research areas in need of resources.

PREPARED STATEMENT OF THE FEDERATION OF ASSOCIATIONS IN BEHAVIORAL AND BRAIN SCIENCES

The Federation of Associations in Behavioral and Brain Sciences (FABBS) represents 26 scientific societies and nearly 70 university departments whose scientific members and faculty share a commitment to advancing knowledge in the sciences of mind, brain, and behavior. Through research in these sciences, FABBS members increase understanding of the human element of the most pressing challenges facing society, improving the health and education of our citizens. FABBS appreciates the opportunity to submit testimony in support of the Federal agencies investing in behavioral and cognitive science. For fiscal year 2021, FABBS encourages your subcommittee to provide the National Institutes of Health (NIH) with a budget of at least $44.7 billion, the National Center for Health Statistics (NCHS) within the Center for Disease Control, a budget of at least $189 million, the Agency for

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[5] IPCC AR5 Climate Change 2014, Chapter 11: Human Health: Impacts, Adaptation, and Co-Benefits.

[6] Aging Well in the 21st Century: Strategic Directions for Research on Aging, National Institute on Aging, Bethesda, MD.

Healthcare Research and Quality (AHRQ) at $471 million, and the Institute of Education Sciences (IES) within the Department of Education a budget of $670 million.

During this unprecedented time, FABBS members are actively working to help mitigate the extensive damage of the COVID–19 pandemic. Behavioral and brain scientists are conducting research on strategies to reduce transmission of the virus such as hand washing and restraint from touching one's face; identifying interventions to support mental health and recovery from addiction; developing decision-making tools for response actions; and adjusting to online learning for students. These efforts are contributing to the Federal and local responses. In many cases, prior federally-sponsored research at NIH, NCHS, AHRQ and IES has helped create the expertise and capabilities essential during the global pandemic. We thank the subcommittee for its role in providing supplemental appropriations to fight the pandemic including the funds provided to the NIH.

FABBS would like to thank this subcommittee for their strong bipartisan vision and diligence last year. The community is extremely grateful that this subcommittee successfully completed a final Labor, Health and Human Services, Education budget for fiscal year 2020, sparing these agencies from experiencing an extended government shutdown. We very much hope that we will see similar success funding these agencies for fiscal year 2021.

NATIONAL INSTITUTES OF HEALTH

We sincerely thank the Labor HHS Appropriations Subcommittee for its diligent work and considerable increases to NIH over the past 4 years. As members of the Ad Hoc Group for Medical Research and the Coalition for Health Funding, FABBS recommends at least $44.7 billion for NIH in fiscal year 2021. FABBS members contribute to the NIH mission of seeking fundamental knowledge about the behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability. FABBS members contribute to the advances in numerous institutes and centers.

FABBS members have a particular interest in the Office of Behavioral and Social Science Research (OBSSR). OBSSR was created to coordinate and promote basic, clinical, and translational behavioral and social science research at NIH. The office serves an essential function in enhancing trans-NIH investments in longitudinal datasets, technology in support of behavior change, innovative research methodologies, and promoting the inclusion of behavioral science in initiatives at the NIH Institutes and Centers (IC). In partnership with other Institutes and Centers, OBSSR co-funds highly rated grants that the ICs cannot fund alone, and coordinates NIH's high-priority program on gun violence prevention research.

While the NIH budget has grown in recent years, funding for OBSSR has not seen commensurate increases. We recognize that, located in the Office of the Director, OBSSR does not have a specific appropriation. Nonetheless, FABBS appreciates the opportunity to express support for OBSSR, underscore its key role supporting the mission of NIH, and raise concerns about recent flat funding.

National Center for Health Statistics (NCHS), Center for Disease Control—As members of the Friends of NCHS, FABBS urges the Subcommittee to appropriate $189 million (an increase of $14.6 million and realignment of $14 million in ongoing transfers) to NCHS in fiscal year 2021. This increase would restore the NCHS budget to the fiscal year 2010 funding level (adjusted for inflation) enabling NCHS to continue to produce its essential existing surveys and reports without interruption. Communities across the country rely on the high-quality data provided by NCHS to understand and improve health. We greatly appreciate the Subcommittee's longstanding support of NCHS and the data it produces on all aspects of our healthcare system, such as opioid and prescription drug use, healthcare disparities, and causes of death.

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY (AHRQ)

Consistent with the Friends of AHRQ, FABBS requests $471 million for AHRQ in fiscal year 2021. AHRQ is the only Federal agency that funds research at universities and other research institutions throughout the nation on health systems—the "real-life" patient who has complex comorbidities, the interoperability of different technological advances, and the interactions and intersections of healthcare providers.

Institute of Education Sciences (IES), U.S. Department of Education.—As members of the Friends of IES, FABBS encourages the subcommittee to appropriate at least $670 million to IES in fiscal year 2021. This funding level would restore IES to the fiscal year 2011 real dollar purchasing power level. IES is a semi-independent, nonpartisan branch of the U.S. Department of Education and is the research foundation for improving and evaluating teaching and learning. The four centers—the National Center for Education Statistics (NCES), National Center for Education Research (NCER), National Center for Special Education Research (NCSER) and National Center for Education Evaluation (NCEE)—work collaboratively to efficiently and comprehensively produce and disseminate rigorous research and high-quality data and statistics.

Thank you for the opportunity to express support for the following fiscal year 2021 budget requests:

—National Institutes of Health at least $44.7 billion
—National Center for Health Statistics at least $189 million
—Agency for Healthcare Research and Quality at least $471 million
—Institute of Education Sciences at least $670 million

These investments to strengthen behavioral and cognitive research are critical to the health and education of our citizens. Thank you for considering this request.

FABBS Member Societies:

Academy of Behavioral Medical Research, American Educational Research Association, American Psychological Association, American Psychosomatic Society, Association for Applied Psychophysiology and Biofeedback, Association for Behavior, Analysis, Behavior Genetics Association, Cognitive Neuroscience Society, Cognitive Science Society, International Society for Developmental Psychobiology, Massachusetts Neuropsychological Society, National Academy of Neuropsychology, The Psychonomic Society, Society for Behavioral Neuroendocrinology, Society for Computers in Psychology, Society for Judgement and Decision Making, Society for Mathematical Psychology, Society for Psychophysiological Research, Society for the Psychological Study of Social Issues, Society for Research in Child Development, Society for Research in Psychopathology, Society for the Scientific Study of Reading, Society for Text & Discourse, Society of Experimental Social Psychology, Society of Multivariate Experimental Psychology, Vision Sciences Society

FABBS Affiliates:

APA Division 1: The Society for General Psychology; APA Division 3: Experimental Psychology; APA Division 7: Developmental Psychology; APA Division 28: Psychopharmacology and Substance Abuse; Arizona State University; Binghamton University; Boston University; California State University, Fullerton; Carnegie Mellon University; Columbia University; Cornell University; Duke University; East Tennessee State University; Florida International University; Florida State University; George Mason University; George Washington University; Georgetown University; Georgia Institute of Technology; Harvard University; Indiana University Bloomington; Indiana University—Purdue University Indianapolis; Johns Hopkins University; Kent State University; Lehigh University; Massachusetts Institute of Technology; Michigan State University; New York University; North Carolina State University; Northeastern University; Northwestern University; The Ohio State University, Center for Cognitive and Brain Sciences; Pennsylvania State University; Princeton University; Purdue University; Rice University; Southern Methodist University; Stanford University; Syracuse University; Temple University; Texas A&M University; Tulane University; University of Arizona; University of California, Berkeley; University of California, Davis; University of California, Irvine; University of California, Los Angeles; University of California, Riverside; University of California, San Diego; University of Chicago; University of Colorado, Boulder; University of Delaware; University of Houston; University of Illinois at Urbana-Champaign; University of Iowa; University of Maryland, College Park; University of Massachusetts Amherst; University of Michigan; University of Minnesota; University of Minnesota, Institute of Child Development; University of North Carolina at Greensboro; University of Pennsylvania; University of Texas at Austin; University of Texas at Dallas; University of Washington; Vanderbilt University; Virginia Tech; Wake Forest University; Washington University in St. Louis; Yale University

[This statement was submitted by Juliane Baron, Executive Director, Federation of Associations in Behavioral and Brain Sciences.]

PREPARED STATEMENT OF FLORIDA A&M UNIVERSITY

Chairmen Shelby and Blunt, Vice Chairman Leahy, Ranking Member Murray, and Members of the Labor, Health and Human Services, and Education, and Related Agencies Subcommittee, thank you for the opportunity to submit public testimony on the subcommittee's fiscal year 2021 appropriations bill. Florida A&M University (FAMU) supports maintaining or enhancing funding at the fiscal year 2020 enacted level for programs of interest to the University and our students, including the Department of Education's Historically Black Colleges and Universities (HBCU) programs, the HBCU Capital Financing Program, and the Federal Pell Grants program. FAMU also supports two programs at the Department of Health and Human Services—the National Institutes of Health's Research Centers in Minority Institutions and the Health Resources and Services Administration's Health Careers Opportunity Program. These Federal programs provide critical support to the University, our students as well as other institutions of higher education and the nation.

Florida A&M University, based in the State capitol of Tallahassee, Florida, was founded in 1887 with only 15 students and two instructors. Today, FAMU has grown to nearly 10,000 students and we are proud to be the highest ranked among public Historically Black Colleges and Universities (HBCU) according to the U.S. News and World Report National Public Universities. Our University offers 56 bachelor's degrees, 29 master's degrees, 12 doctoral degrees and three professional degrees. We are a leading land-grant research institution with an increased focus on science, technology, research, engineering, agriculture, and mathematics. As noted by Diverse Issues, FAMU is a top producer of African American doctoral degrees in pharmacy and pharmaceutical sciences.

Federal support is critical for institutions of higher education, particularly HBCUs, which are historically under-resourced. Robust Federal funding for programs that help to improve our institutions, broaden access for students, and improve student success is paramount. The Department of Education HBCU programs help us achieve these goals and the Federal Pell Grant program is an imperative resource for our students as the majority of our students are Pell-eligible. Furthermore, the Department of Health and Human Services' research and career development programs that support minority students also benefit FAMU, our students, and the nation. FAMU strongly supports funding for these vital Federal programs.

Department of Education Historically Black Colleges and Universities Programs

FAMU strongly supports robust funding for the Department of Education HBCU programs under the Higher Education, Aid for Institutional Development Programs account. These programs, authorized under Title III of the Higher Education Act, provide critical support to higher education institutions that enroll large proportions of minority and financially disadvantaged students. One of the primary missions of the Title III programs has been to support the nation's HBCUs. The Strengthening Historically Black Colleges and Universities program and the Historically Black Graduate Institutions program provide FAMU and other HBCUs with formula grants to help strengthen our academic, administrative, and fiscal capabilities.

The President's fiscal year 2021 budget requests $324.8 million for the Strengthening Historically Black Colleges and Universities program. These formula grants provide critical support to HBCUs that help to improve our facilities, develop faculty, support academic programs, strengthen institutional management, enhance our development and recruitment activities, and provide tutoring and counseling services to students. In fiscal year 2019, FAMU received $7 million under the program.

We also support the President's fiscal year 2021 budget request of $84 million for the Strengthening Historically Black Graduate Institutions, which funds five-year grants to provide for scholarships for disadvantaged students, academic and counseling services to improve student success, and supports infrastructure and facilities improvements. FAMU received $3.8 million under the current five-year grant period for this program.

FAMU, like other HBCUs, has a critical need for funding to support equipment upgrades and purchases, construction and renovation of our facilities, and development of our academic programs. This includes a wide variety of projects to strengthen the University and its programs, such as expansion of our online education offerings to enhance pathways to degree attainment, upgrading our information technology infrastructure, construction of laboratories, research and education facilities, and upgrading our health sciences and technology equipment and facilities. Continued funding for these HBCU programs and other Aid for Institutional Development programs is essential to postsecondary institutions, like FAMU, that educate the nation's minority students.

Department of Education Historically Black Colleges and Universities Capital Financing Program

FAMU supports maintaining the fiscal year 2020 enacted level of $46.848 million for the Department of Education's HBCU Capital Financing Program, which provides low-cost capital to finance improvements to the infrastructure of the nation's HBCUs. Specifically, the program provides accredited HBCUs with access to capital financing or refinancing for the repair, renovation, and construction of classrooms, libraries, laboratories, dormitories, instructional equipment, and research instrumentation.

FAMU, like other HBCUs, has a critical need to upgrade and rehabilitate our aging facilities. This program makes capital available for HBCUs to improve our academic facilities, which will enhance the learning experience for our students. The $46.484 million requested for fiscal year 2021 will be used to pay the loan subsidy costs in guaranteed loan authority under the program. The President's fiscal year 2021 budget only proposes $40.848 million for the program. FAMU urges to the Subcommittee to reject the President's proposal and provide the current level of funding for fiscal year 2021, which will allow HBCUs to continue to refinance previous capital project loans, renovate existing facilities, or build new facilities to improve our institutions.

Department of Education Pell Grant Program

FAMU supports robust funding for the Pell Grant program under the Department of Education's Student Financial Assistance account. The Federal Pell Grant program, authorized by Title IV of the Higher Education Act, is the largest source of Federal grant aid supporting college students. The Pell Grant Program provides need-based grants to low-income undergraduate students to promote access to postsecondary education.

For 2017–2018, there were 5,543 Pell Grant recipients attending FAMU, amounting to $27.7 million in Pell Grant awards. More than half of our enrolled students rely on Pell grants to attend our institution. Given the ongoing coronavirus crisis, which will have devastating impacts on the economy for the foreseeable future, we expect that our current and prospective students will be dependent on financial assistance, including Pell Grants, in order to continue pursuing their postsecondary education goals.

The President's fiscal year 2021 budget requests level funding of $22.475 billion for Discretionary Pell Grants. For fiscal year 2020, Congress increased the maximum award by $150, to $6,345 in academic year 2020–2021. FAMU would encourage Congress to double the total maximum Pell grant award in fiscal year 2021 to provide critical support for economically disadvantaged college students during this particularly challenging time.

National Institutes of Health Research Centers in Minority Institutions

FAMU supports funding at the fiscal year 2020 enacted level of $75 million for the NIH National Institute on Minority Health and Health Disparities (NIMHD), Research Centers in Minority Institutions (RCMI) Program. The RCMI Program, established in 1985, supports critical infrastructure development and scientific discovery in historically minority graduate and health professional schools. The program serves the dual purpose of bringing more racial and ethnic minority scientists into mainstream research and promoting minority health research because many of the investigators at RCMI institutions study diseases that disproportionately affect minority populations.

Over the five-year period of 2013–2018, FAMU was awarded $13.7 million under the RCMI Program to support drug discovery and research aimed at better understanding of the makeup and risks associated with various degenerative diseases and their treatment. In the area of drug discovery, the grant aids in developing new drugs that can be used for the treatment of neurodegenerative diseases such as Parkinson's; stroke; cancer (breast, prostate and lung); and emerging infectious diseases to uncover targets for therapy and translational research.

Since 1985, FAMU has received RCMI support in excess of $54 million, which has helped to fund construction for the research wing of the College of Pharmacy and make laboratory improvements. It has provided critical infrastructure to enable the College to achieve national prominence and become a competitive biomedical research center nationally. Since the inception of the RCMI Program at FAMU, the College has implemented four doctoral tracks in pharmaceutical sciences. With concentrations in pharmacology/toxicology, medicinal chemistry, pharmaceutics and environmental toxicology, our College of Pharmacy has graduated more than 60 percent of the African American doctoral recipients in the pharmaceutical sciences nationally.

The President's fiscal year 2021 budget cuts funding for the RCMI Program to $68.25 million. The RCMI Program develops and strengthens the research infrastructure necessary to conduct state-of-the-art biomedical research and foster the next generation of researchers from underrepresented populations. FAMU requests $75 million, the fiscal year 2020 enacted level, for this program to allow NIH to continue supporting this important work.

Department of Health and Human Services, Health Resources and Services Administration (HRSA), Health Careers Opportunity Program

FAMU supports the fiscal year 2020 enacted level of $15 million for HRSA's Health Careers Opportunity Program (HCOP). First authorized in 1972, the HCOP competitive grant program aims to provide individuals from disadvantaged backgrounds an opportunity to develop the skills needed to successfully compete for, enter, and graduate from health or allied health professions schools. HCOP focuses on three key milestones of education: high school completion; acceptance, retention and graduation from college; and acceptance, retention and completion of a health professions degree program. The ultimate goal of the HCOP program is to diversify the health professions workforce by narrowing the educational achievement gaps between individuals from higher-income and lower-income households.

The Health Careers Opportunity Program (HCOP) High School Summer Institute, conducted on FAMU's campus, is designed for high school students interested in pursuing a career in a health profession. The four-week program provides a wide-range of educational and social experiences for rising 10th, 11th and 12th grade students. The entire experience is designed to enhance participants' academic abilities, social skills, and other competencies to increase their competitiveness for admission to a post-secondary health professions program.

The President's fiscal year 2021 budget eliminates funding for HRSA's Health Workforce, Training for Diversity Programs, including the HCOP. Continued funding is critical for these programs that help to increase the supply of underrepresented minorities in health professions.

We urge the Subcommittee to support continued and/or enhanced funding at the fiscal year 2020 level for these critical education programs at the Departments of Education and Health and Human Services. We thank you for your continued support of Federal postsecondary initiatives that not only directly benefit the University and our students, but the region and the nation as well. Thank you for your consideration.

[This statement was submitted by Larry Robinson, Ph.D., President, Florida A&M University.]

PREPARED STATEMENT OF THE FRED HUTCHINSON CANCER RESEARCH CENTER

The Fred Hutchinson Cancer Research Center (Fred Hutch) is grateful to Congress for providing robust, reliable funding for the National Institutes of Health (NIH), a key national priority. The nation's investment in NIH research pays a lifetime of dividends in better health and improved quality of life for all Americans. In fiscal year 2021, Fred Hutch recommends at least $44.7 billion for the NIH. This funding level would continue the momentum of recent increases by enabling meaningful base budget growth above inflation, while ensuring that the NIH Innovation Account supplements the agency's base budget, as intended, through dedicated funding for specific programs.

Through the strong, bipartisan action of this Subcommittee's leaders, Chairman Roy Blunt and Ranking Member Patty Murray, Congress is helping the agency regain lost ground after years of effectively flat budgets. Once more, in the fiscal year 2020 minibus bill, the Subcommittee's leadership ensured continued progress by providing a substantial increase to all NIH institutes and centers.

The Federal investment in biomedical research has yielded a significant number of scientific advances. These advances create economic opportunity as new companies emerge to translate novel research into cures and therapeutics to improve health outcomes for patients. NIH funding enables Fred Hutch to redefine what is possible across the full spectrum of biomedical research. Fred Hutch is committed to working with Congress and the Administration to further bipartisan support for increasing Federal investment in biomedical science and ensuring NIH remains a top priority in fiscal year 2021 and beyond.

ABOUT FRED HUTCH

Fred Hutchinson Cancer Research Center, founded in 1975, is designated by the National Cancer Institute (NCI) as a Comprehensive Cancer Center with the mission to eliminate cancer and related diseases as causes of human suffering and death. Fred Hutch's interdisciplinary team of world-renowned scientists and humanitarians work together to prevent, diagnose, and treat cancer, HIV/AIDS, and other diseases. Our Nobel Prize winning discoveries began in the 1970s with Dr. E. Donnall Thomas' work in bone marrow transplantation, providing the first definitive and reproducible example of the power of the human immune system's ability to cure cancer.

Fred Hutch scientists remain at the vanguard, from the development of innovative treatments and cures for cancer and HIV, to analysis and modeling of emerging pandemics like the novel coronavirus, COVID–19. In addition to paving the way for groundbreaking discoveries in science, Fred Hutch invests in the next generation of researchers through initiatives that embrace diversity and inclusion in team-science, promote women in the scientific enterprise, and empower early career researchers. Below are some examples of how NIH funding drives Fred Hutch innovation and helps shape future generations of scientists.

—Advancing Breakthrough Cures and Discoveries. Fred Hutch is leading the way in developing cures for a wide variety of cancers and other diseases. Recent examples include:

  —*Harnessing the Immune System to Kill Cancer.* Fred Hutch researchers continue to lead new breakthroughs in immunotherapy, including discoveries leveraging nanotechnologies that attach to and shrink tumors, and using a failed Alzheimer's drug to help boost CAR–T cell therapy for cancer patients.

  —*Exploring a Clever Way to Make an AIDS Vaccine.* Fred Hutch researchers have developed a new strategy to counter the frustrating ability of HIV to sidestep vaccines designed to block it by luring out extremely rare immune cells in the human body with genetic bait.

  —*Boosting Cancer Clinical Trial Participation.* Fred Hutch researchers offer new solutions to low clinical trial participation, such as loosening strict comorbidity criteria in order to open trials to thousands of previously exempt patients.

  —*Tracking the COVID–19 pandemic.* Genomic analysis and modeling of COVID–19 by Fred Hutch researchers has helped officials from a local to international level anticipate viral spread and provide scientific guidance as policymakers consider appropriate public health mitigation measures. Researchers are also contributing expertise to studies for the first-in-human vaccine trials and pursuing assays for serologic testing.

—Embracing Diversity and Inclusion in a Team-Science World. Fred Hutch was the first U.S. Cancer Center to commit to the CEO Action for Diversity & Inclusion pledge, and its Office of Diversity, Equity and Inclusion focuses on integrating these efforts as a core value and practice that will catalyze the mission of eliminating cancer and related disease.

—Promoting Women in Science. Fred Hutch is a leader in prioritizing gender parity among faculty members and promoting women in science. Women scientists lead four of the five scientific divisions and hold 12 of 25 endowed faculty chairs at the center.

—Empowering Early Career Researchers. Fred Hutch is dedicated to empowering the next generation of researchers. The Center invests more than $2 million a year in a pipeline of programs to mentor young faculty and encourage trainees from underrepresented backgrounds, from high school to college and graduate school to postdoctoral fellowships. These programs have a broad reach, provide real world opportunities for young scientists, and improves the overall quality of science.

THE VALUE OF FEDERALLY-FUNDED BIOMEDICAL RESEARCH

The Federal Government has an irreplaceable role in supporting biomedical and basic science research. No other public, corporate, or charitable entity is willing or able to provide broad and sustained funding for cutting-edge research necessary to yield new innovations and technologies of the future. The partnership between NIH and America's scientists and research institutions is a unique and highly-productive relationship. By leveraging the full strength of our nation's research enterprise to foster discovery, improve our understanding of the underlying cause of disease, and develop the next generation of biomedical innovations—and innovators—we will deliver better treatments and cures to patients.

As an independent research institute with a sole mission to pursue lifesaving discoveries, Fred Hutch depends on NIH funding to focus on basic, translational, clinical, public health, and infectious disease research, and to respond quickly to the research needs of the country. In addition to supporting robust funding, Fred Hutch opposes provisions—such as directives to reduce the salary limit for extramural researchers—which would harm the integrity of the research enterprise and disproportionately affect independent research institutes. Policies to cut salary support hinder Fred Hutch's research mission and ability to recruit and retain the talented researchers who make U.S. institutions global leaders in advancing life-saving biomedical sciences.

The NIH initiatives focusing on career development and recruitment of a diverse scientific workforce are critical to innovation in biomedical research and public health. Robust increases to the NIH budget are critical to fostering the next generation of scientists, as training funds work to attract the brightest minds to pursue a career in research. Fred Hutch is committed to training the diverse group of rising stars in science and supports NIH efforts like the Next Generation Researchers Initiative to address challenges faced by investigators launching their careers.

CONCLUSION

Fred Hutch thanks the Subcommittee for its important work dedicated to ensuring the health of the nation and for its strong support for NIH funding in fiscal year 2021. We appreciate the opportunity to urge the Subcommittee to provide at least $44.7 billion in fiscal year 2021 for NIH, which is the next step toward a multi-year increase in our nation's investment in biomedical research. Advances in bioscience, technology, and data science have brought us to an inflection point. This is not a time to pull back. Given the abundance of scientific opportunity, this recommendation represents a minimum investment to sustain progress that only would be amplified through an even more robust commitment.

PREPARED STATEMENT OF FRIENDS OF THE HEALTH RESOURCES AND SERVICES ADMINISTRATION COALITION

The Friends of HRSA coalition is a nonpartisan coalition of nearly 170 national organizations representing tens of millions of public health and healthcare professionals, academicians and consumers invested in the Health Resources and Services Administration's mission to improve health outcomes and achieve health equity. We are pleased to submit our request of at least $8.8 billion for the Health Resources and Services Administration in fiscal year 2021. We strongly urge you to reject the many proposed cuts to important HRSA programs contained in the president's fiscal year 2021 budget proposal. These requests do not reflect any additional resources that may be needed to address the immediate and ongoing efforts to combat the COVID–19 pandemic. HRSA programs are especially critical as the U.S. grapples with the COVID–19 pandemic. Adequate funding for programs that promote public health in underserved communities, support health centers and bolster America's public health workforce will be critical in facing the short-term and long-term health impacts of COVID–19.

HRSA's 90-plus programs and more than 3,000 grantees support tens of millions of geographically isolated, economically or medically vulnerable people, in every state and U.S. territory, to achieve improved health outcomes by increasing access to quality healthcare and services; fostering a healthcare workforce able to address current and emerging needs; enhance population health and address health disparities through community partnerships; and promote transparency and accountability within the healthcare system. The agency is a national leader in improving the health of Americans by addressing the supply, distribution and diversity of health professionals and supporting training in contemporary practices, and providing high-quality health services to populations who may otherwise not have access to healthcare.

HRSA programs work in coordination with each other to maximize resources and leverage efficiencies. For example, Area Health Education Centers, a health professions training program, was originally authorized at the same time as the National Health Service Corps to increase the number of primary care providers at health centers and other direct providers of healthcare services for underserved areas and populations. AHECs play an integral role to recruit providers into primary healthcareers, diversify the workforce and develop a passion for service to the underserved among future providers.

HRSA's programs also work in collaboration across the Federal Government to enhance health outcomes. For example, HRSA's HIV/AIDS Bureau partners with the Office of the Assistant Secretary for Health, the Centers for Disease Control and Preventions, the Substance Abuse and Mental Health Services Administration, the Centers for Medicare and Medicaid Services, the Indian Health Services, the National Institutes of Health, the Agency for Healthcare Research and Quality, the Department of House and Urban Development, the Department of Veterans Affairs and the Department of Justice to ensure an effective use of resources, and a coordinated and focused public health response to the HIV epidemic. This Federal response has contributed to the number of annual HIV infections dropping 5.6 percent between 2010 and 2016, with HRSA's Ryan White HIV/AIDS Program serving as the foundation for delivering healthcare and support services to reach the public health goal of ending the HIV epidemic. Despite this success, an estimated 1.1 million people in the U.S. are living with HIV today, and nearly 38,000 become newly infected every year—1 in 7 of whom are unaware of their infection. HRSA programs will play an integral role in achieving the public health goal of ending the HIV epidemic.

HRSA grantees also play an active role in addressing emerging health challenges. For example, HRSA's grantees provide outreach, education, prevention, screening and treatment services for populations affected by health emergencies such as the opioid epidemic. However, much of this work required additional funding to increase capacity in health centers, support National Health Service Corps providers to deliver relevant care and expand rural health services. Strong, sustained funding would allow HRSA to quickly and effectively respond to emerging and unanticipated future health needs across the U.S., while continuing to address persistent health challenges.

HRSA programs and grantees are providing innovative and successful solutions to some of the nation's greatest healthcare challenges including the rise in maternal mortality, the severe shortage of health professionals, the high cost of healthcare, and behavioral health issues related to substance use disorder—including opioid misuse. We are grateful for the increases provided for HRSA programs in the fiscal year 2020, however HRSA's discretionary budget authority remains over 20 percent below the fiscal year 2010 level (adjusted for inflation). We recommend Congress build upon the important increases they provided for HRSA programs in fiscal year 2020 and provide at least $8.8 billion for HRSA's total discretionary budget authority in fiscal year 2021. Additional funding will allow HRSA to pave the way for new achievements and continue supporting critical HRSA programs, including:

—Primary care programs support over 11,000 health center sites in every state and territory, improving access to preventive and primary care for more than 28 million people in geographic areas with few healthcare providers. Health centers coordinate a full spectrum of health services including medical, dental, vision, behavioral and social services in the nation's most underserved communities. Health centers reach 1 in 3 people living at or below the Federal poverty line; 1 in 5 rural residents; 1 in 5 uninsured persons; and 1 in 6 Medicaid beneficiaries.

—Health workforce programs support the education, training, scholarship and loan repayment of primary care physicians, nurses, oral health professionals, optometrists, physician assistants, nurse practitioners, clinical nurse specialists, public health personnel, mental and behavioral health professionals, pharmacists and other allied health providers. With an emphasis on primary care and training in interdisciplinary, community-based settings, these are the only Federal programs focused on filling the gaps in the supply of health professionals, as well as improving the geographic distribution and diversity of the workforce.

—Maternal and child health programs, including the Title V Maternal and Child Health Block Grant, Healthy Start and others, support initiatives designed to promote optimal health, reduce disparities, combat infant and maternal mortality, prevent chronic conditions and improve access to quality healthcare for mothers and babies. MCH programs help assure that nearly all babies born in the U.S. are screened for a range of serious genetic or metabolic diseases, and that coordinated long-term follow-up is available for babies with a positive screen. They also help improve early identification and coordination of care for children with sensory disorders, autism and other developmental disabilities. The MCH Block Grants funded 59 states and jurisdictions to provide healthcare and public health services for an estimated 76 million people, reaching 91 percent of pregnant women, 99 percent of infants, and 54%55 percent of children nationwide.

—HIV/AIDS programs provide the largest source of Federal discretionary funding assistance to states and communities most severely affected by HIV/AIDS. The Ryan White HIV/AIDS Program delivers comprehensive care, prescription drug assistance, and support services to more than 550,000 people impacted by HIV/AIDS. HRSA's Ryan White HIV/AIDS Program effectively engages clients in comprehensive care and treatment, including increasing access to HIV medication, which has resulted in 87 percent of clients achieving viral suppression, compared to just 59 percent of all people living with HIV nationwide. Additionally, the program provides education and training for health professionals treating people with HIV/AIDS, and works toward addressing the disproportionate impact of HIV/AIDS on racial and ethnic minorities.

—Title X ensures access to a broad range of reproductive, sexual and related preventive health services for nearly 4 million women, men and adolescents, with priority given to low-income individuals. Services include patient education and counseling for family planning; provision of contraceptive methods; cervical and breast cancer screenings; sexually transmitted disease prevention education, testing and referral; and pregnancy diagnosis. This program helps improve maternal and child health outcomes and promotes healthy families.

—Rural health programs improve access to care for people living in rural areas. The Office of Rural Health Policy serves as the nation's primary advisor on rural policy issues, conducts and oversees research on rural health issues and administers grants to support healthcare delivery in rural communities. Rural health programs are designed to support community-based disease prevention and health promotion projects, help rural hospitals and clinics implement new technologies and strategies and build health system capacity in rural and frontier areas.

—Special programs include the Organ Procurement and Transplantation Network, the National Marrow Donor Program, the C.W. Bill Young Cell Transplantation Program and National Cord Blood Inventory. These programs maintain and facilitate organ marrow and cord blood donation, transplantation and research, along with efforts to promote awareness and increase organ donation rates. Special programs also include the Poison Control Program, the nation's primary defense against injury and death from poisoning for over 50 years. Poison control centers contribute to significantly decreasing a patient's length of stay in a hospital and save the healthcare system over $1.8 billion per year, including $662.8 million saved by the Federal Government each year in medical and productivity costs.

Our recommendation is based on the need to continue improving the health of Americans and to provide HRSA with the resources needed to pave the way for new achievements. We urge you to consider HRSA's central role in strengthening the nation's health and advise you to adopt our fiscal year 2021 request of at least $8.8 billion for HRSA's discretionary budget authority. Thank you for the opportunity to submit our recommendation to the subcommittee.

[This statement was submitted by Jordan Wolfe, Manager of Government Relations, American Public Health Association.]

PREPARED STATEMENT OF THE FRIENDS OF THE INSTITUTE OF EDUCATION SCIENCES

Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee; thank you for the opportunity to submit written testimony on behalf of the Friends of IES, a consortium of scientific and professional societies, research universities, and independent research organizations interested in supporting the mission of IES and the use of research and statistics. As Congress continues to address the current public health and economic needs related to COVID–19, there are ongoing education research programs and statistical infrastructure needs that would be appropriately addressed through the regular appropriations process. We recommend $670 million for the Institute of Education Sciences (IES) in the fiscal year 2021 Labor, Health and Human Services, and Education Appropriations bill.

This is a critical time to invest in education research, data, and statistics to produce essential knowledge about teaching and learning across all levels of education as the COVID–19 pandemic has impacted students, parents, teachers, and school leaders in unprecedented ways. IES has proactively worked to provide future data and evidence-based resources, including the addition of questions to gauge the impact of COVID–19 on National Center for Education Statistics longitudinal surveys, a meta-analysis study being conducted to highlight effective distance learning practices, and webinars and guidance from the Regional Educational Laboratories.

IES is the independent and nonpartisan statistics, research, and evaluation arm of the U.S. Department of Education charged with supporting and disseminating rigorous scientific evidence on which to ground education policy and practice. As such, it serves as the critical Federal source for funding groundbreaking research in myriad aspects of teaching and learning, as well as rigorous analysis of educational programs and initiatives.

Its four centers—the National Center for Education Statistics (NCES), National Center for Education Research (NCER), National Center for Special Education Research (NCSER) and National Center for Education Evaluation (NCEE)-work collaboratively to efficiently and comprehensively deliver rigorous research and high-quality data and statistics to educators, parents, and policymakers. As one example of the need for more ongoing research, school districts are implementing school improvement plans for their lowest performing schools under the new framework provided under the Every Student Succeeds Act (ESSA). The investment in IES for evidence-based resources and strategies helps school districts make smart decisions about what plan elements will positively impact student and school performance.

Our member organizations rely on IES to support vital research that addresses many of the most important issues in our nation's schools—from literacy and numeracy at the elementary level to the integration of technology in teaching and learning, and from examining ways to enhance career and technical education to closing achievement gaps at every level of our educational systems. Yet, only one of every ten grant proposals receives funding support, limiting the ability of IES to support emerging lines of inquiry and tackle pressing questions about education, such as what can be done support student learning, bolster the impact of technology in the classroom, address challenges facing rural districts, and improve literacy for adult learners. Additional funding for IES would also support additional capacity for communicating findings on areas of interest to teachers, including research-based reading instruction, effective technology use, and student engagement.

The National Center for Education Statistics (NCES) is the primary Federal entity dedicated to collecting data related to education and is the only principal statistical agency dedicated to this mission. NCES compiles and disseminates important, scientifically valid data on the condition of education that is essential to the research being conducted across the nation. NCES also provides the funding support and infrastructure for the Statewide Longitudinal Data Systems (SLDS), providing critical investment for states to link K–12, postsecondary, and workforce systems to gain a better understanding of education and workforce outcomes. IES is also promoting the research use of SLDS to measure the effects of interventions on long-term student outcomes. Sufficient funding for NCES would allow for more timely collection and dissemination of data on key indicators, including teacher salaries, the amount of loans taken out by undergraduate students, and the participation of students in English language learner programs.

In addition to the research supported by the National Center for Education Research, the Regional Educational Laboratories (RELs) conduct applied research that is directly relevant to state and district administrators, principals and teachers. RELs also ensure that research is shared widely through its deep dissemination networks. Recent work across the REL network has focused on ways to address the teacher shortage; how to increase family involvement in developing foundational reading skills; and the relationship between teacher qualifications and student performance in Algebra I. This work is all driven by the state education agencies and other stakeholders in the regions. With additional resources the RELs could produce additional research-based materials to improve teaching and learning with consideration given to regional context.

The National Center for Special Education Research (NCSER) is the only Federal agency specifically designated to develop and provide evaluations for programs for students with disabilities Research funded by NCSER has resulted in programs that support youth with high functioning autism experiencing high levels of anxiety, individuals with Down syndrome learning to read, and students with learning disabilities studying to master math word problems. NCSER also provides special educators and administrators research-based resources that support the provision of a free appropriate public education and interventions to foster self-determination in students with disabilities as they transition into adulthood. With a budget that is only two-thirds of the amount appropriated in 2005 and has remained relatively flat since 2014, NCSER has been unable to fund critical topics such as special education teacher quality and shortages, high leverage practices, and potential linkages between students with disabilities and enrollment in developmental education classes in higher education.

To this end, we urge the Committee to support funding IES at $670 million in fiscal year 2021. A commitment at this level will enable IES to more fully support research that addresses the challenges of preparing young Americans to succeed in the knowledge-based economy that is not only upon us now, but also the key to future American prosperity.

[This statement was submitted by Felice J. Levine, Chair, Friends of the Institute of Education Sciences.]

PREPARED STATEMENT OF THE FRIENDS OF NATIONAL CENTER FOR HEALTH STATISTICS

The Friends of NCHS is a coalition of public health associations, patient organizations, scientific societies, and research institutions who rely on the information produced by the National Center for Health Statistics (NCHS) within the Centers for Disease Control and Prevention (CDC). In order to support NCHS's continued work to monitor the health of the American people and to allow the agency to make much-needed investments in the next generation of its surveys and products, the Friends of NCHS recommend an appropriation of at least $189 million for the agency in fiscal year 2021. Our recommendation reflects an increase to NCHS's base budget of $14.6 million from its fiscal year 2020 appropriation, as well as the formalization of an ongoing $14 million transfer from Surveillance, Epidemiology, and Informatics as proposed in the President's fiscal year 2021 Budget Request. We urge the Subcommittee to reject the Administration's proposed $5.4 million cut to the agency, which would have a devastating impact on NCHS's ability to continue to provide timely, unbiased, and accurate data on Americans' health. It is important to note that the enclosed request is for NCHS's baseline budget for fiscal year 2021 and, without supplemental funding, will not be sufficient in making the agency and its programs whole once the pandemic subsides and Federal agencies return to regular activity.

The coalition greatly appreciates the Subcommittee's longstanding support of NCHS and the data it produces on all aspects of our healthcare system. We also thank the Subcommittee for the prominent inclusion of NCHS within the $50 million Public Health Data Surveillance/IT Systems Modernization initiative in the fiscal year 2021 appropriations agreement. As the CDC's leadership determines how to allocate this new funding, we ask that the Subcommittee exercise its oversight authority over this initiative to ensure that NCHS receives sufficient funding to invest in innovation as directed by the Explanatory Statement.

Investing in the agency now will allow NCHS to put its expertise to transformative use to create a true twenty-first century statistical agency and reaffirm NCHS's status as the world's gold-standard producer of health statistics. With additional funding, NCHS could capitalize on advances in survey methodology, big data, and computing by:

—Building platforms that better integrate electronic health records (EHRs) into NCHS's data production by standardizing data from the major EHR vendors.

—Determining how best to achieve efficiencies among its hallmark population health surveys (the National Health Interview Survey and the National Health and Nutrition Examination Survey), making them less costly to taxpayers and less burdensome on participants.

—Supporting states as they modernize their vital records registration systems by ensuring they have the flexibility to collect information on new and rapidly-changing causes of death, such as emerging infectious diseases, deaths due to natural disasters, and drug overdoses, as well as collecting geocoded information to better measure the spread of disease in real time.

—Linking and integrating data reporting systems to receive and process information more efficiently, reduce burden on local data providers, and analyze and release statistics faster.

—Upgrading its computing technology and capacity to protect the confidentiality and security of NCHS's data while improving speed and quality.

—Expanding its use of machine learning and artificial intelligence to spot trends in Americans' health earlier. These technologies could allow NCHS to automate the coding of deaths of high public health interest such as drug overdose deaths, emerging infectious diseases, deaths due to natural disasters, and infant and maternal deaths, which are currently coded manually.

—Improving external users' access to public and restricted NCHS data by enhancing data visualization and usability and piloting the use of remote access to restricted NCHS data files.

Even under a tightly constrained budget, NCHS has pioneered innovative new techniques to get the most value out of every taxpayer dollar. Over the past several years, NCHS has closed the gap between data collection and publication for leading causes of death, resumed official estimates of maternal mortality after over a decade, implemented literal text analysis to identify the drugs most frequently involved in overdose deaths, and executed a redesign of the Health Interview Survey to reduce the burden on respondents. Yet, these achievements only serve to highlight how far additional investment in NCHS would go towards helping the agency rise to the challenges it faces.

We thank you again for your continued support of NCHS's essential data and statistics and encourage to you make sustained investments in how we measure our nation's health. We urge you to support a funding level of at least $189 million for NCHS in fiscal year 2021. Please do not hesitate to contact me should you require additional information.

[This statement was submitted by Julia Milton, Chair, Friends of NCHS, Director of Public Affairs, Consortium of Social Science Associations.]

PREPARED STATEMENT OF THE FRIENDS OF THE NATIONAL INSTITUTE ON DRUG ABUSE

Thank you for the opportunity to submit testimony in support of the National Institute on Drug Abuse (NIDA). The Friends of the National Institute on Drug Abuse is a coalition working with about 150 scholarly organizations with a total membership of at least 2 million scholars, clinicians and educators who are committed to eliminating drug abuse in society. We coordinate the opinions of the participating organizations, who also actively participate on their own to provide important information to policy makers to make decisions that will lead to the elimination of this disease which now is killing so many of our citizens. For example, former research which led to the creation of drugs such as naloxone and buprenorphine has provided important mechanisms which have prevented the death rate from being even much higher. We need more research in all areas of basic and clinical science to make additional advances.

In the fiscal year 2021 Labor-HHS Appropriations bill, we request that the subcommittee provide at least $3 billion above the fiscal year 2020 level for the National Institutes of Health (NIH), and within that amount a proportionate increase for the National Institute on Drug Abuse (NIDA) using the Institute's conferenced level of $1,462,016,000 as NIDA's base budget for Fiscal 2021. In addition, within the NIH total, we request at least $500 million for targeted research on opioid misuse and addiction, development of opioid alternatives, pain management, and addiction treatment, of which at least $250 million is allocated to NIDA and included in its base budget for Fiscal 2021. We also respectfully request the inclusion of the following NIDA specific report language.

Opioid Initiative. The Committee continues to be extremely concerned about the epidemic of prescription opioids, heroin, and illicit synthetic opioid use, addiction and overdose in the U.S. Approximately 174 people die each day in this country from drug overdose (over 100 of those are directly from opioids), making it one of the most common causes of non-disease-related deaths for adolescents and young adults. This crisis has been exacerbated by the availability of illicit fentanyl and its analogs in many communities. The Committee appreciates the important role that research plays in the various Federal initiatives aimed at this crisis. To combat this crisis, the bill includes at least $250,000,000 for research related to preventing and treating opioid misuse and addiction. With additional funding for NIDA targeted at addressing the opioid epidemic, the Institute's opioid specific allocation should be targeted for the following areas: development of safe and effective medications and new formulations and combinations to treat opioid use disorders and to prevent and reverse overdose; conduct demonstration studies to create a comprehensive care model in communities nationwide to prevent opioid misuse, expand treatment capacity, enhance access to overdose reversal medications, and enhance prescriber practice; test interventions in justice system settings to expand the uptake of medication assisted treatment and methods to scale up these interventions for population-based impact; and develop evidence-based strategies to integrate screening and treatment for opioid use disorders in emergency department and primary care settings.

Methamphetamines and Other Stimulants. The Committee is concerned that, according to the latest data released by the Centers for Disease Control and Prevention, the number of deaths from the drug categories that include methamphetamine and cocaine more than doubled from 2015–2018, leading some to refer to stimulant overdoses as the "fourth wave" of the current drug addiction crisis in America following the rise of opioid-related deaths involving prescription opioids, heroin, and fentanyl-related substances. The Secretary has also stated that methamphetamine is highly addictive and there are no FDA-approved treatments for methamphetamine and other stimulant use. The Committee continues to support NIDA's efforts to address the opioid crisis, has provided continued funding for the HEAL Initiative, and supports NIDA's efforts to combat the growing problem of methamphetamine and other stimulant use and related deaths.

Barriers to Research. The Committee is concerned that restrictions associated with Schedule I of the Controlled Substance Act effectively limit the amount and type of research that can be conducted on certain Schedule I drugs, especially opioids, marijuana or its component chemicals and new synthetic drugs and analogs. At a time when we need as much information as possible about these drugs to find antidotes for their harmful effects, we should be lowering regulatory and other barriers to conducting this research. The Committee directs NIDA to provide a short report on the barriers to research that result from the classification of drugs and compounds as Schedule I substances including the challenges researchers face as a result of limited access sources of marijuana including dispensary products.

Raising Awareness and Engaging the Medical Community in Drug Abuse and Addiction Prevention and Treatment. Education is a critical component of any effort to curb drug use and addiction, and it must target every segment of society, including healthcare providers (doctors, nurses, dentists, and pharmacists), patients, and families. Medical professionals must be in the forefront of efforts to curb the opioid crisis. The Committee continues to be pleased with the NIDAMED initiative, targeting physicians-in-training, including medical students and resident physicians in primary care specialties (e.g., internal medicine, family practice, and pediatrics). NIDA should continue its efforts in this space, providing physicians and other medical professionals with the tools and skills needed to incorporate substance use and misuse screening and treatment into their clinical practices.

Marijuana Research. The Committee is concerned that marijuana public policies in the states (medical marijuana, recreational use, etc.) are being changed without the benefit of scientific research to help guide those decisions. NIDA is encouraged to continue supporting a full range of research on the health effects of marijuana and its components, including research to understand how marijuana policies affect public health.

Electronic Cigarettes. The Committee understands that electronic cigarettes (e-cigarettes) and other vaporizing equipment are increasingly popular among adolescents, and requests that NIDA fund research on the use and consequences of these devices. The Committee also supports the Population Assessment of Tobacco and Health (PATH) Study, a collaboration between NIDA and the U.S. Food and Drug Administration (FDA) Center for Tobacco Products to help scientists learn how and why people start using tobacco products, quit using them, and start using them again after they have quit, as well as how different tobacco products affect health outcomes over time.

In addition, we request the following report language within the Office of the Director account:

The HEALthy Brain and Child Development (BCD) Study. The Committee recognizes and supports the NIH HEALthy Brain and Child Development Study, which will establish a large cohort of pregnant women from regions of the country significantly affected by the opioid crisis and follow them and their children for at least 10 years. This knowledge will be critical to help predict and prevent some of the known impacts of pre- and postnatal exposure to drugs or adverse environments, including risk for future substance use, mental disorders, and other behavioral and developmental problems. The Committee recognizes that the BCD Study is supported in part by the NIH HEAL Initiative?, and encourages other NIH Institutes, such as NICHD, NIMH, NHLBI, NCI, NIAAA, NIMH, NINR, as well the Office of the Director to support this important study.

Drug abuse is costly to Americans; it ruins lives, while tearing at the fabric of our society and taking a financial toll on our resources. Over the past three decades, NIDA-supported research has revolutionized our understanding of addiction as a chronic, often-relapsing brain disease -this new knowledge has helped to correctly emphasize the fact that drug addiction is a serious public health issue that demands strategic solutions.

NIDA supports a comprehensive research portfolio that spans the continuum of basic neuroscience, behavior and genetics research through medications development and applied health services research and epidemiology. While supporting research on the positive effects of evidence-based prevention and treatment approaches, NIDA also recognizes the need to keep pace with emerging problems. We have seen encouraging trends in strategies to address these problems, but areas of continuing significant concern include the recent increase in lethalities due to heroin and synthetic fentanyl, as well as continued abuse of prescription opioids. Our knowledge of how drugs work in the brain, their health consequences, how to treat people already addicted, and what constitutes effective prevention strategies has increased dramatically due to research. However, since the number of individuals who are affected is still rising, we need to continue the work until this disease is both prevented and eliminated from society.

We understand that the fiscal year 2021 budget cycle will involve setting priorities and accepting compromise, however, in the current climate we believe a focus on substance abuse and addiction deserves to be prioritized accordingly. Thank you for your support for the National Institute on Drug Abuse.

[This statement was submitted by William L. Dewey, Ph.D., Friends of the National Institute on Drug Abuse.]

PREPARED STATEMENT OF THE FRIENDS OF THE NATIONAL INSTITUTE ON AGING

Dear Chairman Blunt, Ranking Member Murray and Members of the Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies:

On behalf of the Friends of the National Institute on Aging (FoNIA), we are grateful for your leadership in advancing the mission of National Institutes of Health (NIH), and, in particular, the research supported and conducted by the National Institute on Aging (NIA). FoNIA is a coalition of more than 50 academic, patient-centered and non-profit organizations supporting NIA's mission to understand the nature of aging and the aging process, and diseases and conditions associated with growing older in order to extend the healthy, active years of life.

As you prepare the fiscal year 2021 appropriations legislation, we ask that Federal resources be dedicated to sustain and enhance the timely and promising aging research at NIA and across the National Institutes of Health (NIH). FoNIA requests:

—$44.7 billion—a $3 billion increase—in fiscal year 2021 for total spending at NIH, which aligns with the overall recommendation of the Ad Hoc Group for Medical Research;

—Within this amount, an increase of least $500 million specifically dedicated to support cross-Institute aging research at the NIH, including but not limited to biomedical, behavioral and social sciences aging research;

—A minimum increase of $354 million specific to research on Alzheimer's disease and related dementias (ADRD). The NIA is the primary Federal agency supporting and conducting Alzheimer's disease and related dementias research.

FoNIA understands that during this time of crisis, the Senate Appropriations Committee is working hard to stem fallout of both the human and fiscal toll of COVID–19. We are grateful for your efforts and urge that the Committee continues work on policies that benefit us all in this unprecedented pandemic. We know that through determination, sacrifice and resilience, Americans will rise to the challenge and take the necessary steps to mitigate the fallout of this public health emergency.

Looking to fiscal year 2021, we must continue funding investments in aging research, including research for Alzheimer's disease and related dementias (ADRD). The number of people ages 65 and older in the United States is projected to more than double from 46 million today to more than 98 million by 2060.[1] Between 2020 and 2030 alone, the number of older persons is projected to increase by almost 18 million as the last of the large baby boom cohorts reaches age 65.[2] Although much smaller in total size, the number of people ages 85 and older is projected to more than triple from 6 million today to nearly 20 million by 2060.[3]

As growing numbers of Americans live well into their 80s, aging-related diseases and multiple chronic conditions will become an even larger public health concern. Advancing age is the major risk faster for a number of chronic diseases. For example, as our nation ages, incidences of the number of persons affected by dementia are expected to double by 2060 from around 5 million cases today to 14.9 million cases.[4]

The NIA sponsors and conducts the lion's share of Federal aging-related research and this pioneering research contributes significantly to the improved care and quality of life of older adults. A key NIA priority is to translate research into better and more efficient care through the development of effective interventions that are disseminated to healthcare providers, patients and caregivers. These interventions for the prevention, early detection, diagnosis and treatment of disease will help reduce the burden of illness for older adults and reduce the cost of care.

NIA is at the forefront of applying scientific advancements to enhance the health of older adults, lengthen life, and reduce illness and disability. NIA supports studies on aging through extramural and intramural programs, focusing on aging processes, age-related diseases, and special problems and needs of the aged. The extramural program funds research and training at universities, hospitals, medical centers, and other public and private organizations nationwide.

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[1] POPULATION REFERENCE BUREAU, Population Bulletin, VOL. 70, NO. 2 (December, 2015) (www.prb.org/wp-content/uploads/2016/01/aging-us-population-bulletin-1.pdf).

[2] Ibid.

[3] Ibid.

[4] Matthews, Kevin A. et al., Racial and ethnic estimates of Alzheimer's disease and related dementias in the United States (2015–2060) in adults aged ≥65 years, Alzheimer's & Dementia: The Journal of the Alzheimer's Association, Volume 15, Issue 1, 17—24 (2018)(www.ncbi.nlm.nih.gov/pubmed/30243772). The burden of ADRD in 2014 was an estimated 5.0 million adults aged ≥65 years or 1.6 percent of the population. ADRD burden will double to 3.3 percent by 2060 when 13.9 million Americans are projected to have the disease.

In the area of dementia, NIA supports vital research where more scientific investigation is needed to improve AD/ADRD prevention, diagnosis, treatment and care; basic science approaches to illuminate neurodegenerative mechanisms/pathways; and computational/biological systems approaches to identify, model and predict the architecture and dynamics of the molecular interactions underlying AD/ADRD pathogenesis.

With your continued support, NIA is accelerating scientific discoveries in aging. With millions of Americans facing the loss of their functional abilities, their independence and their lives to chronic diseases of aging, there is a pressing need for robust and sustained investment in the vital work of the NIA. Continued, and meaningful investments in the NIA will make it possible to ultimately enhance the quality of care for older adults across the nation.

Thank you for your consideration of this funding request. Should you need additional information, feel free to contact me at esokol@alzfdn.org.

Sincerely.

[This statement was submitted by Eric W. Sokol, Chair, Friends of the National Institute on Aging.]

PREPARED STATEMENT OF FSHD SOCIETY

Honorable Chairman Blunt, Ranking Member Murray, and distinguished members of the Subcommittee, thank you for the opportunity to testify.

Facioscapulohumeral Disease (FSHD) is a heritable disease and one of the most common neuromuscular disorders with a prevalence of 1:8,000.[1] It affects 934,000 children and adults of both sexes worldwide. FSHD is characterized by progressive loss of muscle strength that is asymmetric and widely variable. Muscle weakness typically starts at the face, shoulder girdle and upper arms, often progressing to the legs, torso and other muscles. In addition to affecting muscle it can bring with it breathing issues, hearing loss, eye problems and cardiac arrhythmias. FSHD causes significant disability and death.

FSHD is associated with epigenetic changes at chromosome 4q35 in the D4Z4 DNA macrosatellite repeat array region leading to an inappropriate gain of expression (function) of the D4Z4-embedded double homeobox 4 (DUX4) gene.[2] DUX4 is a transcription factor that kick starts the embryonic genome during the 2- to 8-cell stage of development.[3,4,5] Ectopic expression of DUX4 in skeletal muscle leads to muscle death. DUX4 is never expressed in 'healthy' muscle. FSHD has had few clinical trials,[6,7,8,9,10] and currently there is no cure or therapeutic option available to patients. DUX4 requires and needs to activate its direct transcriptional targets for DUX4-induced gene aberration and muscle toxicity.[11,12,13,14,15,16,17,18,19,20,21,22,23,24]

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Blocking DUX4's RNA or DUX4's protein ability to activate its targets has profound therapeutic relevance.[25]

NIH-supported basic research on muscle disease and muscular dystrophy over the past 25 years has improved health outcomes. Small molecule and genetically engineered therapies are now in the works for FSHD and on the market for several neuromuscular diseases! [26,27,28,29,30,31,32] Each year, the non-profit, private and public investment in research yields critical advances in FSHD. Together we foster new treatments, diagnostics, and intervention strategies that affect the health of our nation. Meticulous efforts by FSHD researchers/clinicians working with funding from FSHD Society, the NIH and others have brought forth significant advancements in epigenetic diseases. FSHD is the only human disease known to be caused by the contraction of repetitive "junk" DNA. The Society has funded approximately $15 million in seed grants for research.

The FSHD scientific community listed 2020–2021 priorities as:

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2020 Industry and Scientific Research Priorities

—Clinical Trials Readiness Infrastructure and Therapeutics
—Biomarkers, Direct and Surrogate
—Genetic Testing, Genetics and Epigenetics
—Imaging and Outcome Measures
—Registries and Patient Reported Outcomes

Your Subcommittee and Congress in partnership with NIH, patients and scientists have made truly outstanding progress in understanding and treating the nine major types of muscular dystrophy through the Muscular Dystrophy Community Assistance, Research and Education Amendments of 2001 (MD–CARE Act, Public Law 107–84). The Federal advisory committee mandated by MD CARE Act, called the MDCC, along with working groups of outside scientific experts in the field assembled the '2015 NIH Action Plan for the Muscular Dystrophies.' It was presented by the Director of NIH to Congress. It specifies 81 objectives, in six sections (mechanism, screening, treatments, trial readiness, access to care, infrastructure including workforce) in need of funding and further development.[33] The genetics that give rise to FSHD are so remarkable, NIH Director Dr. Francis Collins emphasized its significance on the front page of the New York Times, saying "If we were thinking of a collection of the genome's greatest hits, this [FSHD] would go on the list." [34]

Honorable Chairman, these advances in scientific understanding and epidemiological surveillance come at a significant cost. Since passing the MD CARE Act in 2001, NIH funding for FSHD has been unbalanced given the growth in discoveries and needs to be set right.

FSHD RESEARCH DOLLARS & FSHD AS A PERCENTAGE OF TOTAL NIH MUSCULAR DYSTROPHY FUNDING

[Dollars in millions]

Fiscal Year	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020
All MD ($ millions) ..	$56	$83	$86	$75	$75	$76	$78	$77	$79	$81	$85ea	$83	$88e
FSHD ($ millions)	$3	$5	$6	$6	$5	$5	$7	$8	$9	$12.8	$13.7a	$17	$17.7a
FSHD (percent total MD)	5%	6%	7%	8%	7%	7%	9%	10%	11%	16%	16%	20%	20%

Sources: NIH/OD Budget Office & NIH OCPL & NIH RePORT RCDC (e=estimate, a=actual)

The NIH is the principal worldwide source of funding of research on FSHD. Currently active projects are $16.552 million fiscal year 2021 (current actual), a 21 percent portion of the estimated $80 million spent on all muscular dystrophies. (source: NIH Research Portfolio Online Reporting Tools (RePORT) keyword 'FSHD or facioscapulohumeral or landouzy-dejerine').

Without research on muscle disease, supported by the FSHD patient-advocacy groups in concert with the NIH biomedical research funding—families with FSHD would be living shorter, less productive, and far less hopeful lives. Nearly 41,000 Americans have FSHD, a disease that can cause damage to skeletal muscle, hearing, vision, breathing and lead to death.

What we need. Viewing at the current portfolio alongside the areas in need of bolstering in FSHD the NIH needs to fast expand its portfolio. Specifically, NIH needs to increase funding by adding R01 and R21 style grants in areas outlined by hundreds of experts in the DHHS NIH MD Plan. The engine of Federal research runs on the basic building blocks of workforce training, exploratory/developmental research grants (parent R21) and research project grants (parent R01). NIH can issue targeted funding announcements covering FSHD. A request for applications (RFA) on FSHD will yield results. These efforts will help convey to FSHD patients and allied researchers that NIH encourages more grant applications coming through its front door.

We request for fiscal year 2021, a tripling of the NIH FSHD research portfolio to $54 million. We are very appreciative of the slow but steady year-to-year increases and thank NIH and Congress. At this moment in time, FSHD needs an infusion of NIH grants both submitted and funded—investments in centers, collaborative research grants—and, most importantly, a rapid ramp up of basic/exploratory, preclinical and therapeutic research awards along with moderate expansion of post-

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doctoral and clinical training fellowships. FSHD research calls for and needs this additional funding in order to succeed.

Honorable Chairman, thank you again for your help and efforts.

[This statement was submitted by Daniel Paul Perez, Co-founder, FSHD Society.]

PREPARED STATEMENT OF THE GATEWAY GERIATRIC WORKFORCE ENHANCEMENT PROGRAM AND THE GERIATRICS WORKFORCE ENHANCEMENT PROGRAM

As the Co-Project Directors of the Gateway Geriatric Workforce Enhancement Program at Saint Louis University School of Medicine, we are pleased to submit this joint statement for the record recommending appropriations of at least $51 million in fiscal year 2021 to support geriatrics workforce training under the Geriatrics Workforce Enhancement Program (GWEP) and the Geriatric Academic Career Award (GACA) program administered by the Health Resources and Services Administration (HRSA). We thank you for your past support.

We would like to thank you and HRSA for providing funding for the 48 GWEP sites to develop telehealth delivery systems for providing geriatric education, training, and services and hope that the GWEP sites will be able to receive additional funds to expand this work through the HEROES Act or next emergency legislation. The staff at the GWEP sites and GACA recipients, both funded by HRSA, are playing a major role in the COVID–19 response for the most susceptible populations as front-line practitioners and by supporting, educating, and training healthcare professionals, community-based partners, caregivers, and patients. The National Association of Geriatric Education (NAGE) conducted a survey of GWEP sites to assess how these programs are adapting to the impact of COVID–19 and how sites could use additional resource during the pandemic. Current adaptations include: converting healthcare professional and community education events to online opportunities; converting evidence-based programs to online opportunities; creating COVID–19 training materials for clinical and social service settings as well as community partners; implementing or supporting implementation of telehealth; conducting community education through media appearances/interviews; converting academic offerings to online platforms; conducting outreach to patients to facilitate advanced care planning; increasing outreach to older adults; and increasing outreach to community/GWEP partners. Multiple GWEPs are creating educational materials focused on COVID–19-related topics including social isolation, loneliness, telehealth delivery and training for older adults/caregivers, advance care planning, and infection prevention. Here at Saint Louis University, we have developed a COVID–19 webpage, begun to deliver geriatric education and services virtually through video/phone conferencing and social media, and are utilizing HRSA telehealth funds to develop a HIPAA-compliant telehealth platform to expand our geriatric education and service delivery.

At this time, GWEP sites and GACA recipients are in need of additional resources to continue and expand our COVID-related work, including funds for technology/equipment; webpage and materials conversion; expanding Project ECHO/telehealth; expanding community, hospital, long term care, and community programs and education; staff support for phone reassurance and education with patients/caregivers including homebound older adults; rural community outreach; management of psychosocial issues such as social isolation and loneliness, anxiety and depression among older adults; and dementia friendly resources and programs. We have requested $10.9 million to be included in the next emergency package. This is separate from our fiscal year 2021 request described below.

The most resent Notice of Funding Opportunity (NOFO) for geriatrics funded 48 GWEP sites and one of their primary responsibilities is to educate primary care providers in caring for older adults. Unfortunately, each GWEP received about $100,000 less for their programs than the first round of grants provided in 2015. Our funding request for $51 million would allow for additional GWEP sites in rural and underserved communities and for supplemental payments for GWEPs that provide additional training for caregivers, including family caregivers. This request would also include at least the cost of the recent NOFO for 26 GACA Program awards. These two geriatrics programs were funded at $40.7 million in fiscal year 2020.

In fiscal year 2015, HRSA combined the geriatric education programs in Titles VII and VIII of the Public Health Service Act, including the Geriatric Academic Career Award, as well as portions of the Alzheimer's Disease Prevention, Education, and Outreach Program to establish the Geriatrics Workforce Enhancement Program (GWEP). The GWEP is one of only two Federal programs designed to develop a healthcare workforce specifically trained to care for the complex health needs of older Americans with the most effective and efficient methods, providing higher quality care and saving valuable resources by reducing unnecessary costs. As you are aware, the number of Americans ages 65 and older will double to over 98 million by 2060, creating an imperative for policymakers to enhance the education of health professionals to improve care of older persons and, thus decrease costs of care.

Proven results from activities under the GWEP and its predecessor programs include an important increase in the number of teaching faculty with geriatrics expertise in a variety of disciplines, plus thousands of healthcare providers and family caregivers better prepared to support older Americans with complex chronic conditions. We recognize that the Subcommittee faces complex decisions in a constrained budget environment, but we believe a top priority should be a commitment to geriatric education programs that help the nation's health workforce better serve the rapidly increasing number of older persons.

The nation faces a shortage of geriatrics health professionals and direct service workers. There are not enough geriatricians, advanced practice nurses, and other health professionals with the knowledge, skills, and training in geriatrics to meet the needs of our rapidly growing population of older adults and to support their family caregivers. Too often, the result is expensive walk-in care and inappropriate return to hospital within thirty days of discharge. We believe that funding for GWEP-based geriatric education supports a sustainable future for the nation's healthcare and Social Security systems by ensuring that (a) healthcare specialists trained in geriatric care do not become an expensive resource from which only a select few are able to benefit and (b) direct service workers and family caregivers are prepared to support a lower cost, independent lifestyle for community residing elders.

In recent years, GWEPs have continued the impressive work of the Geriatric Education Centers. Approximately half of the GWEPs provide education for areas that are more than 50 percent rural. In the 2017–2018 academic year, GWEPs provided gerontological education to more than 49,000 fellows and students. Continuing education for the current workforce is another critical part of the program's success with 212,444 faculty and practicing professionals participated in 1,564 unique continuing education courses offered by GWEP grantees during this period. Saint Louis University and other GWEPs are partnering with federally Qualified Health Centers to provide geriatric primary care education and didactic training. GWEPs create opportunities for healthcare providers in underserved and remote areas of the country to consult with top experts in geriatric care through Interactive Televideo (ITV), interactive teleconsults, and synchronous webcasts, and make available thousands of hours of online geriatric education programs.

The Gateway Geriatric Education Center at Saint Louis University has provided education to 25,611 health professionals and 5,904 members of the public since 2016. These health professionals have provided screenings for geriatric problems such as frailty, sarcopenia (muscle weakness), falls, and dementia to 9,280 older adults in all six Congressional districts in Missouri. More than 80 percent of this trainings and evaluation of older persons were in primary care settings and medically underserved communities. Developed specifically for the GWEP, the Rapid Geriatric Assessment has been computerized in multiple health systems, including Perry County Memorial Hospital in Perryville, Missouri, a critical access hospital in rural Perry County, and CARESTLHealth, a federally Qualified Health Center in north St. Louis city, Missouri. In Perry County, over 25 percent of the older adults in the county have been screened using this assessment process. Our screenings thus far, have identified 25.4 percent with dementia and 31.9 percent with falls. Early intervention for these conditions can decrease medical costs. Upon identifying concerns in any of the assessment areas, older patients are referred for other GWEP-initiated services, to include: Cognitive Stimulation Therapy-a nonpharmacologic intervention for persons with dementia or Exercise and Strengthening programming. In addition, our GWEP has provided education through in-person and on-line continuing education, through daily tweets on Twitter (@meddocslu)-828, to date—and with 102 postings to LinkedIn and Facebook. Our GWEP also coproduced a regional prime time television program on aging which was viewed by 340,739 persons. The YouTube site has had 103,200 views.

Obviously, the GWEPs are playing a major role in improving healthcare for older adults in the United States. Multiply this by 44 (the number of existing GWEPs) and you can begin to visualize the scope and impact of this program across the nation. It is important to note that every GWEP is focused on meeting the needs of rural and/or underserved populations; many serve predominantly people of color and those who are economically challenged.

GWEP awardees have received expanded authorization to provide family caregivers and direct service workers with instruction on prominent issues in the care of older adults, such as Alzheimer's Disease and other dementias, palliative care, self-care, chronic disease self-management, falls, and maintaining independence, among others. In Missouri, we have developed Cognitive Stimulation Therapy (CST) aimed at enhancing functioning in persons with moderate Alzheimer's disease. We have trained over 1200 persons to deliver this intervention and this has led to over 500 persons with dementia participating in this effective intervention which our research has shown to improve cognition. Our GWEP has recently been designated by the founders of CST as the North American CST Training Center.

HRSA has estimated that more than 50,000 paid and family caregivers will participate in GWEP training programs. For example, the GWEP at Saint Louis University is partnering with several Area Agencies on Aging, the local Alzheimer's Association, a rural hospital, a rural osteopathic school, the regional Area Health Education Centers, and dementia-focused community care agencies to train staff and family caregivers in assessing and supporting them through the caregiving process. The 2016 National Academies of Sciences, Engineering, and Medicine (NASEM) report Families Caring for an Aging America acknowledged that training must go beyond the healthcare professions and support family caregivers. This will improve the quality of health outcomes while saving valuable resources in the healthcare system.

In summary, GWEPs have improved the supply, distribution, diversity, capabilities, and quality of healthcare professionals who care for our nation's growing older adult population, including the underserved and minorities. They train physicians, nurses, social workers, dentists, mental health professionals, pharmacists, and caregivers. In some states, the GWEP is offering training to first responders to keep elders safe in their communities. Some of the professionals trained through GWEPs will become academicians in geriatric medicine, dentistry, psychiatry, nursing, and allied health professions, thereby giving additional cohorts of professionals skills they need to properly serve older Americans. Furthermore, GWEPs create and deliver community-based programs that provide patients, families, and caregivers with the skills to care for older adults and improve health outcomes, including Alzheimer's disease education. The GWEPs are serving as change agents and helping to transform a fragmented and outmoded system.

We ask for your continued support for geriatric programs to adequately prepare the next generation of health professionals and care providers for the rapidly changing and emerging needs of the growing and aging population.

On behalf of NAGE and those who have benefitted in Missouri and from our colleagues around the country, thank you for your thoughtful consideration of our request for funding for GWEPs and GACAs in fiscal year 2021. NAGE is a non-profit membership organization representing GWEPs, Geriatric Education Centers, Centers on Aging, and other programs that provide education and training to healthcare professionals and others in geriatrics and gerontology.

PREPARED STATEMENT OF GBS|CIDP Foundation International

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2021

- —Provide $44.7 billion for the National Institutes of Health (NIH) and proportional increases across its Institutes and Centers
- —Continue expanding GBS research supported by NIH with proportional funding increases for the National Institute of Neurological Disorders and Stroke (NINDS), and the National Institute of Allergy and Infectious Diseases (NIAID)

Chairman Blunt, Ranking Member Murray and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the community of individuals impacted by Guillain-Barré Syndrome (GBS), Chronic Inflammatory Demyelinating Polyneuropathy (CIDP), and related conditions as you work to craft the fiscal year 2021 L–HHS Appropriations Bill.

ABOUT GBS, CIDP, VARIANTS, AND RELATED CONDITIONS

Guillain-Barré Syndrome

Guillain-Barré Syndrome (GBS) is an inflammatory disorder of the peripheral nerves outside the brain and spinal cord. GBS is characterized by the rapid onset of numbness, weakness, and often paralysis of the legs, arms, breathing muscles, and face. Paralysis is ascending, meaning that it travels up the limbs from fingers and toes towards the torso. Loss of reflexes, such as the knee jerk, are usually found. Usually, a new case of GBS is admitted to ICU (Intensive Care) to monitor breathing and other body functions until the disease is stabilized. Plasma exchange (a blood "cleansing" procedure) and high dose intravenous immune globulins are often helpful to shorten the course of GBS. The acute phase of GBS typically varies in length from a few days to months. Patient care involves the coordinated efforts of a team such as a neurologist, physiatrist (rehabilitation physician), internist, family physician, physical therapist, occupational therapist, social worker, nurse, and psychologist or psychiatrist. Recovery may occur over 6 months to 2 years or longer. A particularly frustrating consequence of GBS is long-term recurrences of fatigue and/or exhaustion as well as abnormal sensations including pain and muscle aches.

Chronic Inflammatory Demyelinating Polyneuropathy

CIDP is a rare disorder of the peripheral nerves characterized by gradually increasing weakness of the legs and, to a lesser extent, the arms. It is the gradual onset as well as the chronic nature of CIDP that differentiates it from GBS. Like GBS, CIDP is caused by damage to the covering of the nerves, called myelin. It can start at any age and in both genders. Weakness occurs over two or more months. Unlike GBS, CIDP is chronic, with symptoms constantly waxing and waning. Left untreated, 30 percent of CIDP patients will progress to wheelchair dependence. Early recognition and treatment can avoid a significant amount of disability.

Post-treatment life depends on whether the disease was caught early enough to benefit from treatment options. The gradual onset of CIDP can delay diagnosis by several months or even years, resulting in significant nerve damage that may take several courses of treatment before benefits are seen. The chronic nature of CIDP differentiates long-term care from GBS patients. Adjustments inside the home may need to be made to facilitate a return to normal life.

ABOUT THE FOUNDATION

The Foundation's vision is that every person afflicted with GBS, CIDP, or variants has convenient access to early and accurate diagnosis, appropriate and affordable treatments, and dependable support services.

The Foundation's mission is to improve the quality of life for individuals and families across America affected by GBS, CIDP, and their variants by:

—Providing a network for all patients, their caregivers and families so that GBS or CIDP patients can depend on the Foundation for support, and reliable up-to-date information.

—Providing public and professional educational programs worldwide designed to heighten awareness and improve the understanding and treatment of GBS, CIDP and variants.

—Expanding the Foundation's role in sponsoring research and engaging in patient advocacy.

CENTERS FOR DISEASE CONTROL AND PREVENTION

CDC and the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) have resources that could be brought to bear to improve public awareness and recognition of GBS, CIDP and related conditions. The Foundation supports a meaningful increase to the Centers for Disease Control and Prevention as well as the establishment of a Chronic Disease Education and Awareness Program. This program seeks to provide collaborative opportunities for chronic disease communities such as ours that lack dedicated funding from ongoing CDC activities. Such a mechanism allows public health experts at the CDC to review project proposals on an annual basis and direct resources to high impact efforts in a flexible fashion.

NATIONAL INSTITUTES OF HEALTH

NIH hosts a modest research portfolio focused on GBS, CIDP, variants, and related conditions. This research has led to important scientific breakthroughs and is well positioned to vastly improve our understanding of the mechanism behind these conditions. We ask that resources continue to be used to support the important collaboration between NIAID, NINDS and the GBS|CIDP community. This May we will be participating in a conference with NINDS that would allow intramural and extramural researchers to develop a roadmap that would lead research into these conditions into the next decade, and encourage younger investigators to apply for grants that lead to sustained research activities. We are continuing to have conversations with the leadership of both institutes to facilitate a robust agenda and list of goals for the Conference. In our meetings with the leadership, we also spoke about the possibilities of cross-institute work between NINDS and NIAID to expand the research and understanding of the link between Zika and GBS. While such a conference would not require additional appropriations, the Foundation urges you to provide NIH with meaningful funding increases to facilitate growth in the GBS, CIDP, and related conditions research portfolio.

PATIENT ACCESS

As we have seen from communities that currently have access to home infusion, such as primary immunodeficiency diseases, the ability to choose the home as the preferred site of care has tremendous benefit in terms of health outcomes and overall convenience for patients. Individuals with CIDP and MMN often face mobility issues as limbs suffer nerve damage. Traveling to receive an infusion presents a tremendous hardship to many patients and their families. This hardship greatly affects rural patients who have to travel hundreds of miles to major cities in order to receive treatment, which can be both inconvenient and costly. The Foundation has seen that when there are obstacles to receiving regular infusions, patients tend to skip scheduled infusions, which leads to progressive disability. Many CIDP and MMN patients have access to IVIG home infusion through private insurance, which allows them to lead productive and active lives. When these individuals age on to Medicare, they can face disruption in their routine and suboptimal circumstances when managing their condition. Further, because the body's immune system is depressed at the end of an infusion cycle, CIDP and MMN patients face an elevated risk of contracting illness from visiting well-traveled sites of care for infusions. Most importantly, patients and physicians should have the authority to choose their preferred site of care. We hope that members of this subcommittee and Congress as a whole support legislation that will grant our patients this important access.

The Foundation was founded 40 years ago, and the four pillars that guide our mission are: support, education, advocacy, and research. Our patients rely on the premier research that is carried out at the NIH to improve the diagnosis and treatment process of these devastating illnesses. Without appropriate funding to the NIH and CDC, my fear as a parent of a GBS survivor and the Executive Director of the Foundation, is that many patients will needlessly suffer. There is so much to learn; there is no bio-marker and we do not know why the immune system reacts to trigger these conditions. I ask the Committee to provide $44.7 billion to the NIH with proportional increases to NIAID and NINDS to continue the potentially lifesaving work being done for our community, and ask for Congressional support of our initiative to improve access to life-saving treatments.

[This statement was submitted by Lisa Butler, Executive Director, GBS|CIDP Foundation International.]

PREPARED STATEMENT OF KAITLIN GEE

To the United States Subcommittee on Labor, Health and Human Services and Education,

I am writing to you as a 29-year-old sister with a research background supporting a biological brother formally diagnosed with schizophrenia. I am disclosing this information because I anticipate that the majority of the testimonies you receive will be from a different generation, but I need you to understand that there are many individuals in all generations diagnosed with severe mental illness (i.e.: schizophrenia and bipolar disorder) and their families who are impacted and are yet left without a voice or unable to speak up because they do not have accessible resources to contact individuals in a position to make positive change on their behalf. I assure you, these families are struggling as they work to support a family member diagnosed with severe mental illness often because that individual is likely to suffer from anosognosia, which is when the diagnosed individual is incapable of realizing they themselves are mentally ill (as a result of said illness). Slashing funding will hurt all of these citizens and the families and organizations supporting them. Removing financial support for trials carried out by the NIMH will not make the issue go away; rather, the issue will only get worse than it already is and become more costly for the country long term than if we proactively support—financially support—research geared towards finding a solution for the severely mentally ill.

Over the last 7 years, it has been immensely frustrating to watch my brother suffer the side effects as his medication regimen as his psychiatrists rotate through the same antipsychotics repeatedly because there are no new medications, no better medications developed or discovered available because there's so little funding for it. Continuing to de-fund research and drug treatment trials will result in trapping America's most vulnerable population in what would be the never-ending cycle of homelesness, incarceration This continued neglect of the severely and seriously mentally ill will have a ripple effect in the unraveling of the nation's fabric. There are family members like myself who are struggling to support our loved ones diagnosed with mental illnesses like schizophrenia while continuing to live what appears as "normal" a life as much as possible, who will mask that there's nothing wrong.

Increasing funding to research and drug treatment trials surrounding severe mental illness including schizophrenia and bipolar disorder will help the nation's experts better understand what is working and what is not working. We learn something from each research investigation, from each clinical trial, from each drug treatment trial that we pursue in full. As we learn more, we get closer to finding the solution.

The NIMH must continue to support drug treatment trials and demonstrate itself to be a leader in advocating for its most affected, yet neglected population. Please do the right thing on behalf of American citizens who are unable to advocate for themselves, who you are representing.

Thank you for accepting my testimony.

PREPARED STATEMENT OF DEBORAH GEESLING

My name is Deborah Geesling. I am a mother, advocate, and President of P82 Project Restoration, a nonprofit organization focused on supporting individuals and families who battle against serious mental illness. My son is 28 years old and suffers with Schizophrenia and Bipolar Disorder.

I am writing to appeal to you that the National Institute of Mental Health should return to its core mission and prioritize our citizens who suffer from the devastating effects of serious mental illnesses like Schizophrenia and Bipolar Disorder. I am asking that NIMH prioritize trials that find better drugs for these disorders. As a parent and advocate I was horrified to learn that this has mostly been ignored over the past few years.

How can the only agency charged with oversight of such a vulnerable group of people abandon those who need our help the most? It is unconscionable! According to NIMH's own research from 2017, approximately 4.5 percent of the U.S. population has a serious mental illness. There is no excuse as to why the other 95.5 percent cannot figure out a way to help the 4.5 percent. Allowing them to languish in our prisons and homeless shelters is not acceptable. Schizophrenia and Bipolar disorder are brain illnesses. We would never accept this sort of dereliction of duty in relation to any other disability.

May 2021 be a year of new beginnings.

Thank you.

[This statement was submitted by Deborah Geesling, President, P82 Project Restoration.]

PREPARED STATEMENT OF THE GERIATRICS WORKFORCE ENHANCEMENT PROGRAM AND THE GERIATRIC ACADEMIC CAREER AWARD PROGRAM

As the Co-Project Directors of the Gateway Geriatric Workforce Enhancement Program at Saint Louis University School of Medicine, we are pleased to submit this joint statement for the record recommending appropriations of at least $51 million in fiscal year 2021 to support geriatrics workforce training under the Geriatrics Workforce Enhancement Program (GWEP) and the Geriatric Academic Career Award (GACA) program administered by the Health Resources and Services Administration (HRSA). We thank you for your past support.

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[This statement was submitted by John E. Morley, MB, BCh, Professor, Division of Geriatric Medicine, Dept. Internal Medicine, Saint Louis University School of Medicine, Co-Project Director, Gateway Geriatric Workforce Enhancement Program and Marla Berg-Weger, PhD., LCSW, Professor, School of Social Work, Saint Louis University, Executive Director, Gateway Geriatric Education Center; Co-Project Director, Gateway Geriatric Workforce Enhancement Program.]

PREPARED STATEMENT OF GAYLE GIESE

I am the mother of an adult child with schizophrenia. I would give anything to have a cure or at least better treatment for this awful brain disease that often leaves its victims in jail, homeless, or hospitalized; and destroys families. This serious brain illness is not rare as many believe, but affects 1.1 percent of the population and that statistic has been true since first recorded, and is basically the same throughout the world. Its cause is primarily genetic, but is believed to be triggered by environmental factors. Schizophrenia (and schizoaffective disorder) robs the person of motivation, concentration, and cognition, as well as presenting positive symptoms such as hallucinations and delusions. The disease usually occurs in late teen or early adult years, just when our bright and beloved children are preparing for jobs, universities, careers, serious relationships.

The National Institute of Mental Health (NIMH) is the main Federal Government agency for research into mental illness. The NIMH was authorized through the passage of the National Mental Health Act in 1946 to better help individuals with mental health disorders through better diagnosis and treatments. With a budget of almost $2 billion in 2020, the NIMH conducts research and funds outside investigators to better understand mental illness and develop new treatments to reduce the burden these disorders have on individuals.

I beg you to have NIMH prioritize research for the 5 percent of our population that has serious mental illnesses that include chronic depression (the leading cause of disability in the U.S.), schizophrenia (and schizoaffective disorder), and bipolar illness. This makes sense because it's the humane thing to do, but it also makes good fiscal smarts. The most severe mental illnesses account for the most dollars spent in hospitals, jails, prisons, emergency rooms, and services for the homeless.

Dr. E. Fuller Torrey wrote in Psychiatric Times earlier this month:

> "Congress awarded the National Institute of Mental Health an additional $98 million as part of the National Institutes of Health budget resolution in December 2019, which brings the NIMH budget to just under $2 billion and represents a 35 percent increase since 2015, one of the largest increases in the history of the NIMH. Yet, during the 5 years from 2015 through 2019, NIMH funded a total of TWO new drug treatment trials for schizophrenia and bipolar disorder, according to clinicaltrials.gov. This contrasts with the 5-year period from 2006 through 2010 when NIMH funded 48 such trials . . ."

In December 2019, the NIMH released a draft of their five-year strategic plan for public comment. They reported receiving more than 6,000 responses identifying examples of research initiatives the NIMH could be pursuing today to help people with serious mental illness recover and live better lives. Despite this robust response, NIMH made no substantive changes to the research goals or objectives in the final version released to the public earlier this week.

The NIMH research goals for 2020–2025 heighten the existing imbalance in NIMH research. In doing so, they offer little hope for new or better treatments for individuals who are currently afflicted with a mental illness during their lifetime, especially a serious mental illness. This failure is inexcusable given the large increase in research funding given to NIMH in recent years.

Future NIMH funding must be used to correct the existing imbalance, not worsen it, especially now that the COVID–19 pandemic has upended the mental health treatment system and will likely result in an exacerbation of symptoms in people currently affected and an increase in serious mental illnesses among Americans. Those with the most severe forms of mental illness deserve to be prioritized.

Thank you for your consideration,

Sincerely.

PREPARED STATEMENT OF GLOBAL HEALTH COUNCIL

Global Health Council (GHC) is the leading membership organization of nonprofits, businesses, universities, and individuals dedicated to saving lives and improving the health of people worldwide. GHC thanks the Subcommittee for the opportunity to share this testimony in support of global health programs under the jurisdiction of the Departments of Labor and Health and Human Services. For fiscal year 2021, GHC encourages continued support for global health at a minimum of fiscal year 2020 levels enacted by Congress. However, in order to achieve U.S. global health goals and commitments, we ask that you support a greater investment in global health programs for fiscal year 2021, which includes at a minimum: $5.808 billion for the National Institute of Allergy and Infectious Disease (NIAID), $3.45 billion for the Office of AIDS Research, and $84.9 million for the Fogarty International Center at the National Institutes of Health (NIH); an investment of $699.3 million for the Center for Emerging Zoonotic and Infectious Diseases and no less than $642 million for the Center for Global Health at the Centers for Disease Control and Prevention (CDC).

In light of the COVID–19 pandemic we must urge Congress to appropriate funds not only to sustain America's legacy as a leader in global health, but also to support existing programs in their continued response to the coronavirus. Recently, Global Health Council distributed a letter to Congressional Appropriators advocating for at least $5 billion in global health funding to support U.S. global health initiatives affected by the COVID–19 pandemic. It is our hope that appropriators will consider the additional needs and negative effects the COVID–19 pandmeic has had on global health initiatives, when making appropriations for fiscal year 2021.

We know these programs work and have secured their place as some of the most cost-effective, critical, and successful tools for U.S. global health. They are an essential component of how the United States engages with the world. By investing in global health and development, the U.S. is continuing to build healthier and more self-reliant communities, which ultimately become economically and politically stable. Early in 2020, we saw programs struggle to respond to the massive need caused by COVID–19. The pandemic exacerbated weak points in health systems in rich and poor countries alike, ultimately weakening the effectiveness of our own health system. It highlighted inequalities, inefficiencies, and a sheer lack of access around the world. We are losing ground on the progress that the United States has already made towards building healthier and more self-reliant communities. A failure to backstop or to ignore these investments would roll back the critical progress already made, and eventually undermine U.S. foreign policy and global health goals.

A robust U.S. investment has historically been the foundation for increasingly larger contributions from corporations and low- or middle-income countries. Without this, global health programs lose access to alternative funding sources and technical assistance that ultimately enable them to become self-sustaining. Further, global health investments benefit the U.S. economy, particularly in research and development. Approximately 89 cents of every dollar spent by the U.S. government on global health research and development goes directly to U.S.-based researchers and product developers. This funding creates much-needed jobs, builds U.S. research and technological capacity—a boon to the economy as well as the health of Americans who equally benefit from such innovation.

We undeniably live in a global environment. Global health is important for medical professionals here at home, too. Every year more than 500 million people cross borders in planes, and with them the potential for infectious diseases to enter our country, demanding more of our health workforce. But U.S.-based providers and other responders have the opportunity to learn from health programs abroad about how best to tackle diseases whenever they arrive. We have an opportunity here, to mobilize everyone involved in health, from scientists, pharmaceutical companies, frontline workers, advocates, and policymakers, to create a world where health threats can become a thing of the past.

By at the very least maintaining U.S. investment in global health, we can continue to build upon the hard work and achievements of previous years in order to prevent the persistent global health challenges of our time and ensure a healthy future for citizens around the world. In our current environment, in response to COVID–19, we must consider increasing investments in global health and development assistance funding. We have a moral obligation to resolve the challenges that U.S. global health programs now face in light of the pandemic. And it is in our national interest to demonstrate that these are essential commitments.

Thank you for your consideration of this request.

[This statement was submitted by Loyce Pace, MPH, President and Executive Director, Global Health Council.]

PREPARED STATEMENT OF THE GLOBAL HEALTH TECHNOLOGIES COALITION

On behalf of the Global Health Technologies Coalition (GHTC), a group of 30 nonprofit organizations, academic institutions, and aligned businesses advancing policies to accelerate the creation of new drugs, vaccines, diagnostics, and other tools that bring healthy lives within reach for all people, I am providing testimony on fiscal year 2021 appropriations for the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and the Biological Advanced Research and Development Authority (BARDA). My testimony reflects the needs expressed by our members working in nearly one hundred countries to develop new and improved technologies for the world's most pressing health issues. We appreciate the Committee's support for global health, particularly continued research and development (R&D) to advance new drugs, vaccines, diagnostics, and other tools for longstanding and emerging health challenges-like COVID–19. This pandemic has demonstrated again that R&D must be the tip of the spear of our response to global health emergencies and that innovation is our exit strategy from the economic and social crises spurred by the public health containment measures necessitated by our lack of effective tools. This reality holds across many everyday emergencies in global health-conditions affecting communities around the globe that cause suffering and death often absent from the headlines.

As the subcommittee considers fiscal year 2021 appropriations in light of this crisis, to accelerate progress towards life-saving tools for the full range of emerging and enduring global health threats, we respectfully request maintaining robust funding for NIH, particularly the National Institute for Allergy and Infectious Diseases (NIAID) and the Fogarty International Center; providing funding to match CDC's growing responsibilities in global health and global health security, at minimum level funding of $570.8 million for the Center for Global Health (CGH) and $635.8 million for the National Center for Emerging Zoonotic and Infectious Diseases (NCEZID); and supporting funding for BARDA's critical work in emerging infectious diseases. GHTC members strongly believe that sustainable investment in R&D for a broad range of neglected diseases and health conditions is critical to tackling both longstanding and emerging global health challenges that impact people around the world and in the United States. This means investing between and beneath global health crises: both for rapid innovation for emerging infectious diseases when they strike and to enable continued progress on less visible but life-saving, decades-long efforts to combat persistent challenges like HIV/AIDS, tuberculosis (TB), and malaria.

Coordination is also key: We urge the Committee to request that leaders of the Department of Health and Human Services (HHS) agencies work with counterparts at the State Department and the United States Agency for International Development to develop a cross-government global health R&D strategy to ensure that U.S. investments are efficient, coordinated, and streamlined. Operation Warp Speed is an audacious effort to combine the unique strengths of several U.S. agencies, the U.S. military, and private-sector partners with the goal of producing 300 million COVID–19 vaccine doses by January of next year. This unique whole-of-government effort to combat this global health emergency provides an inspiring model that could be replicated to dramatically accelerate progress against other persistent global health threats and leave us better prepared for the next health emergency.

With supplemental funding afforded in emergency COVID–19 relief bills, NIH, CDC, and BARDA have moved at historic speed to launch research partnerships and support product development to combat COVID–19. In just a few months, these agencies have begun advancing more than 50 innovations, including at least 20 diagnostics, 16 therapeutics, and 7 vaccine candidates. The pandemic has spurred an unprecedented scientific response, enabled by a U.S. biomedical research infrastructure primed and ready to act thanks to a decade of historic investment by this subcommittee. These foundational investments have enabled products to be developed and rolled out much faster than in previous health emergencies. For example, it took researchers about 5 months to even identify the SARS virus after it was already spreading in 2003. COVID–19 was sequenced in just weeks with work on vaccines and diagnostics launched soon after. Our ability to mount this rapid response is a testament to the strengthening of our biomedical research infrastructure enabled by forward-thinking investment.

While COVID–19 demands our immediate attention and accelerated efforts, the everyday emergencies of persistent health threats continue to threaten communities around the globe. Though we have made tremendous gains in global health over the past fifteen years, millions of people around the world are still threatened by HIV/AIDS, TB, malaria, and other neglected diseases and conditions. In 2018, TB killed 1.5 million people, surpassing deaths from HIV/AIDS, while 1.7 million people were newly diagnosed with HIV. Nearly half the global population remains at risk for malaria, and drug-resistant strains are growing. Women and children remain the most vulnerable with around 80 percent of all global maternal and child deaths occurring in sub-Saharan Africa and 1 out of every 13 children in the region dying before the age of 5, often from vaccine-preventable and other communicable diseases. These figures highlight the tremendous global health challenges that remain and the need for sustained investment in global health R&D to deliver new tools to combat endemic and emerging threats. New tools and technologies are also critical to address challenges of drug resistance, outdated and toxic treatments, and difficulty administering current health technologies in poor, remote, and unstable settings.

The COVID–19 pandemic has demonstrated once again that we do not readily have all the tools needed to tackle many neglected and emerging infectious diseases—a reality brought into sharp focus during the Zika and West African Ebola epidemics just a few years ago. Yet, the impact of the rVSV–ZEBOV Ebola vaccine on the now-waning epidemic in the Democratic Republic of the Congo (DRC) demonstrates the power of having the right tool at the right time to respond to a health emergency. This new vaccine, developed with critical funding from NIH and other U.S. Government partners, is 97.5 percent effective—a game-changer for this and future outbreaks. As part of the rapid research response to COVID–19, the U.S. Government and global partners are leveraging past investments in R&D for other global health threats to advance innovations for COVID–19. For instance, a vaccine development platform originally developed to advance vaccine candidates for HIV/AIDS is being repurposed to develop COVID–19 vaccine candidates, and an emergency use authorization was recently granted to Remdesivir, a broad-spectrum antiviral compound originally developed as an Ebola and Marburg virus treatment that is now showing promise as a COVID–19 therapeutic. The United States is at the forefront of COVID–19 innovation today because of past investments in NIH, CDC, and BARDA.

NIH: The groundbreaking science conducted at NIH has long upheld U.S. leadership in medical research. Within NIH, NIAID, the Office of AIDS Research, and the Fogarty International Center all play critical roles in developing new health technologies that save lives at home and around the world. Recent activities have led to the creation of new tools to combat neglected diseases, including vaccines for dengue and trachoma, new drugs to treat malaria and TB, and multiple tools for Ebola. Leadership at NIH has long recognized the vital role the agency plays in global health R&D and has named global health as one of the agency's top five priorities.

Today, NIH is leading U.S. R&D for COVID–19, supporting at least 17 vaccine, therapeutic, and diagnostic candidates, and, with emergency supplemental funding, rapidly identifying new candidates to support. Thanks to research investments in response to the SARS and MERS outbreaks, NIAID scientists and partners are better prepared to develop diagnostics, therapeutics, and vaccines for COVID–19. It remains critical that support for NIH considers all pressing areas of research-including research in neglected and emerging infectious diseases.

CDC: CDC also makes significant contributions to global health research, particularly through CGH and NCEZID. CDC's ability to respond to disease outbreaks is essential to protecting the health of citizens both at home and abroad, and the work of its scientists is vital to advancing the development of tools, technologies, and techniques to detect, prevent, and respond to urgent public health threats. Important recent global health contributions by NCEZID includes innovative technologies to provide a rapid diagnostic test for the Ebola virus, a new vaccine to improve rabies control, and a new diagnostic test for dengue virus. The center also plays a leading role in the National Strategy for Combating Antibiotic-Resistant Bacteria to prevent, detect, and control outbreaks of antibiotic-resistant pathogens, such as drug-resistant TB. NCEZID was instrumental in the development of the first COVID–19 diagnostic used in the U.S., and their Office of Advanced Molecular Detection is leading the SARS–CoV–2 Sequencing for Public Health Emergency Response, Epidemiology and Surveillance (SPHERES) initiative, a new national genomics consortium to coordinate SARS–CoV–2 sequencing across the country that will provide crucial information to track the spread of the virus and identify diagnostic and therapeutic product targets.

Programs at CDC's CGH—including the Divisions of Global HIV and TB, Global Immunization, Parasitic Diseases and Malaria, and Global Health Protection—have also yielded tremendous results in the development and refinement of vaccines, drugs, microbicides, and other tools to combat HIV/AIDS, TB, malaria, and neglected tropical diseases like leishmaniasis and dengue fever. CGH develops and validates innovative tools for use by U.S. bilateral and multilateral global health programs and leads laboratory efforts to monitor and combat drug and insecticide resistance—functions essential to ensuring that global health programs are responsive, efficient, and tailored for maximum impact.

As global disease outbreaks have grown in frequency and intensity, CDC's work in novel technology development and global health security has only become more important. This includes the agency's efforts to quash the most recent Ebola outbreak in DRC through its international leadership on the Global Health Security Agenda (GHSA). GHTC supports the funding increase to the Division of Global Health Protection (DGHP) within CGH proposed by the Administration for fiscal year 2021 and urges the Committee to continue annual increases to this and other accounts critical to global health security-related R&D. As shown through COVID–19 and the still-recent epidemics of Ebola and Zika, these functions are being called upon with greater frequency and are critical to protecting the health of Americans and the health of people around the world. CDC monitors 30 to 40 international public health threats each day, has identified disease outbreaks in over 150 countries, responded to over 2,000 public health emergencies, and discovered 12 previously unknown pathogens. We also urge increased funding for NCEZID, which supports DGHP's response efforts globally with laboratory expertise.

BARDA: BARDA plays an unmatched role in global health R&D by providing an integrated, systematic approach to the development and purchase of critical medical technologies for public health emergencies. By leveraging unique contracting authorities and targeted incentive mechanisms, BARDA partners with diverse stakeholders from industry, academia, and nonprofits to bridge the valley of death between basic research and advanced-stage product development for medical countermeasures—an area where more traditional U.S. Government research programs do not operate. With these unique assets, BARDA has played a vital role in the development of urgently needed countermeasures for pandemic influenza, antimicrobial resistance, and emerging infectious diseases (EIDs), like Ebola and Zika. Today, BARDA's unique strengths are on full display in its response to COVID–19. The agency has received supplemental resources many times its annual base appropriation to advance medical countermeasures for the pandemic, and is moving at unprecedented speed to use these resources to advance more than 30 products to diagnose, treat, and prevent COVID–19.

To date, BARDA's work in advancing tools to protect against the threat of EIDs has largely been supported through emergency funding, and today it is being forced to curtail critical work on a range of naturally occurring threats to focus on COVID–19. A dedicated funding line for EIDs would ensure that they are resourced for a wide range of future threats and would prevent delays like those seen between the onset of the COVID–19 pandemic and the first BARDA awards made with supplemental funding. In a public health emergency, science cannot wait, and we must ensure our research agencies have a funding pipeline ready to resource innovation for the next threat as soon as it is identified.

In addition to bringing lifesaving tools to those who need them most, investment in global health R&D is also a smart economic investment for the United States, with 89 cents of every US dollar invested in global health R&D going directly to U.S.-based researchers. U.S. Government investment in global health R&D between 2007 and 2015 generated an estimated 200,000 new jobs and $33 billion in economic growth. As the COVID–19 crisis is demonstrating, investments in global health R&D today can help achieve significant cost-savings and mitigate the economic impact of outbreaks in the future.

It bears repeating: innovation is our exit strategy for COVID–19 and we will not be safe from the pandemic in the United States until we end it everywhere. HHS research agencies advancing COVID–19 innovations should be encouraged to assess whether and how such products might be adapted for use in low-resource settings, where electricity is limited or delivery methods such as intravenous administration are not always feasible. Furthermore, as we continue to focus our immediate energies on combatting this global pandemic, we must also work to ensure that research on other critical global health issues is not sidelined indefinitely—investment will be needed to restart clinical trials, extend participant enrollment, and shore up critical research infrastructure through the eye of this storm and in the aftermath of this public health emergency.

At this time of crisis, Congress must make forward-thinking choices to respond to the emergency before us and draw on the painful lessons emerging from it to ensure that we are primed and ready for the next health threat—while also committing to continue progress against the full range of global health challenges. Global health research, which improves the lives of people around the world while supporting U.S. interests and health security, creating jobs, and spurring economic growth, is a win-win investment.

[This statement was submitted by Jamie Bay Nishi, Director, Global Health Technologies Coalition.]

PREPARED STATEMENT OF GLOBAL WATER 2020

With COVID–19 dominating the news, the importance of handwashing is front and center as one of the only effective ways of preventing infection. Both the Centers for Disease Control and Prevention (CDC) and the U.S. Surgeon General have touted the importance of washing your hands. More broadly, access to safe drinking water, sanitation, and hygiene (including handwashing), or WASH, is one of the first lines of defense in slowing the spread of most infectious disease outbreaks such as the flu and Ebola, as well as protecting communities, patients, and frontline health workers over the long-term. For this reason, Global Water 2020 recommends funding the Global WASH program within the Center for Global Health (CGH) and the National Center for Emerging and Zoonotic Infectious Diseases (NCEZID) at CDC at $10 million for fiscal year 2021. In addition, we support overall funding for the Center for Global Health at $642 million and the National Center for Emerging and Zoonotic Infectious Diseases at $699.3 million. Both of these Centers support global WASH programs at the agency.

The CDC Global WASH program works to address the impact of WASH-related diseases such as cholera, hepatitis, and typhoid fever, by improving access to safe water, adequate sanitation, and improved hygiene in communities, schools, and healthcare facilities. CDC works to identify and scale up the most effective WASH interventions, using proven technologies to treat and safely store drinking water in homes, schools, and healthcare facilities, and the integration of sanitation and hygiene programs in schools and communities.

To accomplish this work, CDC partners with other U.S. government agencies, non-governmental organizations, Ministries of Health, and other international organizations. Through these partnerships, CDC provides the technical backbone to better understanding water-borne pathogens and assists countries with establishing sustainable and country-led WASH services.

In addition, the Global WASH program is critical to CDC's work to advance the U.S. Global Health Security Strategy, as well as U.S. commitments to the Global Health Security Agenda (GHSA). Investing in WASH, and more broadly health systems, puts in place preventative measures that help countries to better prevent, detect, and respond to infectious disease outbreaks. WASH also plays a role in combatting the rise of "superbugs," or drug-resistant diseases, by preventing infections and lowering the need to use antibiotics.

However, there is a dangerous lack of WASH in many healthcare facilities around the world. One in four healthcare facilities lacks basic water services, one in five has no sanitation services, and two in five lack basic hand hygiene services. So during a time when people are encouraged to wash their hands to prevent the spread of the coronavirus, there are frontline health workers and other healthcare professionals, as well as patients, who are unable to do so. We also saw this during the Ebola epidemic in West Africa, where the lack of access to safe WASH in healthcare facilities and communities was a factor in the inability to contain the disease. And the lack of WASH in many healthcare facilities during this outbreak puts patients seeking routine services such as neonatal care at risk of infection.

Currently, CDC does not receive dedicated and consistent funding for the Global WASH program. The ongoing COVID–19 outbreak and the focus on the importance of handwashing underscore the critical need to ensure that CDC can continue this work without worrying about where funding will come from every fiscal year.

Specifically, $10 million could ensure that CDC's global WASH program could continue its work on:

—Improving access to WASH in healthcare facilities to prevent disease outbreaks and the overuse of antibiotics through better infection prevention and control;

—Strengthening CDC's work to control or eliminate Neglected Tropical Diseases (NTDs) that are exacerbated by inadequate WASH; and

—Continuing CDC's work towards eliminating cholera as a public health threat.

In addition, this request will help maintain CDC's efforts to identify the most effective WASH interventions and provide technical assistance in scaling up those interventions. And by leveraging the WASH investments made by USAID, multilateral banks, and non-governmental organizations, CDC is helping to make WASH interventions more efficient and sustainable.

We highly recommend that funding for the Global WASH program be new funding and not taken from existing programs at CDC.

Making investments in WASH now is critical to putting in place preventive measures that can slow the spread of the next novel coronavirus, Ebola outbreak, or the yet to be identified disease X and perhaps prevent multi-billion dollar emergency supplementals in the future. Access to WASH services is critical to protecting the health, well-being, and resilience of individuals and communities. WASH is one of the most cost-effective interventions available for improving global health and development, which leads to more resilient and prosperous communities.

[This statement was submitted by Danielle Heiberg, Advocacy Advisor, Global Water 2020.]

PREPARED STATEMENT OF LINDA GUTIERREZ

My brother was diagnosed with Schizophrenia when he was 16 years old, he is 62 now. His life from adolescence through adulthood has been consumed by mental illness. His dreams and ambitions were never fulfilled. I would give anything to have a cure or at least better treatment for this awful brain disease that often leaves its victims in jail, homeless, or hospitalized; and destroys families. This serious brain illness is not rare as many believe, but affects 1.1 percent of the population and that statistic has been true since first recorded, and is basically the same throughout the world. Its cause is primarily genetic, but is believed to be triggered by environmental factors. Schizophrenia (and schizoaffective disorder) robs the person of motivation, concentration, and cognition, as well as presenting positive symptoms such as hallucinations and delusions.

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I beg you to have NIMH prioritize research for the 5 percent of our population that has serious mental illnesses that include chronic depression (the leading cause of disability in the U.S.), schizophrenia (and schizoaffective disorder), and bipolar illness. This makes sense because it's the humane thing to do, but it also makes good fiscal smarts. The most severe mental illnesses account for the most dollars spent in hospitals, jails, prisons, emergency rooms, and services for the homeless.

Dr. E. Fuller Torrey wrote in Psychiatric Times earlier this month:

> "Congress awarded the National Institute of Mental Health an additional $98 million as part of the National Institutes of Health budget resolution in December 2019, which brings the NIMH budget to just under $2 billion and represents a 35 percent increase since 2015, one of the largest increases in the history of the NIMH. Yet, during the 5 years from 2015 through 2019, NIMH funded a total of TWO new drug treatment trials for schizophrenia and bipolar disorder, according to clinicaltrials.gov. This contrasts with the 5-year period from 2006 through 2010 when NIMH funded 48 such trials . . ."

In December 2019, the NIMH released a draft of their five-year strategic plan for public comment. They reported receiving more than 6,000 responses identifying examples of research initiatives the NIMH could be pursuing today to help people with serious mental illness recover and live better lives. Despite this robust response, NIMH made no substantive changes to the research goals or objectives in the final version released to the public earlier this week.

The NIMH research goals for 2020–2025 heighten the existing imbalance in NIMH research. In doing so, they offer little hope for new or better treatments for individuals who are currently afflicted with a mental illness during their lifetime, especially a serious mental illness. This failure is inexcusable given the large increase in research funding given to NIMH in recent years.

Future NIMH funding must be used to correct the existing imbalance, not worsen it, especially now that the COVID–19 pandemic has upended the mental health treatment system and will likely result in an exacerbation of symptoms in people currently affected and an increase in serious mental illnesses among Americans. Those with the most severe forms of mental illness deserve to be prioritized.

Thank you for your consideration,

Sincerely.

PREPARED STATEMENT OF HEAD START

Dear Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee,

On behalf of the Head Start community, thank you for the opportunity to submit written testimony regarding funding for Head Start and Early Head Start (collectively referred to as "Head Start") in fiscal year 2021. For 55 years, Head Start has provided early learning opportunities for our country's most vulnerable children and comprehensive support to families that address long-term economic stability and better health prospects, ultimately mitigating the devastating impacts that poverty can have on the future success of young children. As a community, we are grateful for the Subcommittee's tradition of strong bipartisan support for Head Start and its leadership on issues related to children and families. This Subcommittee has been a tremendous advocate for Head Start, Early Head Start, and other programs that give hardworking families sustained, unmatched support, providing the chance for children not just to succeed in school but to thrive in life. In light of the COVID–19 pandemic, we would like to thank you for the immense amount of time and effort that you have put into ensuring that children and families' needs are met as the impact in local communities continues to take shape. To build on these critical successes, the National Head Start Association (NHSA) recommends $11,369,445,000 in Head Start funding for fiscal year 2021.

My personal journey with Head Start began over 30 years ago. I was teaching in the elementary schools when I took a summer job with a Community Action Program in Iowa. By the end of that summer, I had accepted a job as an Education Coordinator for Head Start. Really, Head Start found me and set my trajectory in motion. Because of my employment with Head Start, I was able to finish a master's degree in education and pursue a doctoral degree in organizational leadership. Now, I have been the Head Start program director at Douglass Community Services (DCS) in Hannibal, Missouri for more than 15 years.

Everyone says, 'Head Start gets into your blood,' and it is true. I quickly grew to love Head Start's intergenerational approach. From the beginning, my work has been inspired by watching families define success for themselves and then going on to achieve it. I have seen many parents in our program earn their degrees and start careers. Many chose nursing school, and now, one of our former parents is the head emergency room nurse at our local hospital. All across our community, Head Start parents are stepping up as heroes right now. In all my years with Head Start, many things have changed, but one constant is seeing the success of families, and that is why I am still here more than 30 years later.

Our staff are the engine of the work we do. At DCS, we employ 140 people-teachers, nurses, managers, and mental health specialists. Every year, we compete with our local school districts to keep the qualified, quality staff who we have trained and invested in. We, our program and our families, need our teachers' skill and passion for educating children, but year after year, it is a challenge to compete with public schools that can offer better compensation and benefits. At DCS, we prioritize offering creative, robust benefits to stay competitive with the local school districts, but supporting our workforce requires so much more.

While further financial investment in our workforce is crucial, we have also addressed staff turnover by creating an apprenticeship program, which has been beneficial for our whole community. When our CEO Stephanie Cooper came to DCS 5 years ago, we were able to start building our career and professional development program. We knew that if staff could see their work in Head Start as part of a career path, the work would get in their blood just like it did mine.

The apprenticeship program is a career ladder that allows teachers to grow within Head Start. We were the first Head Start program, and the first program of any kind in our community, to establish an official apprenticeship program. With the help of community partners and the whole-hearted support of the DCS team, we have seen incredible success with the apprenticeship program. Now, many of our staff have been with us for a number of years, and many have earned CDAs and degrees and stayed with us. Each year, DCS depends on Congress to be able to provide small increases to our staff to incentivize them to stay with us. For fiscal year 2021, Head Start requests that Congress maintains its strong history of providing this critical cost-of-living adjustment to Head Start that can help maintain services as the costs of business increase. These investments have exponential benefits for the continuity of our workforce and for the outcomes of our children and families.

Another development in recent years is the way we have changed our mental health practices in response to new and evolving needs within our community. Knowing that many of our children have experienced trauma and understanding the possible lifelong effects of adverse childhood experiences, we shifted our practices to a trauma-informed approach. Our staff now approach children's challenging behaviors with the understanding that they may be coping with the effects of trauma, and we work with them to understand their emotions and behaviors. As a part of this intensive effort, we decreased class sizes, so that teachers in the classroom have the opportunity to build trusting relationships with all children.

These efforts do not end with the children who we serve. Our trauma-informed mindset extends to our interactions with parents and with one another on the DCS team. By simply asking parents,'How are you doing today?' when they walk in our doors, and really listening, we are building relationships and empowering them to be the best parents they can be. When we provide trauma-related training for parents and staff, we work hard to make it feel not like a training, but instead, a strengths-based conversation. Parents are their children's first and most important teachers, and we want them to know how valued they are.

One of our parents, Jessika, is a 30-year-old mother of four children and has been with Head Start for a little over 4 years. Jessika shared what she learned and applied to her own life from Trauma Smart, the trauma-informed care curriculum provided by DCS Head Start. Having spent her youth in 23 foster homes, she was still in foster care at age 16 when she became pregnant. She was blessed to have a foster mom who was willing to keep her and her baby, so she did not have to give her first child up for adoption. She shared that our Trauma Smart program helped her learn a lot about herself and identify that it was the trauma she had experienced early in life that was leading her behaviors as an adult.

In Trauma Smart, we learn the analogy of the brain as a car. When you feel that you are in control of decisions, can solve problems, and regulate your emotions, you are in the front seat. In the back seat, you are in an emotional state, and when you are in the trunk, you are in a survival mode of fight, flight, or freeze. Jessika stated that through training she realized that she had spent most of her life "in the trunk," so much of it in fact that although it did not feel good, it felt safe.

She shared that the training took her through a healing process, where she could let go of the fear of moving from the safety of her trunk and to see things through the eyes of others, including the eyes of her own kids. In talking with me about her experience with Trauma Smart, she ended by saying, "I realized I was a broken adult, and I was tired of just surviving." She keeps her training materials by her bedside and refers to them often. Through her progress with Trauma Start, Jessika has a new-found confidence and has set positive goals for herself and her family. She is taking college courses with the goal of completing a bachelor's degree. She knows that she is a much better parent and can see changes in her children's behaviors that will make them much more successful as well.

The trauma training we provide also builds a sense of camaraderie among our staff that enables them to support each other, and this work reminds us that we are doing more than going into a classroom and teaching: we are making a substantial impact in children's lives. We made these intentional changes in Hannibal long before much of the talk about trauma-informed care began, and we are glad such practices are reaching many more Head Start children and families today. That said, we know that there is so much more that could be done, here in Hannibal and in Head Start programs across the country working to provide the interventions needed for children to succeed in school and later in life. In fiscal year 2021, the Head Start community is seeking an increase of $495 million in quality improvement funding, so that even more children and families can see the benefits of services like our trauma intervention.

Today, as we watch our communities adapt to respond to COVID–19, children and families are facing new challenges and need Head Start more than ever. With stay-at-home orders in place, Head Start programs have continued to operate remotely, serving the needs of both children and caregivers with delivery of food and sanitation supplies, provision of learning materials, and virtual home visits. While there has long been an urgent need to respond to children and families' mental health needs, COVID–19 has dramatically compounded those needs.

While operating completely remotely, technology has become one of our greatest areas of need, for both families and our DCS staff. For our staff without home Internet access, we purchased hotspots. We have also purchased track phones for teachers to stay in contact with families. But the need for better technology is still there.

Even if we could get devices for every family, it would not be much use for those without Internet, unlimited data plans, or cell service. Head Start is the option for families in our area, and meeting the needs that stem directly from COVID–19 is critical if we are going to be able to fulfill our mission of sending children to kindergarten prepared.

Nationwide, there are roughly 1,600 Head Start grantees that serve more than one million children and pregnant mothers each year and a workforce of more than 270,000 Head Start staff who partner with those children and families. As you make difficult decisions around fiscal year 2021, I ask that you keep them in mind—the members of the early childhood workforce who are such strong pillars in our programs and our communities, who step up in times of crisis with selfless, untiring commitment to the betterment of our community, innovative ideas to meet our families' needs, and unending compassion. I ask that you keep in mind the parents, like Jessika, who thrive through Head Start and the children who depend on Head Start to arrive at kindergarten with a love of learning and a readiness to succeed.

Above all, please remember that trauma does not go away. Trauma was on the rise in the communities that Head Start serves before COVID–19, and soon, we will see the effects of the trauma brought on by the pandemic. Our efforts to address challenges stemming from trauma, faced by our communities are not slowing down either. I ask you to remember that the Quality Improvement Funds that came in fiscal year 2020 fuel this unending work, and I urge you to consider just how critically important it is that the trauma intervention services funded through QIF are sustained as our community meets new challenges.

Thank you for your consideration.

Sincerely.

[This statement was submitted by Linda Bleything, Director, Douglass Community Services Head Start & Early Head Start.]

PREPARED STATEMENT OF HEALING MINDS NOLA

Healing Minds NOLA, is a non-profit organization based in New Orleans, Louisiana. Our mission is to explore and create alternatives to incarceration, homelessness and death for people living with untreated and undertreated severe mental illnesses. We appreciate the opportunity to provide written testimony regarding the National Institute of Health fiscal year 2021 budget appropriations.

Over the years, Americans have witnessed the steady decline of long-term support programs and services for people with chronic, debilitating severe mental illnesses. Despite the lifetime care needs of people with mental diseases, a large percentage of people go without treatment every year.

"Based on 2016 population numbers, the analysis found the following: 8.2 million U.S. adults had schizophrenia or severe bipolar disorder at the combined NIMH prevalence rate of 3.3 percent. 3.9 million people with these diseases were untreated at any given time during the year" [1]

Many exist within a never-ending system of crisis care—being shuffled between the revolving doors of ERs, hospitals, jails, shelters and various states of homelessness. 40–50 percent are treatment non-adherent [2] due to Anosognosia, defined as a deficit of self-awareness, a condition in which a person with a disability is unaware of having it.[3] It is highly unlikely that anyone would seek treatment and care for an illness they didn't have.

Anosognosia is just one syndrome associated with severe mental illness that we see on a regular basis. Other barriers to care include negative attitudes toward medication due to side effects. Consequences of non-adherence include poor quality of life or psycho-social outcomes, relapse of symptoms, increased co-morbid medical conditions, wastage of healthcare resources, and increased suicide.[4]

To mitigate the enormous humanitarian and economic costs of untreated and under-treated severe mental illness, now is the time to increase support for drug trials and treatments for schizophrenia, bipolar disorder, and major depressive disorder. Better medications with less side-effects and evidence-based treatments would do much to end the suffering for people who struggle with mental diseases.

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[1] https://www.treatmentadvocacycenter.org/fixing-the-system/features-and-news/3828-research-weekly-2016-prevalence-of-treated-and-untreated-severe-mental-illness-by-state.

[2] https://www.treatmentadvocacycenter.org/key-issues/anosognosia/3628-serious-mental-illness-and-anosognosia.

[3] https://en.wikipedia.org/wiki/Anosognosia.

[4] https://www.dovepress.com/why-do-psychiatric-patients-stop-antipsychotic-medication-a-systematic-peer-reviewed-fulltext-article-PPA.

Given that the NIMH has failed to prioritize funds for the most at-risk and vulnerable mentally ill population,[5] we urge the United States Senate Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies to require it.

Thank you for your consideration of this matter.

[This statement was submitted by Janet Hays, Director, Healing Minds NOLA.]

PREPARED STATEMENT OF THE HEALTH PROFESSIONS AND NURSING EDUCATION COALITION

The Health Professions and Nursing Education Coalition (HPNEC) is an alliance of 80 national organizations representing schools, students, health professionals, and communities dedicated to ensuring that the healthcare workforce is trained to meet the needs of our diverse population. Together, the members of HPNEC advocate for adequate and continued support for the health professions and nursing workforce development programs authorized under Titles VII and VIII of the Public Health Service Act and administered by the Health Resources and Services Administration (HRSA). For fiscal year 2021, HPNEC encourages the subcommittee to adopt at least $790 million for HRSA Titles VII and VIII programs.

HRSA's Title VII health professions and Title VIII nursing workforce development programs are structured to allow grantees to test educational innovations, respond to changing delivery systems and models of care, and timely address health threats, such as COVID–19. Titles VII and VIII programs are structured to respond to changing delivery systems and models of care, such as telehealth, while addressing immediate health threats in all communities. Through scholarships, loan repayment programs, grants, and contracts to academic institutions, students, and non-profit organizations, HRSA's workforce development programs address health threats in all communities by filling the gaps in the supply of health professionals not met by traditional market forces.

As our population grows, ages, and becomes increasingly diverse, our health professions workforce must adapt to the ever-changing health needs of patients from all backgrounds in communities across the country. Now more than ever support is needed for Title VII and Title VIII programs that improve the supply, distribution, and diversity of the workforce—to ensure health professionals are prepared to address the healthcare challenges of today and the future.

Public Health.—Public Health Workforce Development trains America's public health workforce to identify underlying causes of health issues, new disease strains, health disparities, and other public health issues vital to the country's response to any pandemic. These programs support education and training in public health and preventive medicine through different initiatives, including the only funding for physicians to work in state and local departments of health. In AY 2018–2019, Public Health Workforce grantees delivered unique continuing education courses more than 226,500 practicing professionals in the workforce.

Diversity Pipeline Programs.—Title VII and Title VIII programs play an essential role in improving the diversity of the health workforce and connecting students to healthcareers by supporting recruitment, education, training, and mentorship opportunities. With public health issues, such as COVID–19, disproportionately impacting racial and ethnic minorities, these programs recruit and train a diverse and culturally competent health workforce, tasked to mitigate health disparities.

Diversity programs include the Health Careers Opportunity Program (HCOP), Centers of Excellence (COE), Faculty Loan Repayment, Nursing Workforce Diversity, and Scholarships for Disadvantaged Students (SDS). Studies have demonstrated the effectiveness of such pipeline programs in strengthening students' academic records, improving test scores, and helping minority and disadvantaged students pursue careers in the health professions. Title VII diversity pipeline programs reached over 10,000 students in the 2018–2019 academic year (AY), with SDS graduating nearly 1,400 students and COE reaching more than 5,600 health professionals; 56 percent of which were located in medically underserved communities.

Title VIII's Nursing Workforce Diversity Program increases nursing education opportunities for individuals from disadvantaged backgrounds, through stipends and scholarships, and a variety of pre-entry and advanced education preparation. In AY 2018–19, the program supported more than 11,000 students, with approximately 46 percent of the training sites located in underserved communities

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[5] https://www.psychiatrictimes.com/article/riches-abound-so-where-are-trials-schizophrenia-and-bipolar-disorder.

Primary Care Workforce.—The Primary Care Medicine Programs expand the primary care workforce, including general pediatrics, general internal medicine, family medicine, and physician assistants through the following programs: Primary Care Training and Enhancement (PCTE); academic units for PCTE; PCTE: Training Primary Care Champions; and Primary Care Medicine and Dentistry Career Development. The Primary Care programs are also intended to encourage health professionals to work in underserved areas. In AY 2018–2019, 61 percent of PCTE programs were located in medically underserved communities and 30 percent in rural areas.

The Medical Student Education program, which supports the healthcare workforce by expanding training for medical students to become primary care clinicians, targets institutions of higher education in states with the highest primary care workforce shortages. By providing grants to institutions, the program develops partnerships among institutions, federally recognized tribes, and community-based organizations to train medical students to provide primary care that improves health outcomes for those living in rural and other underserved communities.

Interdisciplinary, Community Based Linkages.—Support for community-based training of health professionals in rural and urban underserved areas is funded through Title VII. By assessing the needs of the local communities they serve, Title VII programs can fill gaps in the workforce and increase access to care for all populations. The programs emphasize interprofessional education and training, and using telehealth to bring together knowledge and skills across disciplines to provide effective, efficient, and coordinated care.

Programs such as Graduate Psychology Education (GPE); Opioid Workforce Enhancement Program; Mental and Behavioral Health; Behavioral Health Workforce Education and Training (BHWET); and Allied Health Training test educational innovations, respond to changing delivery systems and models of care, and timely address emerging health issues in their communities. The BHWET and Mental and Behavioral Health programs, which include GPE, provides training to expand access to mental and behavioral health services for vulnerable and underserved populations. In AY 2018–19, nearly 50 percent of all BHWET and GPE grantees provided substance use disorder treatment services.

Area Health Education Centers (AHEC) support the recruitment and training future physicians in rural areas, as well as providing interdisciplinary healthcare delivery sites, which respond to community health needs. In AY 2018–19, AHECs supported 192,000 pipeline program participants, provided over 34,000 clinical training rotations for health professions trainees.

Title VII Geriatric Workforce programs integrate geriatrics and primary care to provide coordinated and comprehensive care for older adults. These programs provide training across the provider continuum (students, faculty, providers, direct service workers, patients, families, and lay and family caregivers), focusing on interprofessional and team-based care and on academic-community partnerships to address gaps in healthcare for older adults. To advance the training of the current workforce, the Geriatrics Workforce Enhancement Program (GWEP) provided 1,342 unique continuing education courses to 187,955 faculty and practicing professionals in AY 2018–19, including 445 courses on Alzheimer's and dementia-related diseases

Nursing Workforce Development.—Title VIII nursing workforce development programs provide Federal support to address all aspects of nursing workforce demands, including education, practice, recruitment, and retention, with a focus on rural and medically underserved communities. These programs include Advanced Nursing Education; Nursing Workforce Diversity; Nurse Education, Practice, Quality, and Retention; NURSE Corps; and Nurse Faculty Loan Program. In AY 2018–2019, the Title VIII Advanced Education Nursing programs supported more than 9,000 nursing students in primary care, anesthesia, nurse midwifery, and other specialty care, all of whom received clinical training in primary care in medically underserved communities and/or rural settings.

Oral Health.—The Primary Care Dentistry program invests in expanding programs in dental primary care for pediatric, public health, and general dentistry. The Pre- and Postdoctoral Training, Residency Training, Faculty Development, and Faculty Loan Repayment programs encourage integrating dentistry into primary care.

Workforce Information and Analysis.—The Workforce Information and Analysis program Provides funding for the National Center for Health Workforce Analysis as well as grants to seven Health Workforce Research Centers across the country that perform and disseminate research and data analysis on health workforce issues of national importance.

While HPNEC's members acknowledge the increasing demands and fiscal challenges facing appropriators, funding for HRSA's workforce development programs is critical in creating a culturally competent workforce that can respond to current and future public health threats facing all Americans. Therefore, HPNEC encourages the subcommittee to adopt at least a $790 million for HRSA's Title VII and VIII programs to continue the nation's investment in our health workforce.

PREPARED STATEMENT OF THE HEPATITIS B FOUNDATION

HBF RECOMMENDATIONS FOR FISCAL YEAR 2021 APPROPRIATIONS

National Institutes of Health

- —Along with the biomedical research community, the Hepatitis B Foundation (HBF) recommends at least $44.7 billion for NIH in fiscal year 2021. This would be a $3 billion increase over NIH's program level funding in fiscal year 2020. This funding level would allow for meaningful growth above inflation in the base budget that would expand NIH's capacity to support promising science in all disciplines beyond the directed funding included in the 21st Century Cures Act.
- —HBF commends NIAID, NIDDK, NCI for the development of a Trans-NIH Strategic Plan to Cure Hepatitis B and urges the Institutes to issue targeted calls for research to implement and fund the Strategic Plan.

Centers for Disease Control and Prevention

- —HBF supports $8.3 billion for the Centers for Disease Control and Prevention programs in fiscal year 2021, and within that $134 million for the Division of Viral Hepatitis. HBF further urges the CDC to allocate the necessary resources to address serious surveillance shortcoming without adversely impacting other CDC hepatitis B programs.

Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to provide testimony as you consider funding priorities for fiscal year 2021. I am Tim Block, President of the Hepatitis B Foundation (HBF). The Hepatitis B Foundation and its associated Baruch S. Blumberg Institute in Bucks County, Pennsylvania has grown to more than 100 researchers and public health professionals and has one of the largest, if not the largest, concentration of nonprofit scientists working on the problem of hepatitis B and liver cancer in the United States. The Foundation is a national disease advocacy organization that has become the world's leading portal for patient-focused information about hepatitis B. The Baruch S. Blumberg Institute is internationally recognized, and we believe, home to some of as the most exciting and promising work in the field.

Mr. Chairman, HBF joins the Ad Hoc Group for Medical Research Funding, a coalition of 300 patient and voluntary health groups, medical and scientific societies, academic research organizations and industry, in recommending $44.7 billion, an increase of $3 billion, for the National Institutes of Health in fiscal year 2021. While HBF recognizes there are demands on our Nation's resources, we believe the ever-increasing health threats and expanding scientific opportunities continue to justify increased funding for NIH. HBF further urges that NIH increase investments in hepatitis B research in order to find a cure for the 2.2 million Americans infected with the hepatitis B virus (HBV) and more than 10 deaths each day as a direct result of hepatitis B.

In addition to the NIH, there are a number of programs within the jurisdiction of the subcommittee that are important to HBF, including the Centers for Disease Control and Prevention. We join the CDC Coalition, an advocacy coalition of more than 140 national organizations, in recommending $8.3 billion for the Centers for Disease Control and Prevention in the fiscal year 2021 bill. Within that total, we join the Hepatitis Appropriations Partnership in urging $134 million for the CDC's Division of Viral Hepatitis.

RECOGNIZING THE LEADERSHIP OF THE SUBCOMMITTEE

Mr. Chairman, HBF appreciates your leadership and the leadership of this Subcommittee in supporting public health service programs. Your support is greatly recognized and appreciated. We applaud the Committee's leadership in making progress in these important areas and to allocating increased funding to these programs during periods of fiscal austerity. We are particularly grateful for your leadership in securing generous and steady increases for the NIH in your tenure as Chairman.

NATIONAL INSTITUTES OF HEALTH

As previously noted, HBF recommends an fiscal year 2021 funding level of $44.7 billion for the NIH, which would enable real growth over health research inflation as an important step to ensuring stability in the Nation's research capacity over the long term. The Administration's request of $38.7 billion in fiscal year 2021, translating to a $3.0 billion cut, is reckless and shortsighted. Cuts to NIH would affect every American, including patients, their families, researchers, and communities where NIH investment spurs economic growth.

In addition to overall funding for the NIH, HBF urges that NIH investments in hepatitis B research be increased at least $38.7 million a year for 6 years in order to fund identified research opportunities that would help cure and eliminate the disease once and for all. The Hepatitis B Foundation appreciated the creation of the Hepatitis B Trans-NIH Working Group and was even more encouraged by the release of a Strategic Plan for Trans-NIH Research to Cure Hepatitis B in December of 2019. Report language is requested in the fiscal year 2021 Report urging the NIAID and NIDDK to issue targeted calls for HBV research proposals in fiscal year 2021 focused on the many new research opportunities identified by the Strategic Plan.

In the U.S., 1 in 20 Americans has been infected with hepatitis B virus (HBV) and an estimated 2.2 million are chronically infected. Worldwide, HBV is associated with 840,000 deaths each year, making it the 10th leading cause of death in the world. Left undiagnosed and untreated, 1 in 4 of those with chronic HBV infection will die prematurely from cirrhosis, liver failure and/or liver cancer. Although HBV is preventable and treatable, there is still no cure for this disease. In view of the epidemic scope of hepatitis B and the fact that the virus was discovered 50 years ago, it is disappointing that funding for HBV research at the NIH is only expected to be funded at $66 million in fiscal year 2021.

There is the need, the know-how, and the tools to find a cure that will bring hope to almost 300 million people worldwide suffering from chronic hepatitis B. A cure was accomplished for hepatitis C with increased Federal attention and funding. It can be accomplished for hepatitis B as well. Each year, despite an effective vaccine, there are 30 million new HBV infections worldwide and over 80,000 new infections in the U.S. Moreover, despite the availability of seven approved medications to manage chronic HBV infection, none are curative, most require lifelong use, and only reduce the likelihood of death due to liver disease by 40–60 percent.

In addition to the devastating toll on patients and their families, ignoring hepatitis B is costing the United States an estimated $4 billion per year in medical costs. By increasing the NIH budget for hepatitis B we have a good chance of success in finding a cure in the next few years. There are exciting new research developments and opportunities in the field that make finding a cure very possible.

CENTERS FOR DISEASE CONTROL AND PREVENTION

Given the challenges and burdens of chronic disease and disability, public health emergencies, new and reemerging infectious diseases and other unmet public health needs, HBF joins the 140 organizations in the CDC Coalition and urges a funding level of at least $8.3 billion for CDC's programs in fiscal year 2021. This is $693 million more than the Administration's request. The CDC serves as the command center for the nation's public health defense system against emerging and reemerging infectious diseases. States, communities, and the international community rely on CDC for accurate information and direction in a crisis or outbreak. The proposed reduction, especially in the time of a global pandemic is reckless and we are strongly opposed.

The CDC's Division of Viral Hepatitis (DVH) is part of the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention at CDC. In collaboration with domestic and global partners, DVH provides the scientific and programmatic foundation and leadership for the prevention and control of hepatitis virus infections and their manifestations. HBF joins the Hepatitis Appropriations Partnership in recommending $134 million for the DVH in fiscal year 2021. This is $95 million more than the Administration's request.

The CDC Division of Viral Hepatitis spends less than 5 percent on HBV focused projects, despite hepatitis B infected patients comprising more than 35 percent of all those infected with viral hepatitis. Furthermore, tremendous HBV-related health disparities exist for people of Asian and Pacific Islander descent and recent African immigrants. These groups represent less than 5 percent of the U.S. population but make up over 50 percent of the U.S. burden of chronic HBV infection. CDC has not adequately addressed the issue of chronic HBV infections among high-risk, foreign-born populations and their children. Of particular concern, surveillance within the

CDC surveillance program is not robust enough to accurately report the prevalence of the disease in high incidence states such as California and Hawaii. In view of the fundamental importance of good surveillance data to develop, manage and analyze public health programs and interventions, HBF urges CDC to allocate the necessary resources to address this shortcoming without adversely impacting other CDC hepatitis B programs.

HBF is further concerned that despite the availability of an effective hepatitis B (HBV) vaccine, less than 25 percent of adults age 19 and older are vaccinated. According to CDC's most recent survey of Vaccination Coverage Among Adults, this poor vaccination rate remains flat and has not improved in several years. We are encouraged that CDC is evaluating new universal HBV vaccination recommendations including a comprehensive plan to increase adult HBV vaccinations. The CDC is further urged to promote awareness about the importance of hepatitis B vaccination among medical and health professionals, communities at high risk, and the general public and to improve collaboration and coordination across CDC to achieve this goal.

SUMMARY AND CONCLUSION

Mr. Chairman, again we wish to thank the Subcommittee for its past leadership. Significant progress has been made in meeting the many public health concerns facing this Nation, due to your efforts. Mr. Chairman, if this country is to continue to see advances in improving the health and well-being of our Nation adequate funding for the public health service is paramount.

There is the need, the know-how, and the tools to find a cure that will bring hope to more than 292 million people worldwide suffering from hepatitis B. A cure was accomplished for hepatitis C with increased Federal attention and funding. It can be accomplished for hepatitis B as well. Each year, despite an effective vaccine, there are an estimated 30 million new HBV infections worldwide and over 50,000 new infections in the U.S. Moreover, recent advances in the scientific understanding of new viral and immunological antiviral targets, and new experimental systems, are leading to innovations in drug discovery. There are 46 drugs currently in development, of which 27 are already in clinical trials. The findings of two recent National Academy of Science reports that not only is a cure for hepatitis B within reach, but the virus could be totally eliminated when coupled with public health interventions to improve diagnosis, care and treatment. The most recent report, titled "A National Strategy for the Elimination of Hepatitis B and C Phase Two Report", recommends specific actions to hasten the end of these diseases and lays out five areas—including research—to consider in the national plan. HBF appreciates the opportunity to provide testimony to you on behalf of these paramount needs of the Nation.

[This statement was submitted by Timothy Block, Ph.D., President, Hepatitis B Foundation.]

PREPARED STATEMENT OF THE HIV MEDICINE ASSOCIATION

Chairman Blunt, Ranking Member Murray, and members of the Subcommittee my name is Dr. Judith Feinberg, Fellow of the Infectious Diseases Society of America, and Chair of the HIV Medicine Association (HIVMA). I am pleased to submit testimony on behalf of HIVMA. HIVMA represents more than 6,000 physicians, scientists and other healthcare professionals around the country on the frontlines of the HIV epidemic. Our members provide medical care and treatment to people living with HIV in the U.S., lead HIV prevention programs and conduct research that has led to the development of effective HIV prevention and treatment options. Many of them are infectious diseases specialists who are now on the frontlines of their community's coronavirus (COVID–19) response.

For the fiscal year 2021 appropriations process, we urge you to increase funding for the Ryan White HIV/AIDS Program at the Health Resources and Services and Administration (HRSA); increase funding for the Centers for Disease Control and Prevention's (CDC) HIV, hepatitis and STD prevention programs; increase investments in HIV research supported by the National Institutes of Health (NIH); appropriate additional funding to support the "Ending the HIV Epidemic" (EHE) Initiative; and address workforce shortages that affect the implementation of the EHE initiative as well as the response to the COVID–19 pandemic. As the United States responds to the global COVID–19 pandemic, it is paramount to provide robust funding for these vital programs which support global and domestic health security measures and our public health infrastructure.

The COVID–19 pandemic has dramatically impacted public health programs across the country. Critical programs are at their breaking point as they continue to fight against COVID–19 while simultaneously responding to their existing public health priorities. Many programs have been forced to shift and re-focus their work. Any reduction in Federal funding for state and local health departments, community-based organizations and other entities that provide core HIV prevention, diagnosis and treatment services deserve scrutiny and public comment by those of us dealing with these issues firsthand.

The funding requests in our testimony largely reflect the consensus of the Federal AIDS Policy Partnership, a coalition of HIV organizations from across the country. For a chart of current and historical funding levels, along with coalition requests for each program, please click here: https://bit.ly/2SNWk7h.

Health Resources and Services Administration—HIV/AIDS Bureau:

HRSA's Ryan White HIV/AIDS Program provides medical care and treatment services to over half a million people living with HIV. Ryan White Program providers are also on the frontlines of the COVID–19 pandemic, and they need increased and sustained funding to meet the current needs of their patients. Ryan White programs effectively engage clients in comprehensive care and treatment, including increasing access to HIV medication, which has resulted in 87 percent of clients achieving viral suppression, the goal of HIV treatment that also decreases transmission, compared to just 59 percent of all people living with HIV nationwide.

Additional funding across the program's parts to help people living with HIV maintain access to care and treatment during the economic downturn, meet the new needs of people who now are without health insurance, and prevent and contain the spread of COVID–19 is crucial. To continue providing comprehensive, life-saving treatment and to bring many more people into care through the Ending the HIV Epidemic Initiative, we request a $263 million increase over fiscal year 2020 levels for the Ryan White HIV/AIDS Program for a total of $2.652 billion.

Policy—Ryan White Program Income:

Successful HIV prevention for individuals at risk for HIV is available now through education, routine HIV screening, and ready access to pre-exposure prophylaxis (PrEP), post-exposure prophylaxis (PEP), harm reduction services, and other prevention tools, strategies both known now and yet to be discovered. HIVMA supports the HIV/AIDS Bureau in allowing Ryan White Program grantees to use their program income to reduce new HIV infections and services that improve care and treatment outcomes for people living with HIV, as long as the use of that program income does not reduce access to current or critical HIV care and treatment services provided by the grantee.

HIVMA urges an allocation of $225.1 million, or a $24 million increase over current funding, for Ryan White Part C programs. Part C-funded HIV medical clinics are struggling to meet the demand of increasing patient caseloads. The team-based and patient-centered Ryan White care model has been highly successful at improving clinical outcomes for a population with complex healthcare needs. Persons with HIV who receive Ryan White services are more likely to be prescribed HIV treatment and to be virally suppressed, which also limits transmission to others. Between 2010 and 2018, the viral suppression rate for all Ryan White clients increased from 70 percent to 87 percent.[1] We also know that the annual healthcare costs for persons who are diagnosed late and/or do not have reliable access to care and treatment are nearly 2.5 times greater than that of healthier persons with HIV.[2] Increased Ryan White Part C funding also is urgently needed to meet the increasing demand for treatment for substance use disorders and mental health at Ryan White clinics.

We also recommend funding the administration's request of $716 million in funding for the Ending the HIV Epidemic initiative—more than double the 2020 request. The EHE Initiative will focus on 48 counties, the District of Columbia, San Juan, P.R., and seven rural states where the incidence of new HIV infections are the highest. Last year, those jurisdictions developed community-specific plans to combat HIV that addresses the unique needs of each jurisdiction. The funds appropriated last year will allow those plans to be scaled up.

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[1] Health Resources and Services Administration. Ryan White HIV/AIDS Program Annual Client-Level Data Report 2016. https://hab.hrsa.gov/sites/default/files/hab/data/datareports/RWHAP-annual-client-level-data-report-2016.pdf.

[2] Gilman BH, Green, JC. Understanding the variation in costs among HIV primary care providers. AIDS Care, 2008:20;1050–6. doi: 10.1080/09540120701854626.

Health Resources and Services Administration—Bureau of Primary Health Care:

We recommend appropriating $87 million in new funding for HRSA's Community Health Center program for the End the HIV Epidemic initiative. Community health centers, especially those already funded by the Ryan White Program, are critical entry points for people with limited resources or without other access to care to get tested and initiate PrEP. CDC estimates only 10 percent of those who could benefit from PrEP have had it prescribed to them, and those who need it most—black and Latino gay and bisexual men at high risk—are prescribed it at a much lower rate.[3] Scaling up PrEP among the most affected populations in the EHE areas is critical to ending the HIV epidemic. Without a vaccine on the horizon, PrEP for HIV is our most effective prevention tool.

Centers for Disease Control and Prevention—National Center for HIV/AIDS, Viral Hepatitis, Sexually Transmitted Diseases, and Tuberculosis Prevention:

CDC serves as the command center for the nation's public health defense system against emerging and reemerging infectious diseases. From aiding in the surveillance, detection and prevention of the current COVID–19 outbreak to playing a lead role in the control of Ebola in West Africa and the Democratic Republic of the Congo to pandemic flu preparedness, CDC is both a national and global expert resource and response center, coordinating communications and action and serving as the laboratory reference center. To meaningfully address the HIV, viral hepatitis and STD epidemics, as well as the co-occurring crisis of substance use disorder-especially injection drug use— we request a $647 million overall increase above fiscal year 2020 levels for a total of $1.921 billion.

For the Division of HIV/AIDS Prevention (DHAP), we request a total of $1.293 billion, which is a $365 million increase over fiscal year 2020 levels. DHAP conducts our national HIV surveillance and funds state and local health departments and communities to conduct evidence-based HIV prevention activities. As HIV prevention and surveillance staff are shifted to work on the COVID–19 response, it is important that the HIV prevention infrastructure is not impacted. CDC's national surveillance system is a key tool in identifying people and regions most impacted by the HIV epidemic, and tailoring prevention efforts to meet the needs of those populations and prevent HIV transmission clusters. CDC's high impact prevention strategies work, but with flat funding, we cannot reach all the people at risk for HIV. We also recommend appropriating the $371 million requested by the administration for the Ending the HIV Epidemic initiative, which will allow CDC to focus on efforts to scale up HIV testing, implement PrEP programs, and immediately link people newly diagnosed with HIV to care to preserve their health and prevent further spread.

Additionally, we urge the appropriation of the requested $58 million for the CDC to fund surveillance and programming to monitor and prevent opioid-related infectious diseases. Funding for CDC's Infectious Diseases and Opioid Epidemic programming increases prevention, testing and linkage to care efforts to combat the increase in new HIV and viral hepatitis B and C infections and the massive increase in life-threatening bacterial infections such as endocarditis that affects heart function, all of which have spiked in areas impacted by the opioid crisis. The COVID–19 pandemic already has resulted in increased drug overdoses, homelessness, and unemployment, worsening the underlying conditions in regions already hard-hit by the drug epidemic.

Policy—Syringe Services Programs (SSP):

The fiscal year 2020 appropriations bill continued a harmful policy rider that restricts the use of Federal funds for the purchase of sterile syringes, which negatively impacts the ability of state and local public health groups from expanding SSPs. SSPs have been shown to limit HIV and hepatitis C infections and to increase the number of people who enter treatment for substance use disorder, while at the same time decreasing drug-related crime. HIVMA is opposed to restrictions on Federal funding that ban SSPs from purchasing sterile syringes.

For the Division of Viral Hepatitis (DVH), we request a total of $134.0 million, which is a $95 million increase over fiscal year 2020 levels. CDC announced that in 2017 there were over 44,000 recognized new cases of hepatitis C. New hepatitis B and C infections are being driven by injection drug use throughout the country,

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[3] CDC. HIV prevention pill not reaching most Americans who could benefit—especially people of color. https://www.cdc.gov/nchhstp/newsroom/2018/croi-2018-PrEP-press-release.html.

and especially in regions hardest hit by the opioid epidemic.[4] We have the tools to prevent this growing epidemic, but only significantly increased funding can provide the needed level of testing, education, screening, surveillance, treatment and on-the-ground syringe service programs needed to reduce new infections, and to put the U.S. on the path to eliminate hepatitis as a public health threat.

For the Division of STD Prevention (DSTDP), we request a total of $240.8 million, which is an $80 million increase over fiscal year 2020 levels. Data released in October 2019 by the CDC shows that after 5 years of dramatic increases, combined cases of syphilis, gonorrhea, and chlamydia reached all-time highs in the U.S. Tragically, congenital (mother-to-child) syphilis increased by 40 percent in 1 year, leading to a 22 percent increase in newborn deaths related to congenital syphilis. These historic increases have created a public health emergency with devastating long-term health consequences, including infertility, cancer, HIV transmission, and infant and newborn deaths.

National Institutes of Health—Office of AIDS Research:

In order to continue funding 21st-century discoveries that will help us end the HIV epidemic, such as improved HIV prevention modalities and treatment options, we ask that at least $3.502 billion be allocated for HIV research in fiscal year 2021, an increase of $426 million. This level of funding is vital to sustaining the pace of research that will improve the health and quality of life for millions of people in the U.S. and abroad. Flat funding of HIV research from fiscal year 2015 to fiscal year 2020 threatens to slow progress toward a vaccine and a cure, erode our capacity to sustain our nation's leadership in HIV research and innovation, and discourage the next generation of scientists from entering the field.

Indian Health Service—Eliminating HIV and Hepatitis C in Indian Country:

Last year, the community and administration requested $25 million to address the disparate impact HIV and hepatitis C have on American Indian/Alaska Native populations through the Indian Health Service. Between 2011 and 2015, there was a 38 percent increase in new HIV diagnoses among the AI/AN population overall, and a rise of 58 percent among AI/AN gay and bisexual men. We were disappointed that the $25 million request was not included in the final fiscal year 2020 funding and hope that this can be remedied in fiscal year 2021. This year, we urge you to fund the EHE Initiative work within Indian Health Service at $27 million.

COVID–19 Response Funding Request:

As the Senate examines budget requests and the needs of Federal spending programs, immediate supplemental funding for programs negatively affected by COVID–19 is urgently needed. As the impacts of the pandemic spread and accelerate throughout the country, additional funding for the Ryan White Program and the CDC is needed. Investment in the Ryan White program is critical to ensure that no person living with HIV loses access to services during the COVID–19 pandemic and in the economic aftermath. To meet these immediate needs, Congress should allocate $500 million in supplemental funding to be divided amongst all parts of the Ryan White Program and at least $100 million toward the CDC's Division of HIV Prevention in the next COVID–19 response package.

Conclusion:

Thousands of frontline providers, scientists and public health professionals who are working to save lives, contain the spread of disease and inform responses to the threat to health, stability and security worldwide are currently involved on the COVID–19 response. These same professionals who are actively orchestrating the response to COVID–19 are also the same dedicated professionals who are responding to the EHE initiative—from the White House to state and local government-compounding strains on a limited workforce. The current pandemic highlights the importance of preparing for infectious diseases outbreaks by fully funding programs that support public health services and infrastructure so that we are better prepared for the next pandemic.

We are concerned about the long-term impact COVID–19 will have on our nation's healthcare infrastructure and clinical workforce and the impact this may have on the administration's End the HIV Epidemic initiative. We have the tools to end the HIV epidemic in the U.S. To accomplish this, we must substantially increase funding to support comprehensive prevention and care programs, grow a qualified workforce and create a healthcare system which routinely screens people for HIV and provides access to those living with HIV uninterrupted access to care and treatment.

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[4] Centers for Disease Control and Prevention. Viral Hepatitis Surveillance Report 2016. https://www.cdc.gov/hepatitis/statistics/2016surveillance/pdfs/2016HepSurveillanceRpt.pdf.

We need to invest in a strong public health infrastructure and protect Americans from public health threats and emergencies. With congressional support we can be better prepared for preventing future outbreaks and pandemics and get on track to end HIV as an epidemic. Thank you for your time and consideration of these requests. Please contact me or Jose A. Rodriguez, Senior Policy & Advocacy Manager, at Jrodriguez@hivma.org if you have any questions or need additional information.

[This statement was submitted by Judith Feinberg, MD, FIDSA, Chair, HIV Medicine Association.]

PREPARED STATEMENT OF HIV + HEP POLICY INSTITUTE

On behalf of the HIV + Hepatitis Policy Institute, we respectfully submit this testimony in support of increased funding for domestic HIV and hepatitis programs in the fiscal year 2021 Labor, HHS spending bill. The HIV + Hepatitis Policy Institute is a leading HIV and hepatitis policy organization promoting quality and affordable healthcare for people living with or at risk of HIV, hepatitis, and other serious and chronic health conditions.

While our nation and the entire world are currently battling COVID–19, where the science is in its infant stage, we have the science to end two other infectious diseases that have been impacting our country for decades: HIV and hepatitis C. While there still is no cure or vaccine for HIV, we have preventive tools along with treatments that suppress the virus and together can bring the number of new infections down to a point that we can end HIV. For hepatitis C, there are curative treatments. However, Federal leadership and funding for our public health system is necessary to ramp up efforts to address these two epidemics. The programs and funding increases detailed below are pivotal to our nation's ability to end both HIV and hepatitis.

The healthcare workers, community-based organizations, and state and local governments who have been on the front line of the COVID–19 response are the same people and organizations that have been responsible for planning and implementing our nation's response to both HIV and hepatitis and will continue to be once the current crisis subsides. Funding for them to address infectious diseases, such as HIV and hepatitis and others in the future, will particularly be necessary in the year ahead.

FUNDING PUBLIC HEALTH PROGRAMS OUTSIDE BUDGET CAPS

Our nation's public health infrastructure has been underfunded for many years. Now is the time to provide increased funding to allow Federal agencies, state and local jurisdictions, and community organizations on the ground the resources and capacity to build interconnected

and state-of-the-art surveillance, prevention, screening, and educational programs. In order to provide this necessary funding, the HIV + Hepatitis Policy Institute strongly supports funding critical public health programs, including those for ending HIV and hepatitis in the United States, outside of the Budget Control Act spending caps, similar to the creation of the proposed Health Defense Operations (HDO) fund. Without the necessary funding we will never end these infectious diseases or be prepared for future epidemics.

HIV and hepatitis programs across the nation are experts in best practices related to infectious disease prevention, control, and treatment. Jurisdictions across the nation are discussing how to incorporate and bundle screening and testing for COVID–19 infection with the same services for HIV, hepatitis, and sexually transmitted infections. Programs addressing HIV and hepatitis also have significant experience working with populations currently disproportionately affected by COVID–19 including homeless and racial and ethnic minorities.

ENDING THE HIV EPIDEMIC

Announced in the 2019 State of the Union, the Ending the HIV Epidemic (EHE) initiative is a historic effort to reduce new HIV infections by 75 percent in the next 5 years and by 90 percent in the next 10 years. The initiative focuses on four key areas: diagnosing all individuals with HIV as early as possible after infection; treating the infection rapidly after diagnosis, achieving sustained viral suppression; protecting individuals at risk for HIV using proven prevention approaches such a Pre-exposure Prophylaxis (PrEP); and responding rapidly to detect and respond to growing HIV clusters.

We thank the committee for supporting funding for the first year of this initiative. Funding is being distributed to the fifty-seven target Phase-1 cities and states, which have all developed Ending the HIV Epidemic plans. They are ramping up screening to diagnose people unaware of their HIV status and link them to antiretroviral treatment and providing PrEP to those who are at high risk of HIV. For fiscal year 2021, we ask that you fully fund the second year of the initiative to continue to scale up the EHE initiative by supporting the president's budget request of $716 million, an increase of $450 million from fiscal year 2020.

With proposed fiscal year 2021 funding of $371 million, an increase of $231 million, the Centers for Disease Control and Prevention (CDC) will transition from planning to implementation and intensify work already begun in the fifty-seven target jurisdictions. CDC grants will drive additional testing with the goal of doubling the number of new HIV diagnoses rapidly treated with antiretroviral therapy to maintain health and prevent additional HIV transmissions. Funded jurisdictions will use pharmacy data, telehealth, mobile testing, and new science-based networks to ensure individuals enter and adhere to care.

An increase of $182 million for a total of $302 million will allow the Health Resources and Services Administration (HRSA) to expand treatment and prevention services through its vast network of providers. With $137 million, an increase of $87 million, the Bureau of Primary Health Care (BPHC) will fund over 300 additional community health centers to expand the provision of PrEP services, bringing the total number of health centers funded by the initiative to over 500. The Ryan White HIV/AIDS Program would receive an increase of $95 million to the amount of $165 million to reach over 43,000 people living with HIV who are not yet in care or who have not yet received an HIV diagnosis. HRSA's Ryan White Program is a critical safety net program providing care, treatment, and support services to over 500,000 people living with HIV. Almost 86 percent of Ryan White clients are virally suppressed, far exceeding the national average of nearly 60 percent.

The EHE is a critical targeted component of our nation's response to the HIV epidemic; however, we must continue to invest in ongoing HIV programs throughout the nation. This includes the CDC's HIV Prevention Programs (including the Division of School and Adolescent Health), HRSA's Ryan White HIV/AIDS Programs (including the AIDS Drug Assistance Program), the Minority HIV/AIDS Initiative, AIDS Research at the NIH, and the Teen Pregnancy Prevention Program (TPPP).

Each of these programs is necessary to address the HIV epidemic in our nation and each is being negatively impacted by the ongoing COVID–19 pandemic. State and local health departments' staff is being detailed to deal exclusively with COVID–19 and facing furloughs to make up for budget shortfalls. Programs that rely on in-person visits for assessments and testing are having to purchase new equipment to increase telehealth services and organizations are having to work with clients and their families to ensure access to broadband and mobile devices to ensure consistent access. Increased funding will help our HIV infrastructure be able to provide necessary services in the "new normal."

VIRAL HEPATITIS

Additionally, we respectfully request that you provide increased funding for viral hepatitis programs at the CDC. The CDC estimates that more than 4.5 million people in the United States live with hepatitis B (HBV) or hepatitis C (HCV), with nearly half unaware they are living with the disease. The opioid epidemic has significantly increased the number of viral hepatitis cases in the United States, with new cases of HCV rising 374 percent between 2010 and 2017. Newly released CDC data show that in 2018 there were an estimated 50,300 new hepatitis C infections, which represents a three-fold increase in the rate of new infections over the last decade. The CDC also found that due to the ongoing opioid epidemic and injection drug use, there are now just as many new infections among Millennials as Baby Boomers, who in the past bore the brunt of all new cases. Therefore, the CDC is now recommending that every adult eighteen and older be tested at least once for hepatitis C, plus all women during each pregnancy, and those at risk.

From 2006 to 2018, increases in reported cases of acute HBV infection range from 56 percent to 457 percent in states most heavily impacted by the opioid crisis. From 2014–2017, the number of reported cases of hepatitis A increased by 271 percent. There are several curative treatments available for HCV, but individuals must have access to screening and linkage to care programs to be able to take advantage of these medications.

CDC Division of Viral Hepatitis

The viral hepatitis programs at the CDC are severely underfunded, receiving only $39 million-far short of what is needed to build and strengthen our public health response to hepatitis. Currently, the CDC is only able to fund fourteen jurisdictions to conduct enhanced hepatitis surveillance, which is harming our nation's ability to respond to the infectious disease consequences of the opioid epidemic. Additional resources would allow the CDC to enhance testing and screening programs, conduct additional provider education, enhance clinical services specific to hepatitis at sites serving vulnerable populations, and increase services related to hepatitis outbreaks and injection drug use. We urge you to provide the CDC Division of Viral Hepatitis with $134 million, an increase of $95 million over fiscal year 2020 enacted levels.

The CDC recently released a Notice of Funding Opportunity announcement to fifty-eight jurisdictions asking them to prepare ending hepatitis plans that focus on education, surveillance, screening, linkage to care, and syringe service programs. Unfortunately, since the state and local jurisdictions are responding to COVID–19, it had to been withdrawn. Later this year, the administration is expected to release an updated national hepatitis strategy with a stated goal to end hepatitis. However, the current level of funding is completely inadequate for these jurisdictions to even begin to discuss ending hepatitis—particularly hepatitis C, which has a cure, and hepatitis B, which has a vaccine and effective treatments.

CDC's Eliminating Opioid-Related Infectious Diseases Program

This CDC program focuses on addressing the infectious disease consequences of increased rates of injection drug use due to the opioid crisis. Providing full support for this program is another key step in preventing new cases of viral hepatitis and HIV and putting the country on the path towards elimination. We urge the committee to fund this program to eliminate opioid-related infectious diseases at no less than $58 million, an increase of $48 million, and the amount proposed in the president's budget.

SYRINGE SERVICE PROGRAMS (SSPS)

We also ask that the committee support ending any prohibition on the use of Federal funds to purchase sterile needles or syringes for SSPs. A wealth of scientific evidence has shown that SSPs reduce the spread of infectious diseases, such as HIV and hepatitis. Full Federal funding for these programs will only serve to make the programs stronger and more effective.

In conclusion, we urge the committee to continue its investment in our nation's public health infrastructure specifically as it relates to addressing the ongoing HIV and HCV epidemics. Fortunately, we have the tools available to end both these epidemics; however, we must provide the necessary resources to achieve these goals.

[This statement was submitted by Carl Schmid, Executive Director, HIV+HEP Policy Institute.]

PREPARED STATEMENT OF RICHARD HORNER

I am the mother of an adult child with schizophrenia. I would give anything to have a cure or at least better treatment for this awful brain disease that often leaves its victims in jail, homeless, or hospitalized; and destroys families. This serious brain illness is not rare as many believe, but affects 1.1 percent of the population and that statistic has been true since first recorded, and is basically the same throughout the world. Its cause is primarily genetic, but is believed to be triggered by environmental factors. Schizophrenia (and schizoaffective disorder) robs the person of motivation, concentration, and cognition, as well as presenting positive symptoms such as hallucinations and delusions. The disease usually occurs in late teen or early adult years, just when our bright and beloved children are preparing for jobs, universities, careers, serious relationships.

The National Institute of Mental Health (NIMH) is the main Federal Government agency for research into mental illness. The NIMH was authorized through the passage of the National Mental Health Act in 1946 to better help individuals with mental health disorders through better diagnosis and treatments. With a budget of almost $2 billion in 2020, the NIMH conducts research and funds outside investigators to better understand mental illness and develop new treatments to reduce the burden these disorders have on individuals.

I beg you to have NIMH prioritize research for the 5 percent of our population that has serious mental illnesses that include chronic depression (the leading cause of disability in the U.S.), schizophrenia (and schizoaffective disorder), and bipolar illness. This makes sense because it's the humane thing to do, but it also makes good fiscal smarts. The most severe mental illnesses account for the most dollars spent in hospitals, jails, prisons, emergency rooms, and services for the homeless.

Dr. E. Fuller Torrey wrote in Psychiatric Times earlier this month:

> “Congress awarded the National Institute of Mental Health an additional $98 million as part of the National Institutes of Health budget resolution in December 2019, which brings the NIMH budget to just under $2 billion and represents a 35 percent increase since 2015, one of the largest increases in the history of the NIMH. Yet, during the 5 years from 2015 through 2019, NIMH funded a total of TWO new drug treatment trials for schizophrenia and bipolar disorder, according to clinicaltrials.gov. This contrasts with the 5-year period from 2006 through 2010 when NIMH funded 48 such trials . . .”

In December 2019, the NIMH released a draft of their five-year strategic plan for public comment. They reported receiving more than 6,000 responses identifying examples of research initiatives the NIMH could be pursuing today to help people with serious mental illness recover and live better lives. Despite this robust response, NIMH made no substantive changes to the research goals or objectives in the final version released to the public earlier this week.

The NIMH research goals for 2020–2025 heighten the existing imbalance in NIMH research. In doing so, they offer little hope for new or better treatments for individuals who are currently afflicted with a mental illness during their lifetime, especially a serious mental illness. This failure is inexcusable given the large increase in research funding given to NIMH in recent years.

Future NIMH funding must be used to correct the existing imbalance, not worsen it, especially now that the COVID–19 pandemic has upended the mental health treatment system and will likely result in an exacerbation of symptoms in people currently affected and an increase in serious mental illnesses among Americans. Those with the most severe forms of mental illness deserve to be prioritized.

Thank you for your consideration,

Sincerely.

PREPARED STATEMENT OF THE HUMAN FACTORS AND ERGONOMICS SOCIETY

On behalf of the Human Factors and Ergonomics Society (HFES), we are pleased to provide this written testimony to the Senate Subcommittee on Labor, Health and Human Services, Education, and Related Agencies for the official record. HFES urges the Subcommittee to provide $471 million for the Agency for Healthcare Research and Quality (AHRQ) and a minimum of $354.8 million for the National Institute for Occupational Safety and Health (NIOSH), including $32 million for the Education and Research Centers (ERCs), in fiscal year 2021.

AHRQ funds research to protect and promote patient safety and care, while identifying and evaluating efficiencies to save lives and reduce costs. HFES requests $471 million, which is consistent with the fiscal year 2010 level adjusted for inflation. This funding level will allow AHRQ to rebuild portfolios terminated after years of cuts. HFES also urges the Subcommittee to continue to fund AHRQ as its own agency, rather than integrating it into the National Institutes of Health (NIH), as proposed in the President’s fiscal year 2021 budget request.

Additionally, HFES requests $354.8 million for NIOSH, including $32 million for the Education and Research Centers (ERCs). NIOSH supports education and research in occupational health through academic degree programs and research opportunities. With an aging occupational safety and health workforce, ERCs are essential for training the next generation of professionals. The Centers establish academic, labor and industry research partnerships to achieve these goals. Currently, the ERCs are responsible for supplying many of the country’s OSH graduates who will go on to fill professional roles.

The fiscal year 2021 President’s budget request proposes reducing the NIOSH budget and eliminating many NIOSH programs, which would limit the ability of workers to avoid exposures that can result in injury or illnesses, push back improved working conditions, eliminate occupational safety and health educational services to U.S. businesses, and ultimately raise healthcare costs.

HFES and its members recognize and appreciate the challenging fiscal environment in which we as a nation currently find ourselves. However, we believe strongly that investment in scientific research serves as an important driver for innovation and the economy as well as for protecting and promoting the health, safety, and well-being of Americans. We thank the Subcommittee for its longtime recognition of the value of scientific and engineering research and its contribution to innovation and public health in the U.S.

THE VALUE OF HUMAN FACTORS AND ERGONOMICS SCIENCE

HFES is a multidisciplinary professional association with over 4,500 individual members worldwide, including psychologists and other scientists, engineers, and designers, all with a common interest in designing safe and effective systems and equipment that maximize and adapt to human capabilities.

For over 50 years, the U.S. Federal Government has funded scientists and engineers to explore and better understand the relationship between humans, technology, and the environment. Originally stemming from urgent needs to improve the performance of humans using complex systems such as aircraft during World War II, the field of human factors and ergonomics (HF/E) works to develop safe, effective, and practical human use of technology. HF/E does this by developing scientific approaches for understanding this complex interface, also known as "human-systems integration." Today, HF/E is applied to fields as diverse as transportation, architecture, environmental design, consumer products, electronics and computers, energy systems, medical devices, manufacturing, office automation, organizational design and management, aging, farming, health, sports and recreation, oil field operations, mining, forensics, and education.

With increasing reliance by Federal agencies and the private sector on technology-aided decision-making, HF/E is vital to effectively achieving our national objectives. While a large proportion of HF/E research exists at the intersection of science and practice—that is, HF/E is often viewed more at the "applied" end of the science continuum—the field also contributes to advancing "fundamental" scientific understanding of the interface between human decision-making, engineering, design, technology, and the world around us. The reach of HF/E is profound, touching nearly all aspects of human life from the healthcare sector, to the ways we travel, to the hand-held devices we use every day.

CONCLUSION

HFES urges the Subcommittee to provide $471 million for AHRQ and $354.8 million for NIOSH, including $32 million for the Education and Research Centers (ERCs) in fiscal year 2021. These investments fund important research studies, enabling an evidence base, methodology, and measurements for improving healthcare, safety, and public health for Americans.

On behalf of the HFES, we would like to thank you for the opportunity to provide this testimony. Please do not hesitate to contact us should you have any questions about HFES or HF/E research. HFES truly appreciates the Subcommittee's long history of support for scientific research and innovation.

[This statement was submitted by Susan Hallbeck, PhD, President, and Steven C. Kemp, CAE, Executive Director, Human Factors and Ergonomics Society.]

PREPARED STATEMENT OF HURN SHAUNA

My brother Elis Matetich is 38 years old & schizoaffective but does not believe he is sick (anosognosia) and will not take his medication. He was on disability almost 20 years ago, but then got a job and was employed for over 10 years (and was off disability) living independently and taking his meds most the time. Over the years he had become more isolated/adverse to coming to family gatherings and more argumentative and difficult to be around.

Last year (2019) he lost his job, went off his meds for many months, and threatened the life of my stepdad, and believes our mom is a demon who wishes him harm. He has never been threatening or violent toward family prior to 2019 and this devastated us. Subsequently we got him hospitalized twice (two weeks each time/back to back) and were supposed to go to court against him for his threats to our family, but the court case was dropped.

—He got in four fist fights while at Navos Behavioral Hospital, West Seattle, WA (Sep 2019) but was released in just 2 weeks (after many months of being unmedicated).

—He was released with no aftercare plan, or instruction to family or anyone else, on how he was to take his medication. After his release he did not take his medication.

—Our family worked with the Crisis team to get him in the hospital again, this time Fairfax Kirkland, WA (Oct 2019).

—Upon his release he had been resistant to taking any kind of financial aid or help from family unless completely on his terms, he proceeded to spend the last of any money he had and wouldn't allow family to help him apply for disability.

The past 2 months (Apr 2020–Current) he has been off his meds again and in crisis.

—He believes there is a devil in his apartment and that family members have evil powers and intend to harm him.

—He has gotten his two cars impounded in one weekend (while fleeing from the devil in his closet and the evil powers he believes are after him).

—He slept in bushes for 3 nights because he was scared to go to his apartment because he thinks the devil is in it (and because he doesn't know how to get back home//he gets disoriented and does not actually know where he is, even though he has a smart phone he can use).

—In the last 2 weeks he has not been eating or drinking because he is suspicious of food & water. He has probably lost 40–50 lbs within a short timeframe

—He received stimulus money but says someone stole his wallet and he did not take any action with the bank to get a new debit card or with DSHS to apply for food stamps. (He claims to know how to do these things but why wouldn't he do them if he was starving?). Our family can't help him get these things back without his consent which he won't give.

—He has been picked up by police multiple times, was charged with a DUI, but only jailed a few hours.

—Every time I offer to help he insists he can and will do things on his own, but then he doesn't do it. Afterwards he blames other people or things for not following through.

—I've been attending all of his counseling appointments at Valley Cities Federal Way WA to try to get him on track to take injection medication and regain his life. But he is resistant to everything.

It's been about 2 months straight while he is in psychosis and unmedicated where I have been working with him to try to get him to voluntarily ask for help and get on injection medication. I am seeing him fall apart before my eyes and see that he is someone incapable of living without help. Except that he's 38 years, a full grown man with a mind of his own, that doesn't believe he needs help. It's a comparable situation to a grandparent with Dementia or Alzheimer's. If he is able to get stabilized on medication he might be able (over time) to get a job again, but he is nowhere near that right now, my brother is barely surviving and it's unclear if he will ever recover from this.

I am overwhelmed at the level of care my brother needs and depressed that the Healthcare system falls completely short of helping my brother. I am upset the laws will criminalize my brother if he will not get treatment, but how will he accept treatment if he does not believe he is ill? The gaps in the healthcare system and government are putting the tremendous burden on the families to care for our schizophrenic/schizoaffective loved ones. How can someone with a brain disorder (schizoaffective) and/or anosognosia can be expected to voluntarily take medication? Everything I try to help my brother with, requires his consent but he will not give it, so I'm set up to fail/to try to convince a psychotic person to do things to manage their life. I have had so much advice from others to "work around the system" to "stop helping my brother stay afloat financially" (which would make him homeless) so that he can get "help". Basically, wait for his brain disorder to criminalize him, so that he will qualify for financial aid and treatment. Or they suggest we try to take away his legal rights by going to court against him. This is a huge moral conundrum for us as a family members, forcing us against our loved ones who need help!!! It's easy on the outside to tell someone to do this, but imagine it's your own parent or sibling. How would you feel about turning against them in order to help them? The severely mentally ill need a village, they need hope and a place in our communities... a system that requires them to take medication in order to keep a job to contribute to society (for those who are capable) or medication to get food (for those who can't work). Us, as family members, should not be forced to prove our loved ones are ill and need help. Other physical illnesses are treated//but not mental illness. Do you know how invalidating it is to have no hope for treatment for your loved one, no way to help them or make them safe? To wait until their illness gets so bad you are living in fear of the future? Our family should not be forced to take on the financial burden of housing them especially while they unmedicated, undergoing psychosis and resistant to help. But it is the disease causing this!!! But what about, us the family, who become targets of their delusions?? This is not safe for us. "Prove he is going to kill himself or someone else". "Call 911" they say. Or we force our loved ones to live on the streets and then must live with the guilt. The families are left with no rights to help their severely mentally ill loved ones, and no protection from them either. This is a human rights issue that needs to be addressed. Mental Illness is real. Especially as the violence and mass shootings in our country escalate, we need to start addressing mental illness that turns people into criminals.

PREPARED STATEMENT OF THE INFECTIOUS DISEASES SOCIETY OF AMERICA

On behalf of the Infectious Diseases Society of America (IDSA), which represents more than 12,000 physicians, scientists, public health practitioners and other providers involved in infectious diseases prevention, care, research and education, I urge the Subcommittee to provide full fiscal year 2021 funding for public health and biomedical research activities that save lives, contain healthcare costs and promote economic growth. IDSA asks the Subcommittee to provide $8.3 billion for the Centers for Disease Control and Prevention (CDC), $44.7 billion for the National Institutes of Health (NIH), $230 million for the Biomedical Advanced Research and Development Authority (BARDA) Broad Spectrum Antimicrobials and CARB–X programs, and $140 million for the Strategic National Stockpile Special Reserve Fund program.

CENTERS FOR DISEASE CONTROL AND PREVENTION

Antibiotic Resistance Solutions Initiative

We urge at least $200 million in funding for the Initiative in fiscal year 2021. IDSA members see the impact daily that antimicrobial resistance (AMR) has on patients. Antibiotic resistance is one of the greatest public health threats of our time. Drug-resistant infections sicken at least 2.8 million each year and kill at least 35,000 people annually in the United States. Antibiotic resistance accounts for direct healthcare costs of at least $20 billion. If we do not act now, by 2050 antibiotic-resistant infections are predicted to be the leading cause of death. Secondary bacterial infections caused by resistant bacteria and fungi are complicating care for seriously ill patients including those with COVID–19. Antibiotic resistance threatens the safety of major medical advances, including cancer chemotherapy, organ and bone marrow transplants, caesarean sections, and other surgeries—all of which carry risk of infection. The Federal response to AMR must be increased to prevent and detect multi-drug resistant infections. The requested funding would allow the expansion of efforts at state, local and territorial health departments to prevent, detect, contain and respond to multi-drug resistant infections. Funding would also support implementation of antimicrobial stewardship programs (newly required by CMS at hospitals) to reduce inappropriate antibiotic use and improve patient outcomes. Since fiscal year 2016, CDC has provided $300 million to 59 state and local health departments to increase capacity for faster response to outbreaks and emerging infections. Additionally, this funding improved antibiotic use, increased state and regional laboratory capacity to rapidly detect resistant infections, and enhanced tracking of healthcare-associated infections. These substantial payoffs mean a clear net positive for the Federal budget to recoup the direct costs of the program, but a deeper investment in fiscal year 2021 is needed to effectively address current and newly emerging threats and prepare for future challenges.

Advanced Molecular Detection (AMD)

AMD strengthens CDC's epidemiologic and laboratory expertise to effectively detect and respond to the ever-expanding universe of emerging diseases and deadly pathogens. Requested fiscal year 2021 funding of at least $37.5 million is required to ensure AMD has updated cutting-edge technology to allow CDC to more rapidly determine where emerging diseases come from, whether microbes are resistant to antibiotics, and how microbes are moving through a population. Additional funding would help ensure state and local health departments have enhanced expertise to harness DNA sequencing of pathogens to ramp up early detection and response to surging disease outbreaks. AMD is integrating next-generation sequencing in the COVID–19 response, which provides a clearer picture of how the outbreak is evolving and how cases are connected, allowing more effective targeting of response efforts. AMD promotes more effective antimicrobial use when used by antimicrobial stewardship programs.

National Healthcare Safety Network

Fiscal year 2021 funding of at least $25 million for the National Healthcare Safety Network (NHSN) will enable CDC to expand tracking of healthcare-associated infections (HAIs), antibiotic use, and antibiotic resistance. The NHSN is the most widely used HAI tracking system in the country and provides facilities, states, regions, and the nation with data needed to identify problem areas and best practices, and to measure and drive the progress of prevention and stewardship efforts. NHSN is playing a central role in the COVID–19 response. Nursing homes are required by the Centers for Medicare and Medicaid Services to report cases of COVID–19 directly to NHSN, and are strongly encouraged to share information about confirmed COVID–19 cases with patients, residents, families, and loved ones. The responses will be uploaded into NHSN and will complement existing state-level reporting requirements, helping the Federal Government collect nationwide data to assist in COVID–19 response activities.

This new NHSN capability for nursing homes follows the launch of CDC's NHSN Hospital Capacity and Patient Impact COVID–19 module. Given the breadth of reporting capability of NHSN, CDC was able to quickly adapt the system to easily collect nursing home data and report it to state health departments and other parts of the Federal Government emergency response for action.

Additionally, as of April 1, 2018, 776 out of the over 5,500 U.S. hospitals have voluntarily reported antibiotic use data, and 317 hospitals have reported antibiotic resistance data to the CDC NHSN Antibiotic Use and Resistance (AUR) module. While this represents progress, it falls strikingly short of the stated goal in the National Action Plan for Combating Antibiotic Resistant Bacteria for 95 percent of hospitals to report these data by 2020. Comprehensive and real-time data on antibiotic use and resistance are essential to inform and evaluate antibiotic stewardship activities and other efforts to address AMR.

CDC Center for Global Health

IDSA urges the Subcommittee to provide at least $624 million in fiscal year 2021 funding, including $225 million for CDC's Division of Global Health Protection to prevent, detect and respond to infectious disease threats in the places they originate before they reach American soil. As the response to the devastating global COVID–19 pandemic continues, global health security efforts are critical for ensuring America's health security, including strengthening laboratory capacities, disease surveillance and field epidemiology activities in resource-limited countries. Sustained funding for the Division of HIV and TB, a key implementer of PEPFAR, is needed to facilitate access to life-saving antiretroviral treatment for millions, including to pregnant women living with HIV to prevent transmission to their children. The Center works to find, cure and prevent TB, eliminate the global burden of malaria, stop poliovirus transmission, and reduce mortality from vaccine-preventable diseases like measles. The CDC Center for Global Health addresses more than 400 diseases and health threats in 60 countries.

Immunization Program

IDSA supports funding of $710 million for the Section 317 Immunization Grant Program that would allow healthcare providers to obtain necessary vaccines. The program helps decrease the number of children and adults who die each year from vaccine-preventable illnesses and helps prevent outbreaks of diseases due to inadequate vaccination rates. We must strengthen our nation's vaccine infrastructure to prepare to drive access and uptake of a COVID–19 vaccine once one is developed.

Since COVID–19 distancing restrictions and business closures were implemented, childhood immunization rates have dropped considerably due to fears of contracting the virus. During the week of April 5, the administration of MMR vaccines dropped 50 percent; diphtheria and pertussis vaccines dropped 42 percent; and HPV vaccines dropped 73 percent. Even before this pandemic, vaccine hesitancy began fueling a resurgence of vaccine-preventable diseases such as measles, making this a critically important time to invest in a comprehensive response. Many communities have been deemed "at risk" for outbreaks of measles and other vaccine-preventable illnesses due to insufficient vaccination rates. During January 1–October 1, 2019, a total of 1,249 measles cases and 22 measles outbreaks were reported in the United States. This is the greatest number of cases reported in a single year since 1992.

Infectious Diseases Rapid Response Fund

The quick spread of emerging infectious diseases makes clear the need for the Response Fund in regular fiscal year 2021 appropriations. At the beginning of the COVID–19 emergency, the Response Fund allowed HHS to begin initial activities without waiting for congressional action. An investment of at least $85 million is needed to ensure agencies, led by the CDC can move forward with initial response activities to contain the spread of infection; treat infected individuals and launch research for vaccines, diagnostics and therapeutics.

Infectious Diseases and Opioids

IDSA urges $58 million in funding in fiscal year 2021 to address opioid addiction, HIV/AIDS, and hepatitis. We are increasingly concerned about how the opioid crisis is driving higher rates of infectious diseases including hepatitis C, endocarditis, HIV, pneumonia, and skin, soft tissues, bone and joint infections. Before COVD–19, some of our members were reporting that 25 to 50 percent of their inpatient hospital consultations are for infections in patients who inject drugs, and this problem has not gone away.

Vector-Borne Diseases

We advise funding of $66 million for vector-borne diseases efforts to help define disease extent and to reduce the impact of infections such as the Zika virus and tick-borne illnesses including Lyme disease. CDC found that the number of disease cases in the U.S. due to mosquito, tick or flea bites tripled from 2004 to 2016, demonstrating the need for increased funding to support evidence-based surveillance and prevention efforts.

ASSISTANT SECRETARY FOR PREPAREDNESS AND RESPONSE (ASPR)

Biomedical Advanced Research and Development Authority

At least $230 million in fiscal year 2021 for the BARDA broad spectrum antimicrobials program and CARB–X is needed to leverage public/private partnerships to develop products that directly support the government-wide National Action Plan for Combating Antibiotic-Resistant Bacteria. These programs have been successful in developing new FDA-approved antibiotics. Despite this progress, the pipeline of new antibiotics in development is insufficient to meet patient needs, and $230 million in funding is needed to help prevent a post-antibiotic era in which we lose many modern medical advances that depend upon the availability of antibiotics, such as cancer chemotherapy, organ transplants and other surgeries. There is early evidence of secondary bacterial infections among COVID–19 patients. It is, as yet, unclear exactly how significant secondary bacterial and fungal infections will be in this pandemic, but serious viral respiratory infections typically pose some risk of these secondary infections that increases when patients need to be hospitalized or placed on a ventilator. This report on 191 patients found that 50 percent of patients who died had a secondary infection.

Project BioShield

We request at least $140 million in fiscal year 2021 for the Project BioShield Special Reserve Fund (SRF) which is positioned to support the response to public health threats, including AMR. BARDA and NIAID efforts have been successful in helping companies bring new antibiotics to market, but those companies now struggle to stay in business and two filed for bankruptcy in 2019. In December 2019, SRF funds supported a contract for a company following approval of its antibiotic—a phase in which small biotechs that develop new antibiotics are particularly vulnerable. Additional funding is needed to expand this approach to better support the antibiotics market.

NATIONAL INSTITUTES OF HEALTH

National Institute of Allergy and Infectious Diseases (NIAID)

Within NIH, NIAID should be funded at $6.345 billion, with $600 million for AMR research to support the continued response to COVID–19, and research for new rapid diagnostics, vaccines, and therapeutics for all ID threats. With increased investment to combat AMR, NIAID is poised to ramp up valuable research into how to counter the ever-evolving threat posed by resistant microbes. There are significant research needs with regard to COVID–19, including vaccines and therapeutics, better diagnostics, and epidemiologic and pathogenesis studies. NIAID is also planning to expand efforts to support the next generation of researchers, but this will be challenging without additional resources. Funding at the requested level would enable NIAID to increase funding and success rates for early and mid-career research awards, and pilot a new innovator award to promote bold new ideas from early stage investigators. This kind of thinking is precisely what is needed to address growing ID threats.

CONCLUSION

Thank you for the opportunity to submit this statement. The nation's ID physicians and scientists rely on strong Federal partnerships to keep Americans healthy and urge you to support these efforts. Please forward any questions to Lisa Cox at lcox@idsociety.org.

[This statement was submitted by Thomas File, MD, FIDSA, President, Infectious Diseases Society of America.]

PREPARED STATEMENT OF THE INTERNATIONAL ASSOCIATION OF FIRE CHIEFS

On behalf of the more than 13,000 chief fire and emergency medical services (EMS) officers of the International Association of Fire Chiefs (IAFC), I urge you to provide $20 million in fiscal year 2021 for the Rural EMS Training and Equipment Assistance (REMSTEA) program, also known as the Supporting and Improving Rural EMS Needs (SIREN) program, which is housed within the Substance Abuse and Mental Health Services Administration (SAMHSA). America's rural fire departments desperately need assistance in sustaining their operations following the devastation that was brought upon on their budgets by the economic impact stemming from the SARS-CoV–2 virus and it resulting illness, COVID–19. The SIREN program is one of the most effective ways in which Congress can provide direct assistance to these rural fire and EMS agencies to purchase personal protective equipment (PPE), procure medications, and recruit and train personnel. Funding the SIREN program at $20 million in fiscal year 2021 will enable these agencies to be prepared for future waves of COVID–19 as well as the "routine" volumes of critically ill and injured patients which seek emergency medical care each day.

As you know, EMS-related calls account for 80 percent of all fire department calls for service nationwide. EMS is even more important in rural and frontier communities where firefighters and EMS personnel might be the only the only healthcare provider that a critically ill or injured patient sees in the first hour of their emergency. Long transport distances to a hospital make it important for fire departments to be fully staffed and equipped with the latest emergency medications and medical supplies.

Rural fire departments face acute challenges in meeting their community's EMS needs. These agencies often rely upon community fundraisers such as barbeques, bingo, raffles, and auctions to raise the money needed to fund their operations. While this may have once been a plausible funding model, these types of fundraisers are no longer sufficient to meet the needs of the 21st Century EMS systems. Furthermore, these community-based fundraising activities were completely shut down this year as a result of the stay-at-home orders and social distancing guidelines which were implemented in most communities across the nation. In strong financial times, these rural fire departments' limited budgets prevented them from having the latest medical equipment to treat patients or the resources to recruit and retain volunteer EMS personnel. The unprecedented economic downturn has exacerbated these financial struggles and threatens to curtail these agencies' response abilities or even close their departments completely.

Despite the fact that fire departments and EMS agencies transport more than 30 million patients each year, the U.S. Department of Health and Human Services (HHS) provides little support to essential agencies. In 2018, Congress reauthorized the REMSTEA grant as the SIREN grants and revised the criteria to provide funding directly to the rural fire departments and EMS agencies. SIREN is a competitive grant program which helps rural fire departments to procure emergency medications and supplies, purchase EMS vehicles like ambulances and quick response vehicles, establish recruitment and retention programs to attract volunteers, and administer training classes to certify personnel as emergency medical technicians. Congress' support for local EMS agencies through the SIREN program is vital to ensuring that these agencies can continue meeting the emergency medical needs of their communities. A funding level of $20 million for the SIREN program in fiscal year 2021 will help these rural fire departments be prepared to care for COVID–19 patients as well as other patients suffering from medical emergencies, traumatic injuries, natural disasters, and acts of terrorism.

I would like to thank the members of this subcommittee, as well as the entire United States Senate, for their work to support the fire departments in the response to SARS-CoV–2 and COVID–19. I look forward to continuing to work with each of your offices to ensure that fire departments have the resources, personnel, medications, and equipment needed to care for all types of ill and injured patients across the United States. The SARS-CoV–2 epidemic has placed unprecedented strains on fire departments and the IAFC urgently requests your assistance by providing $20 million for the SIREN grant program in fiscal year 2021.

[This statement was submitted by Fire Chief Gary Ludwig, President and Chairman of the Board of Directors, International Association of Fire Chiefs.]

PREPARED STATEMENT OF THE INTERNATIONAL FOUNDATION FOR GASTROINTESTINAL DISORDERS

FISCAL YEAR 2020 L–HHS APPROPRIATIONS RECOMMENDATIONS

—At least $44.7 billion in program level funding for the National Institutes of Health (NIH).

—Proportional funding increase for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

Chairman Blunt, Ranking Member Murray, and distinguished members of the Subcommittee, as you work with your colleagues to develop the fiscal year 2021 Labor-Health and Human Services (L–HHS) appropriations bill, please keep in mind the needs and concerns of the functional GI and motility disorders community. "Nearly two decades ago, I was diagnosed with one of these diseases, irritable bowel syndrome (IBS). As a young adult, I underwent extensive testing and workups over many years in a difficult effort to discover what was causing my symptoms and how best to treat them. I often relied on self-treatment as best as I could, but this was not sustainable. Unfortunately, I am not alone in these experiences. As President of IFFGD, I have heard my story echoed back to me by thousands of others. Patients affected by these disorders often face similar delays in diagnosis, frequent misdiagnosis, and inappropriate treatments including unnecessary and costly surgery. These are common concerns for our community, and they underscore the need for increased research, improved provider education, and greater public awareness."

ABOUT THE FOUNDATION

The International Foundation for Gastrointestinal Disorders (IFFGD) is a registered nonprofit education and research organization dedicated to informing, assisting, and supporting people affected by gastrointestinal (GI) disorders. IFFGD works with patients, families, physicians, nurses, practitioners, investigators, regulators, employers, and others to broaden understanding about GI disorders, support and encourage research, and improve digestive health in adults and children.

ABOUT GASTROINTESTINAL (GI) AND MOTILITY DISORDERS

GI and motility disorders are the most common digestive disorders in the general population. These disorders are classified by symptoms related to any combination of the following: motility disturbance, visceral hypersensitivity, altered mucosal and immune function, altered gut microbiota, and altered central nervous system (CNS) processing. Some examples of functional GI disorders are: dyspepsia, gastroparesis, irritable bowel syndrome (IBS), gastroesophageal reflux disease (GERD), bowel incontinence, and cyclic vomiting syndrome. The costs associated with these diseases range from $25-$30 billion annually; economic costs are also reflected in work absenteeism and lost productivity.

NATIONAL INSTITUTES OF HEALTH

Strengthening the nation's biomedical research enterprise through NIH fosters economic growth and sustains innovations that enhance the health and well-being of the American people. Functional GI disorders are prevalent in about 1 in 4 people in the U.S., accounting for 40 percent of GI problems seen by medical providers. NIDDK supports basic, clinical, and translational research on aspects of gut physiology regulating motility and supports clinical trials through the Motility and Functional GI Disorders Program.

Several of NIH's crosscutting initiatives are currently advancing science in meaningful ways for patients with gastrointestinal disorders. The Stimulating Peripheral Activity to Relieve Conditions (SPARC) Initiative supports research on the role that nerves play in regulating organ function. Methods and medical devices that modulate these nerve signals are a potentially powerful way to treat many chronic conditions, including gastrointestinal and inflammatory disorders. The Human Microbiome Project is also unlocking important discoveries that will help to inform and advance emerging treatment options for many in the community.

PATIENT PERSPECTIVE

Jacqui's Story

I got sick after an emergency appendectomy on Thanksgiving 2010 while I was in Army basic training. I was able to fight off the inevitable and did 4 years in the

Army during which I did a tour in Afghanistan. When I got back, my health really started declining.

I fought and fought and fought for an answer, but it took just over 7 years to be diagnosed with gastroparesis. My main symptoms were nausea, vomiting and pain. It got so bad that I had to give up my dream career and was medically retired from the service.

Because we had tried pretty much every conservative treatment, they told me I would just have to live with it. It got to the point where I was going weeks without eating and was in and out of the ER getting fluids, because anything that went in my stomach came back up. My hair thinned, so I shaved it, and I was having memory problems and confusion, which got so bad that my neuropsych tests came back with my score being in the range of dementia.

My gastroenterologist even told me at one point that she couldn't do anything "drastic" to help me until my blood work was "bad enough."

Thank you for the opportunity to submit our community's perspective, as you consider appropriations priorities for fiscal year 2021. We look forward to continuing to work with you on these critical issues.

Informing, assisting, and supporting people affected by gastrointestinal disorders.

[This statement was submitted by Ceciel T. Rooker, President, International Foundation for Gastrointestinal Disorders.]

PREPARED STATEMENT OF THE INTERSTATE MINING COMPACT COMMISSION

We are writing in regard to the fiscal year 2021 Budget Request for the Mine Safety and Health Administration (MSHA), which is part of the U.S. Department of Labor. In particular, we urge the Subcommittee to support a full appropriation for state assistance grants for safety and health training of our Nation's miners pursuant to section 503(a) of the Mine Safety and Health Act of 1977 (the Act). MSHA's budget includes an amount of not less than $10,537,000 for state assistance grants. We urge the Subcommittee to fund these grants at this statutorily authorized level for state assistance grants so that states are able to meet the training needs of miners and to fully and effectively carry out state responsibilities under section 503(a) of the Act. We believe the states can more than justify the need for funding at the statutorily authorized level.

The Interstate Mining Compact Commission is a multi-state governmental organization that represents the natural resource, environmental protection and mine safety and health interests of its 27 member states. The states are represented by their Governors who serve as Commissioners.

We support full funding $10,537,000 for the state assistance grants that enable the states to provide essential safety and health training for the nation's coal miners, undiminished by use of these funds for other purposes. Section 503 of the Act was structured to be broad in scope and to stand as a separate and distinct part of the overall mine safety and health program. In the Conference Report that accompanied passage of the Federal Coal Mining Health and Safety Act of 1969, the conference committee noted that both the House and Senate bills provided for "Federal assistance to coal-producing States in developing and enforcing effective health and safety laws and regulations applicable to mines in the States and to promote Federal-State coordination and cooperation in improving health and safety conditions in the Nation's coal mines." (H. Conf. Report 91–761). The 1977 Amendments to the Mine Safety and Health Act expanded these assistance grants to both coal and metal/non-metal mines and increased the authorization for annual appropriations to $10 million. The training of miners was only one part of the obligation envisioned by Congress.

With respect to the training component of our mine safety and health programs, IMCC's member states are concerned that without full, stable funding of the State Grants Program, the federally required training for miners employed throughout the U.S. will suffer. Our experience over the past 40 years has demonstrated that the states are often in the best position to design and offer mine safety and health training in a way that insures that the goals and objectives of Sections 502 and 503 of the Mine Safety and Health Act are adequately met. We greatly appreciate Congress' recognition of this fact and this Subcommittee's strong support for state assistance grants, especially in past years when the Administration sought to eliminate or substantially reduce those moneys.

We also appreciate the recognition by Congress that the availability of these funds to states should not be diminished by allowing them to be used for other purposes. A proviso in the Administration's proposed fiscal year 2020 budget for MSHA would have allowed funds from state assistance grants to be used for the purchase and maintenance of equipment required by the final rule entitled “Lowering Miners Exposure to Respirable Coal Mine Dust, Including Continuous Personal Dust Monitors” published by the Department of Labor in the Federal Register on May 1, 2014 (70 Fed. Reg. 24813), for operators that demonstrate financial need as determined by the Secretary. This proviso had appeared in enacted Federal budget legislation for several fiscal years before 2020. In our comments to this Subcommittee on the proposed budget for fiscal year 2020, we requested that this proviso be removed from the budget so that these vital state mine safety and health training programs could be assured of receiving adequate funding. We were pleased to see that this proviso was eliminated in the enacted Federal budget for fiscal year 2020. We urge Congress to reject any other similar attempt to diminish the funds available to states for this purpose in the budgets it adopts for fiscal year 2021 and future years. The budget that is adopted for fiscal year 2021 should include the full amount of $10,537,000 for state assistance grants, without any provisos or other qualifications that could reduce the amount of money states receive.

Thank you for the opportunity to present our views on the proposed fiscal year 2021 budget for MSHA.

[This statement was submitted by Thomas L. Clarke, Executive Director, Interstate Mining Compact Commission.]

PREPARED STATEMENT OF THE INTERSTITIAL CYSTITIS ASSOCIATION

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2021

—Provide $1.1 million for the IC Education and Awareness Program and the IC Epidemiology Study at the Centers for Disease Control and Prevention (CDC)
—Provide $44.7 billion for the National Institutes of Heatlh (NIH) and Proportional Increases Across all Institutes and Centers
—Support NIH Research on IC, Including the Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network and Chronic Pain

Thank you for the opportunity to present the views of the Interstitial Cystitis Association (ICA) regarding interstitial cystitis (IC) public awareness and research. ICA was founded in 1984 and is the only nonprofit organization dedicated to improving the lives of those affected by IC. The Association provides an important avenue for advocacy, research, and education. Since its founding, ICA has acted as a voice for those living with IC, enabling support groups and empowering patients. ICA advocates for the expansion of the IC knowledge-base and the development of new treatments. ICA also works to educate patients, healthcare providers, and the public at large about IC.

IC is a condition that consists of recurring pelvic pain, pressure, or discomfort in the bladder and pelvic region. It is often associated with urinary frequency and urgency. This condition may also be referred to as painful bladder syndrome (PBS), bladder pain syndrome (BPS), and chronic pelvic pain (CPP). It is estimated that as many as 12 million Americans have IC symptoms. Approximately two-thirds of these patients are women, though this condition does severely impact the lives of as many as 4 million men. IC has been seen in children and many adults with IC report having experienced urinary problems during childhood. However, little is known about IC in children, and information on statistics, diagnostic tools and treatments specific to children with IC is limited.

The exact cause of IC is unknown and there are few treatment options available. There is no diagnostic test for IC and diagnosis is made only after excluding other urinary/bladder conditions. It is not uncommon for patients to experience one or more years delay between the onset of symptoms and a diagnosis of IC. This is exacerbated when healthcare providers are not properly educated about IC.

The effects of IC are pervasive and insidious, damaging work life, psychological well-being, personal relationships, and general health. The impact of IC on quality of life is equally as severe as rheumatoid arthritis and end-stage renal disease. Health-related quality of life in women with IC is worse than in women with endometriosis, vulvodynia, and overactive bladder. IC patients have significantly more sleep dysfunction, and higher rates of depression, anxiety, and sexual dysfunction.

Some studies suggest that certain conditions occur more commonly in people with IC than in the general population. These conditions include allergies, irritable bowel syndrome, endometriosis, vulvodynia, fibromyalgia, and migraine headaches. Chronic fatigue syndrome, pelvic floor dysfunction, and Sjogren's syndrome have also been reported.

IC PUBLIC AWARENESS AND EDUCATION THROUGH CDC

ICA recommends a specific appropriation of $1.1 million in fiscal year 2021 for the CDC IC Program. This will allow CDC to fund the Education and Awareness Program, per ongoing congressional intent, as well as the IC Epidemiology Study.

CDC had shifted the focus of the IC program to an epidemiology study and away from education and awareness, but thanks to the Subcommittee the ICA and IC community have been able to open discussions with CDC to ensure a renewed focus on education and awareness activities. The IC community had been concerned that focusing solely on an epidemiology study instead of on education and awareness activities was detrimental to patients and their families. We have recently met with CDC thanks to the actions of this Subcommittee where we openly and effectively communicated the need for CDC to include ICA in any collaboration along with the epidemiology study. We know that CDC has not received as generous increases as NIH over the past few fiscal years, but it is important the CDC continue supporting both critical components of the IC Program. The CDC IC Education and Awareness Program is the only Federal program dedicated to improving public and provider awareness of this devastating disease, reducing the time to diagnosis for patients, and disseminating information on pain management and IC treatment options. ICA urges Congress to provide funding for IC education and awareness in fiscal year 2021.

The IC Education and Awareness program has utilized opportunities with charitable organizations to leverage funds and maximize public outreach. Such outreach includes public service announcements in major markets and the Internet, as well as a billboard campaign along major highways across the country. The IC program has also made information on IC available to patients and the public though videos, booklets, publications, presentations, educational kits, websites, self-management tools, webinars, blogs, and social media communities such as Facebook, YouTube, and Twitter. For healthcare providers, this program has included the development of a continuing medical education module, targeted mailings, and exhibits at national medical conferences.

The CDC IC Education and Awareness Program also provided patient support that empowers patients to self-advocate for their care. Many physicians are hesitant to treat IC patients because of the time it takes to treat the condition and the lack of answers available. Further, IC patients may try numerous potential therapies, including alternative and complementary medicine, before finding an approach that works for them. For this reason, it is especially critical for the IC program to provide patients with information about what they can do to manage this painful condition and lead a normal life. With the recent developments in our conversations with the CDC we are confident that we will continue to provide key education and awareness that will continue to benefit the IC community.

IC RESEARCH THROUGH THE NATIONAL INSTITUTES OF HEALTH

ICA recommends a funding level of $44.7 billion for NIH in fiscal year 2021. ICA also recommends continued support for IC research including the MAPP Study administered by NIDDK.

The National Institutes of Health (NIH) maintains a robust research portfolio on IC with the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) serving as the primary Institute for IC research. The NIDDK Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network has continued to include cross-cutting researchers who are currently identifying different phenotypes of the disease. Phenotype information will allow physicians to prescribe treatments with more specificity. Research on chronic pain that is significant to the community is also supported by the National Institute of Neurological Disorders and Stroke (NINDS) as well as the National Center for Complementary and Integrative Health (NCCIH). The vast majority of IC patients often suffer major and multiple quality of life issues due to this condition. Many IC patients are unable to work full time because pain affects their mobility, sleep, cognition, and mood. These are people that simply want to lead productive lives, and need pain medication to do so. Due to the fact that IC is categorized as a non-cancer pain condition, IC patients already have a difficult time obtaining pain meds. IC doctors do not have time nor the inclination to effectively prescribe or monitor the distribution of the opioid class of medication. They often refer their patients to Pain Management Specialists, many who have never heard of IC, who often refuse to treat them. In addition, antidepressants and benzodiazepines are often used to treat both mood and sleeping disorders for IC patients. Additionally, the NIH investigator-initiated research portfolio continues to be an important mechanism for IC researchers to create new avenues for interdisciplinary research.

PATIENT PERSPECTIVE

IC is a tough disease to diagnose, and it is one of the most challenging things to deal with, finding a Dr. that specializes in IC that can help diagnose and treat. I can't stress enough how important finding the right Dr. is. IC patients need a Dr. who understands and is willing to go along with them on this long, frustrating, painful and confusing road. I have found strength through having this that I never knew I had, strength to keep going when all treatments so far have failed me.

There are a small number of treatments available for managing IC symptoms, but they only work on a small percentage of patients. I have tried those treatments and some drugs that "might" help. I manage my diet, take lots of supplements and have to see all kinds of Doctors now. I have six! That includes holistic medicine doctors, physical therapists, and acupuncturist. That's along with my regular MD, Urologist and two different gynecologists. This is what my life has become. The life of an IC patient. I deal with one or more symptoms of IC EVERY SINGLE DAY. Some days definitely better than others, but every single day. It affects my life in so many ways. Work, social, travel and my intimate relationships. I never know how I'm going to feel from one day to the next. Anxiety and fear included.

Thank you for the opportunity to present the views of the interstitial cystitis community.

[This statement was submitted by Lee Lowery, Executive Director, Interstitial Cystitis Association.]

PREPARED STATEMENT OF THE JAMESTOWN S'KLALLAM TRIBE

Chairman Blunt, Ranking Member Murray and distinguished members of this Subcommittee, on behalf of the Jamestown S'Klallam Tribe, I would like to thank you for this opportunity to submit written testimony on our funding priorities and recommendations for the fiscal year 2021 appropriations process for the Department of Labor, the Department of Health and Human Services, and the Department of Education.

COVID–19 PANDEMIC

—Fund Tribal Fishers and Tribal Employees Unemployment Benefits
—Provide Tribes a Robust Share of the $1.5 Billion DoE Post-Secondary Education Account

TRIBAL SPECIFIC HEALTH & EDUCATION APPROPRIATION PRIORITIES

—Fund Medicare/Medicaid Expansion
—ESSA Title VII Impact Aid—$2 Billion
—Child Welfare Programs Tribal Allocations Subpart 1, $5.5 million; Subpart 2, $3.3 million
—Older Americans Act Title VI, Part A, B Native American Nutrition and Supportive Services—$43 million

NATIONAL REQUESTS

—Special Diabetes Program for Indians—$200 Million
—Alcohol and Substance Abuse Treatment—$503.9 Million

Our Tribal Communities are now on the front lines dealing with the urgency, infection rate, and death toll of the COVID–19 pandemic and it has become increasingly clear that Tribal Governments need significantly more funding and resources to prevent the loss of human life. In order to prevent Tribes from facing legal and regulatory barriers to fighting this pandemic, Indian Country must be explicitly included in any legislative or policy funding vehicle that is being advanced and there must be allowance for greater flexibility in the application and use of funds.

COVID–19 PANDEMIC

100 Percent Fund Tribal Fishers and Tribal Employees Unemployment Benefits

Tribes in Washington State have an agreement with the State whereby Tribes self-ensure rather than participate in FUTA. This agreement has worked well for the Tribes under the normal termination of employee's process. However, the COVID–19 pandemic presents new challenges that were unforeseen at the time of entering these State agreements. The copious revenue loss by the Tribes has been devasting and continues to increase. Tribes should recover 100 percent of the unemployment benefits extended to Tribal fishers and employees because of Covid-19. Tribal unemployment recipients should also receive supplemental income that is made available to other unemployed recipients and included in the COVID–19 relief legislation.

Tribes Share in $1.5 Billion for Department of Education Post-Secondary Education Account

Emergency Funding for Tribes to address the educational needs of Indian students must also be provided. Provide a robust share of the $1.5 Billion for the Department of Education Post-Secondary Education Account to Tribal Colleges and Universities and Educational Institutions serving AI/AN students; Provide $40 Million for the extension of classes for AI/AN students for at least four (4) months; and Ensure access to healthy meals for all AI/AN that are impacted by school closures.

TRIBAL SPECIFIC HEALTH & EDUCATION APPROPRIATION PRIORITIES

Fund Medicare/Medicaid Expansion.—It is vital that the Federal Government continue to fully fund Medicaid for eligible AI/AN because the 3rd party revenue is used to supplement Tribal health programs due to inadequate IHS funding. AI/AN must also be exempted from the cost sharing provision under Medicare. The Medicaid/Medicare system is a critical lifeline to our community and coupled with our innovative approach to healthcare is an effective and efficient use of the Federal investment resulting in better health services and reduced healthcare costs. Tribal consultation is required before any changes, such as, work requirements or block grants are instituted.

ESSA Title VII Impact Aid—$2 Billion.—Currently, 93 percent of Native students are enrolled in local public schools. Impact Aid provides direct essential funding to public schools serving Native students and should be forward funded to avoid the need for cost transfers and other funding issues. Our mission to enhance self-reliance, self-sufficiency and developing strong intellectually astute Tribal citizens includes providing opportunities for personal growth through education. Education is extremely important to our Tribe and continued and increased funding for ESSA Title VII is needed to not only ensure the success of our students and future Tribal leaders but to secure the welfare and vitality of our Tribal community and culture.

Child Welfare Programs Title IV B (subpart 1)—$280 Million Tribal Allocation $5.5 Million & Promoting Safe and Stable Families Social Security Act Title IV B (subpart 2) $110 Million Tribal Allocation $3.3 Million.—Title IV B provides funding to Tribes to support community-based child welfare services. Tribal tradition and culture are an integral component of Tribal child welfare programs because it has been proven that culturally tailored programs and services lead to better outcomes for AI/AN children and families. Cultural integration leads to increased community participation and support for these programs which in turn results in a more effective response rate. Promoting Safe and Stable Families provides funding for coordinated culturally appropriate child welfare services. Maximum flexibility in the use of these funds is essential to allow Tribes to provide ancillary services, including, parenting classes, conducting home visits, and addressing issues, such as, alcohol and substance abuse that have a direct correlation to American Indian/Alaska Native children becoming integrated into the child welfare system. The goal of these programs is to keep children with their families and Tribal communities.

Older Americans Act Title VI—$43 Million.—Title VI programs fund nutritional and other direct supportive services to AI/AN elders. Reducing isolation through community and cultural activities and ensuring our Elders receive proper nutrition and healthcare is a priority for our Tribe. Title VI of the Older Americans Act is the primary funding source for the provision of these programs and services. Our meal delivery program has been in service for over 20 years and serves over 1100 meals per month on average to 80 elders. Providing support services to our elders is deeply rooted in our beliefs and ensures the survival of our culture, traditions, and language. Our elders are the pathway to the past, present and future for the next seven generations.

NATIONAL HEALTH & EDUCATION APPROPRIATION PRIORITIES

Special Diabetes Program for Indians—$200 Million.—The Special Diabetes Program for Indians is a critical program that is saving lives in our Tribal communities. This program has grown to become one of this nation's most strategic and effective Federal investments that is addressing the diabetes epidemic in Indian country. Tribes request permanent reauthorization, remaining a mandatory rather than discretionary appropriation and a minimum increase of $50 million for a total of $200 million for SDPI.

Alcohol and Substance Abuse Treatment—$503.9 Million.—Alcohol and Substance abuse has plagued Tribal communities for years and an increase is needed to break the cycle. Tribal communities will continue to struggle with addiction and the interrelated social issues unless targeted funding is provided to Tribes to address these issues in a culturally appropriate way.

The Jamestown S'Klallam Tribe continues to support the requests and recommendations of the Portland Area Indian Health Board, the National Indian Health Board, and the National Congress of American Indians. Thank you.

[This statement was submitted by W. Ron Allen, Tribal Chairman/CEO, Jamestown S'Klallam Tribe.]

PREPARED STATEMENT OF SUSAN JENNINGS

Chairman Blunt, Ranking Member Murray and Subcommittee Members,

Thank you for your public service and for affording families the opportunity to submit testimony.

I have recently learned that the House passed its fiscal year 2021 LHHS spending bill and that the bill recommends increases or level funding for four programs administered by HHS/Administration for Community Living, the Developmental Disabilities and Bill of Rights Act (DD Act) programs, including the Federal DD Act program that is working to eliminate all intermediate care facilities (ICF's) in the state of Pennsylvania. See testimony below submitted May, 2020.

I learned that the House fiscal year 2021 LHHS spending bill does not include the report language protecting ICF care and we families in Pennsylvania are deeply worried and I am re-submitting my testimony for your consideration. On behalf of Joey and KIIDS, I respectfully request that the attached Report Language be included in the Senate fiscal year 2021 LHHS spending bill.

I am Susan Jennings of Mansfield, Pennsylvania. My interest in providing testimony is because of my son Russell "Joey" Jennings, aged 28, who suffers from severe autism, intellectual disability and co-morbid psychiatric disorders. I submit this testimony on behalf of KIIDS—Keeping Individuals with Intellectual Disabilities Safe, a statewide organization of the friends and families of Pennsylvania State Developmental Centers. Most, but not all, members of KIIDS have loved ones with disabilities receiving residential treatment services in one of Pennsylvania's four human development centers which are Medicaid-certified intermediate care facilities (ICFs).

Our family went through the journey parents travel when they learn that their children have conditions which cannot be healed: denial, grief, and despair. We worked hard to meet Joey's needs when he was younger. As he grew into a strong youth, his care became beyond our capacities. A growing percentage of the population with disabilities should have the centralized structured support of institutional systems of care. Joey is one of those.

KIIDS requests relief from Department of Health and Human Services' (HHS') programs and policies which undermine and eliminate our state's much-needed specialized residential treatment programs. I implore you to halt the use of Federal funds by HHS programs and policies to achieve the deinstitutionalization of at-risk persons like our son and his peers from their safe intermediate care facility (ICF) homes.

HHS DD ACT PROGRAMS IN PENNSYLVANIA

It is clear to me and other parents of disabled persons residing in state developmental centers that HHS through its grants to programs created under the Developmental Disabilities Assistance and Bill of Rights Act (last reauthorized in 2000) has been responsible for many of the groups intent on closing our state's larger residential centers for persons with cognitive deficits and other developmental disabilities. The DD Act programs are: (1) State Councils on Developmental Disabilities, (2) Protection and Advocacy (P&A) systems and (3) National Network of University Centers for Excellence in Developmental Disabilities Education, Research and Service (UCEDD) programs.

I am new in learning about the role that HHS plays in shaping long term care policies for persons with developmental disabilities because, relatively speaking, our family is new to the need for safe residential care for our son. I am new to learning about the HHS funded DD Act programs, that there have been no oversight hearings on them for the past 20 years and that they receive a steady stream of un-checked Federal funds, that they have insufficient oversight. I submit that the general public would not support the DD Act programs' work to eliminate the option of institutional care for persons unable to care for themselves, which is sometimes called "inclusion."

Examples of deinstitutionalization work by DD Act programs in Pennsylvania are:

> (1) PA DD Council: a grant of $50,000.00 for the period March, 1994—to February, 1995 was awarded by Pennsylvania Developmental Planning Council to the advocacy organization the Arc. Purpose of the grant: "To develop strategies for overcoming the obstacles to closing institutions for persons with mental retardation including but not limited to economic, political and attitudinal barriers." Attachment 1,
>
> (2) PA P&A: the Pennsylvania Protection and Advocacy program brought Federal lawsuits which resulted in the closure of Western Center and Embreeville Center.
>
> (3) PA UCEDD: on September 24, 2019, the Director of the Pennsylvania UCEDD program (Temple University Institute on Disabilities) appeared before the Commonwealth's Senate Health and Human Services legislative hearing in her official capacity and urged the closure of Polk Center and White Haven Center, two of the PA State ICF programs.

HHS through its DD Act programs and other long term care policy programs and grants is on a disastrous path of closing institutional (ICF) programs in favor of "Community" (Home and Community Based Service) programs.

NOWHERE TO GO

My own severely autistic son's life is a case study in the superiority and effectiveness of care in an ICF versus the suffering and abuse he sustained in the "Community" HCBS model of care. He was discharged from no less than 6 different community group homes, administered by 3 different state providers, who offloaded him into 5 different psychiatric facilities in the short span of 4 years' time. During his stay in "Community" services, he suffered a broken eye socket, toxic overmedication, and exposure to pornography. He was rescued by a Pennsylvania State Developmental Center (ICF) which affords him quality of life and freedom from abuse.

My son is not an anomaly and he is not alone. According to the National Alliance on Mental Illness, 500,000 autistic adults will be coming of age in the next 5–7 years. Roughly between 10 percent and 50 percent of those adults will have the same severe impairments and dangerous behavioral challenges as my son. If "deinstitutionalization" and the elimination of appropriate residential care facilities continue, there will be a catastrophic shortage of housing and effective services for these adults. With an autism birthrate of 1 in 54, according to the CDC, this is a pressing issue at this time in our nation's history. These young adults will have nowhere to go except into a revolving door of failed "Community" placements, retrofitted Hospital Emergency Rooms, psychiatric wards and jail cells, at great cost to taxpayers, families and traumatized vulnerable young autistic adults. See "Nowhere to Go: Young People with Severe Autism Languish in Hospitals," Kaiser Health News, September 26, 2017

We respectfully request your consideration for report language in the fiscal year 2021 LHHS spending bill barring Federal funds from incentivizing states to close their specialized facilities for persons unable to care for themselves. Suggested Report Language for fiscal year 2021LHHS Spending Bill, Attachment 2.

Respectfully submitted,

KIIDS—Keeping Individuals with Intellectual Disabilities Safe
By: Susan Jennings

PREPARED STATEMENT OF JOHNSON & JOHNSON

On behalf of Johnson & Johnson's 132,000 global employees, I am pleased to provide written testimony to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies in support of increased funding for the National Institutes of Health (NIH) fiscal year 2021 budget.

Robust funding for NIH is necessary to ensure that the agency has the continued ability to fuel innovation in medical research, improving the trajectory of healthcare in the United States and around the world. This funding request also represents what is required to remain competitive in addressing emerging health threats confronting the United States and to encourage the pursuit of innovative solutions essential in addressing these increasingly complex challenges.

As a physician and scientist, I have dedicated much of my life to translating basic scientific research into medical advances. In my role as Global Head of Johnson & Johnson External Innovation and as a board member of Research! America, the nation's largest not-for-profit public education and advocacy alliance, and the American Association for Cancer Research, I am deeply aware of the value of our nation's investment in research.

In the United States, the majority of medical research into the root causes of disease is publicly funded by the NIH through research grants to more than 2,500 institutions across the country. The invaluable research conducted by NIH-funded investigators represents the building blocks of scientific discovery, enabling healthcare companies to expand upon this research to transform scientific findings into the breakthrough healthcare products of tomorrow. Furthermore, NIH research often makes possible the business case for the enormous, at-risk investment and effort it requires to discover, develop and guide an important new medical treatment through the regulatory process and to patients in need.

At Johnson & Johnson, we make a commitment to create life-enhancing innovations and to produce value through partnerships that will profoundly change the trajectory of health for humanity. To that end, in 2019, Johnson & Johnson invested nearly $11.4 billion in research and development across our pharmaceutical, consumer and medical device companies. Our teams of scientists work tirelessly to accelerate the translation of scientific discoveries into meaningful solutions for patients and consumers. Much of our work, and that of scientists across the industry, would not be possible without the constant progression of the understanding of underlying disease biology—precisely the type of research funded by the NIH.

In addition, Johnson & Johnson recognizes the crucial importance of early-stage companies and the critical role NIH plays in supporting these small businesses through Small Business Innovation Research (SBIR) and Small Business Technology Transfer (STTR) funding.

Through our J&J Innovation Centers, entrepreneurs and startups can discuss the innovative ideas they're working on and seek to collaborate with Johnson & Johnson scientists, our global expertise and resources to accelerate what they are working on. Through Johnson & Johnson Innovation—JJDC they may obtain venture capital funding to support their innovations. At Johnson & Johnson Innovation—JLABS incubator sites, we support the life sciences ecosystem by helping entrepreneurs and scientists realize their dreams of creating healthcare solutions that improve lives by identifying and nurturing highly innovative ideas in areas of potentially disruptive, cutting-edge research, which may lead to novel platforms, products or technologies. These are advances that the scientific community could only imagine several years ago, yet they are becoming a reality today through the support of public-private partnerships like these.

The work of the NIH is tied not only to innovation and the vitality of the life sciences, but also to the health of our national economy. NIH is the lifeblood of basic healthcare research for America, and is also an incredible economic engine. In fiscal year 2019, NIH research funding directly and indirectly supported over 475,000 jobs and spurred nearly $81.3 billion in new economic activity. Moreover, the pace of medical research must keep up with the aging of our population and emerging microbial threats. There is an urgent need, both on the individual and socioeconomic level, for strategies to prevent illnesses associated with aging or lifestyle. Diseases such as Alzheimer's, diabetes, cancer and heart disease threaten to overwhelm our healthcare system in a matter of years with enormous costs of care if we do not find ways to prevent, intercept, treat and cure them.

Investments in medical research at the end of the 20th century by the Federal Government and private life sciences companies, combined with the work of industry and NIH-funded investigators across the country, have produced fundamental scientific advances, vast new datasets and increasingly sophisticated areas of scientific research. As the NIH is working on projects in areas like precision medicine, gene therapy and vaccines to prevent infectious diseases, there has never been a more critical and promising time to work in medical research.

Johnson & Johnson believes that fully and consistently funding the NIH represents a commitment to fueling innovation in medical research. It is also a commitment to our communities by advancing science to match medical need, to our current and future generations of scientists by stimulating the life sciences ecosystem, and to the prosperity of our nation as a worldwide leader in medical research. Sustainable, robust investment is needed to strengthen this research and to realize its benefits for improving people's lives and reducing the burden and associated costs of today's major diseases in the United States and around the world.

[This statement was submitted by William N. Hait, MD, PhD, Global Head, Johnson & Johnson External Innovation.]

PREPARED STATEMENT OF KANSAS NEUROLOGICAL INSTITUTE PARENT GUARDIAN GROUP

Chairman Blunt, Ranking Member Murray, and Committee Members, Thank you for the opportunity to submit testimony.

There is a fierce ideological battle to eliminate all Intermediate Care Facility options where defenseless individuals, affected with the most profound disabilities have access to the supports they need (ICFs/IID). These Medicaid approved facilities often disparagingly referred to as institutions. The distortion of truth before this and other Congressional Committees is often presented by well funded entities and so-called "subject matter experts". What is missing from their testimonies is the mounting number of tragedies occurring in community settings nation-wide. This troubling discrimination against defenseless individuals is based on a questionable agenda, and involves the use and mis-use oof millions of dollars through HHS funding.

Having raised my grandson, who is affected with profound autism, and who routinely exhibits extreme, maladaptive and dangerous behaviors, I am well aware first-hand of the diminishing, unsustainable aspects of "inclusion" ideology in community settings. The number of community deaths and community abuse nationwide against helpless I/DD individuals who did not choose to be born this way, are mounting and have been mounting for more than two decades. Yet the forced "trend" of ICF facility closures across the nation continues.

The connection between appropriations work, the Senate LHHS Subcommittee, funding of the Department of Health and Human Services programs and grants, and policies adversely affecting the weakest members of society by closing admissions to ICF programs is striking. Robust Congressional oversight is desperately needed of DD Act related grants and programs.

REQUEST

Our families respectfully request inclusion of attached report language, to be included in the fiscal year 2021 LHHS spending bill, which would bar Federal funds from incentivizing states to close specialized facilities designed to provided adequate support for our highest-risk loved ones. These individuals are our children, grandchildren, brothers, sisters and friends.

Thank you for serious consideration in honoring requests herein. Extensive documentation of nationwide community tragedies in this arena is available upon the Committee's/Sub-committee's request.

Respectfully.

[This statement was submitted by Joan Kelley, Vice-President, Kansas Neurological Institute Parent Guardian Group.]

PREPARED STATEMENT OF SUSAN G. KOMEN

Susan G. Komen (Komen) is the world's leading nonprofit breast cancer organization, representing the millions of women and men who have been diagnosed with breast cancer. Komen has an unmatched, comprehensive 360-degree approach to fighting this disease across all fronts—we advocate for patients, drive research breakthroughs, improve access to high quality care, offer direct patient support and empower people with trustworthy information. Komen is committed to supporting those affected by breast cancer today, while tirelessly searching for tomorrow's cures. We advocate on behalf of the estimated 279,100 women and men in the United States who will be diagnosed with breast cancer and the more than 42,690 who will die from the disease in 2020 alone. Breast screening and diagnostic services allow us to catch potential cancers at earlier stages often yielding better outcomes for patients and resulting in decreased financial pressure on our healthcare system. To this end, Komen is requesting that Congress fully fund the Centers for Disease Control and Prevention's (CDC) National Breast and Cervical Cancer Early Detection Program (NBCCEDP) at the authorized amount of $275 million in fiscal year 2021.

Established in 1990 with the passage of the Breast and Cervical Cancer Mortality Prevention Act, NBCCEDP plays a critical role in helping low-income, uninsured, and underinsured women who do not qualify for Medicaid access breast and cervical cancer screening and diagnostic services that are free or low-cost. The covered services include: clinical breast examinations, mammograms, pap tests, pelvic examinations, human papillomavirus (HPV) tests, diagnostic tests if results are abnormal, and referrals to treatment, education and case management.

Since its inception, NBCCEDP-funded programs have served more than 5.6 million women, provided more than 13.3 million breast and cervical cancer screenings, and diagnosed more than 68,486 invasive breast cancers, and 4,720 invasive cervical cancers. In program year 2018 (the most recent data available), the program screened 276,417 women for breast cancer, diagnosing 2,599 invasive breast cancers and screened 135,148 women for cervical cancer, diagnosing 159 invasive cancers. More than 2.6 million women remain eligible for NBCCEDP breast cancer screening services. However, at current funding levels ($197 million in fiscal year 2020), the program serves around 10 percent of those eligible.

The program functions as a Federal-state partnership, under which states are required to satisfy a 1:3 matching obligation ($1 in state funding, monetary or in-kind, for every $3 in Federal funds provided to that state). Currently, the Federal Government provides program funding to all 50 states, the District of Columbia, six U.S. territories, and 13 American Indian/Alaska Native tribes or tribal organizations. Uninsured and underinsured women at or below 250 percent of the Federal poverty level, ages 40–64 are eligible for breast cancer screenings services through NBCCEDP. Each state program operates within the national framework of legislation, policy, and oversight; however, programs vary in funding, infrastructure, populations served, and geographical barriers. State programs are charged with implementing strategies to reach women in underserved areas, as well as adopting operational models that fit their unique populations and demographics. Programs can prioritize the population they serve based on their cancer burden, environment, available resources, and goals. Unfortunately, these are often influenced and limited by state funding and legislative constraints.

NBCCEDP faces several challenges, most notably funding. The program funding has been targeted for cuts based on the assumption that more women will heave health coverage as a result of the Affordable Care Act (ACA) and thus would be able to get the services elsewhere. However, challenges remain for women who live in states that have limited Medicaid eligibility, fail to obtain insurance coverage, have limited health literacy, and face language barriers. We recently heard from a patient in California, “I am grateful for the screening program to have been here for me. I had a mammogram through the program and the results were abnormal and I needed further studies. Unfortunately, I was diagnosed with breast cancer. I am grateful that I found the cancer at the very beginning stage and I only had to have a lumpectomy and after treatment I am doing great.” The NBCCEDP is even more critical today when many Americans are facing financial and insurance insecurity due to the COVID–19 crisis.

Increasing NBCCEDP funding is key to achieving Komen’s Bold Goal of reducing the number of breast cancer deaths by 50 percent by 2026. The availability of the NBCCEDP impacts every taxpayer, and people in every Congressional district, as the uninsured will eventually show up at our states’ hospitals with late-stage diagnoses, putting an even greater strain on the patients, the health system and state budgets. Increasing funding for NBCCEDP will allow the CDC and its grantees the ability to pursue important goals such as implementing innovative strategies to find eligible women who have not yet benefitted from the program due to lack of access to care or lower incomes, education, or health literacy.

Ensuring adequate NBCCEDP funding is key to ensuring that low-income, uninsured and underinsured women continue to have access to vital screening and diagnostic services, providing newly insured women access to health education and patient navigation services, as well as enabling proper monitoring of state and local breast cancer patterns and trends. Please support increased funding for NBCCEDP in the fiscal year 2021 Labor, HHS, Education Appropriations Bill so that more women can be screened, diagnosed and treated for breast cancer. Recognizing the challenging budget and public health crises facing our nation, we ask that Congress at least maintain the current NBCCEDP funding level to avoid any losses of coverage or access to needed breast imaging.

[This statement was submitted by Molly Guthrie, Director, Public Policy and Advocacy.]

Prepared Statement of LEAD Coalition

Chairman Shelby, Vice Chairman Leahy, Chairman Blunt and Ranking Member Murray, Chairman Hoeven and Ranking Member Merkley, Chairman Moran and

Ranking Member Shaheen, thank you for receiving this testimony. Today, the LEAD Coalition submitted a more detailed letter (see: http://www.leadcoalition.org/2020/05/22/fy2021-appropriations/) to your offices signed by nearly 200 patient advocacy organizations and health non-profits, philanthropies and foundations, trade and professional associations, academic research and clinical institutions, home and residential care providers, biotechnology and pharmaceutical companies, and leading university-based researchers. This summary testimony highlights vital fiscal year 2021 appropriations increases to address immediate needs of people living with dementia and the scientific research that will produce effective pharmacological and non-pharmacological interventions to prevent, treat and eventually cure Alzheimer's disease and related forms of dementia (including cerebrovascular disease, Lewy body dementia, frontotemporal degeneration and Creutzfeldt-Jakob disease). We sincerely thank you for recognizing and decisively responding to these challenges in the fiscal year 2020 appropriations package. Continuing the momentum in fiscal year 2021 is a national priority, an economic and budgetary necessity, a health and moral imperative. Specifically, we request that the fiscal year 2021 appropriations bills include at least the following minimum increases:

—a $354 million increase for National Institutes of Health (NIH) research on Alzheimer's disease and other forms of dementia to accelerate progress as articulated in the NIH Bypass Budget Proposal for fiscal year 2021
—a $500 million increase for aging research across the NIH, in addition to the funding for dementia-specific research, to ensure that the NIH has the resources to address the many other age-related chronic diseases that affect people with dementia
—a $3 billion increase for the NIH, including funds from the 21st Century Cures Act for targeted initiatives, as recommended by the Ad Hoc Group on Medical Research
—a $120 million increase for the FDA, in addition to funds included in the 21st Century Cures Act for targeted initiatives, as recommended by the Alliance for a Stronger FDA
—funding recommendations established in the recent Older Americans Act reauthorization (Supporting Older Americans Act of 2020, H.R. 4334) for all OAA programs and services, as recommended by the Leadership Council of Aging Organizations
—a $8.5 million increase for the ACL/AOA Alzheimer's Disease Program Initiative
—$20 million in new funds for the CDC to implement the BOLD Act
—a $3 million increase for the DoJ Missing Americans' Alert Program

We also recommend that the fiscal year 2021 appropriations bill report language direct HHS to:

—report to Congress within 90 days consensus dementia-specific pandemic preparedness and response action steps to be implemented by Federal, state and local governments along with relevant non-governmental organizations; and
—set a national, measurable, time-bound impact goal to reduce dramatically dementia prevalence and deliver an implementation plan to Congress within 180 days, with annual progress updates provided to Congress and the National Alzheimer's Project Act Federal advisory committee.

As the COVID19 pandemic has brought into starker relief, there are few more compelling or complex issues to confront our aging society, now and over the coming decades, than Alzheimer's disease and other forms of dementia. These neurodegenerative conditions impose enormous costs to our nation's health, prosperity, and social fabric. These costs are skyrocketing and unsustainable for families, public and private insurers, and our nation's economy. Currently, more than 5.8 million Americans have dementia, with combined healthcare and long-term care costs of $305 billion. Taxpayers foot about two-thirds of that bill—$206 billion—directly through the Medicare and Medicaid programs. Individuals with dementia and their families pay out of pocket for another fifth of the cost, $66 billion. More than 16 million Americans provide unpaid care for someone with dementia, resulting in additional healthcare and economic costs. Today, as another person develops the disease every 65 seconds, Alzheimer's and other forms of dementia impose a nearly $550 billion loss in public and private expenditures along with uncompensated caregiving. By 2050, someone in the United States will develop the disease every 33 seconds with as many as 13.8 million Americans living with dementia. This explosive growth will cause direct costs to increase from an estimated $305 billion in 2020 to $1.1 trillion in 2050 (in 2020 dollars) and the hidden costs of uncompensated caregiving to be even more staggering. Alzheimer's disease contributes to the deaths of more than 500,000 Americans each year. Alzheimer's disease is the third leading cause of death in the United States and—despite a powerful body of evidence for risk-reduction strategies, which is being expanded with significant NIH investments—the only one among the top 10 for which there is not yet a proven means of prevention, disease modification or cure. One third of older Americans die with Alzheimer's disease or another form of dementia.

The choice before our nation is not whether to pay for dementia—we are paying dearly. The question is whether we will emulate the investment strategies that have led to remarkable progress in fighting other leading causes of death such as cancer, HIV/AIDS and heart disease and achieve similar breakthroughs, or spend trillions to care for tens of millions of people. A modernized and more robust research portfolio along with rationale and compassionate investments in better support services can help America prevent this catastrophe and move us closer to achieving our national goal of preventing and effectively treating dementia by 2025. The congressional appropriations committees along with Federal agencies have moved mountains to create additional resources, public-private partnerships, and a culture of urgency. Across the NIH, institutes are advancing promising research into Alzheimer's disease and other forms of dementia to: understand genetic risk factors; address health disparities among women, African Americans, Hispanics, and persons with intellectual and developmental disabilities; understand Down syndrome's relationship to Alzheimer's disease; pursue cutting-edge trials aimed at preventing or substantially slowing disease progression by administering treatments much earlier in the disease process; and improve quality of life for people with dementia and their caregivers. In fiscal year 2021, the National Institute on Aging plans to intensify its research focus on better understanding the basic biology of underlying dementia, characterizing novel biomarkers and screening tools such as a blood test, identifying and testing innovative drug targets, supporting clinical trials and infrastructure like the Alzheimer's Clinical Trials Consortium, and improving the diagnosis, care, and support of those living with dementia. The FDA is encouraging new research avenues and clarifying regulatory approval pathways. This year, FDA is expected to review new products to address some of the most heart-breaking symptoms of dementia along with what would be the first disease modifying therapy.

The investments we recommend for Older Americans Act services, BOLD Act implementation and other vital programs are relatively small but crucial complements to vastly larger Medicaid and Medicare expenditures to protect and promote the wellbeing of people living with dementia and their caregivers. As urgently as resources are needed to enable scientific breakthroughs, the millions of Americans currently living with dementia and their family caregivers deserve strengthened commitments to protect and enhance their quality of life.

Thank you for considering our views and for your commitment to overcoming Alzheimer's disease and other forms of dementia.

[This statement was submitted by Ian Kremer, Executive Director, LEAD Coalition (Leaders Engaged on Alzheimer's Disease).]

PREPARED STATEMENT OF VICTORIA LINKIN

My 22-year-old daughter needs help and has been unable to find it in this broken system. She's now on her 6th hospital stay since first experiencing mental illness 1 year ago after returning home from college. There are no long-term facilities in my state (Nevada). Our insurance forces her to be released from acute care before she is ready, and winds up hospitalized again within a few days.

Society and the government put the tremendous burden on the families to care for our schizophrenic/schizoaffective loved ones. We are not equipped to handle this disease nor do we have the expertise. If my daughter had cancer or was a drug addict, she would have access to a plethora of treatment options. Why are serious mental health conditions treated any differently? She has a disease of the brain, why aren't we afforded the resources to help combat the effects of this debilitating disease?

Because we lack necessary resources, most individuals with mental health diseases wind up homeless or in jail. Why is this disease criminalized? Why must we wait for a jail sentence so that they will qualify for financial aid and treatment? They need a village, they need hope and a place in our communities, a system that requires them to take medication. We need help with the financial burden of housing them, especially while they are unmedicated, undergoing psychosis and resistant to help. This is a human rights issue. This ongoing crisis is unmanageable.

Sincerely.

PREPARED STATEMENT OF THE LYMPHATIC EDUCATION & RESEARCH NETWORK

KEY RECOMMENDATIONS

—Provide the National Institutes of Health (NIH) with $44.7 billion for fiscal year 2021 and advance lymphatic disease research by expanding resources and encouraging better coordination among relevant institutes and centers.

—Establish a National Commission on Lymphatic Disease Research at the NIH to identify emerging opportunities, challenges, gaps, structural changes, and recommendations on lymphatic disease research.

—Provide the Centers for Disease Control and Prevention (CDC) with $8.3 billion for fiscal year 2021 and enable programmatic activity on chronic disease education and public awareness.

Chairman Blunt, Ranking Member Murray, and distinguished members of the Subcommittee, thank you for the opportunity to submit the priorities of the lymphatic diseases community you as you consider fiscal year 2021 appropriations for the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC).

ABOUT LE&RN

The Lymphatic Education & Research Network (LE&RN) is an internationally recognized non-profit organization founded in 1998 to fight lymphatic diseases and lymphedema through education, research and advocacy. With chapters throughout the world, LE&RN seeks to accelerate the prevention, treatment and cure of these diseases while bringing patients and medical professionals together to address the unmet needs surrounding lymphatic diseases, which include lymphedema and lipedema.

ABOUT LYMPHEDEMA AND LYMPHATIC DISEASES

The lymphatic system is a circulatory system that is critical to immune function and good health. When it is compromised and lymph flow is restricted, the physical impact to patients can be devastating, life altering, and can lead to shortened lifespan. Lymphedema (LE) is one such lymphatic disease. LE is a chronic, debilitating, and incurable swelling that can be a result of cancer treatment, inherited or genetic causes, and damage to the lymphatic system from surgery or an accident, or from parasites as in lymphatic filariasis. Stanford University estimates that up to 10 million Americans have lymphedema. This represents more Americans than those living with AIDS, Multiple Sclerosis, Parkinson's disease, Muscular Dystrophy and ALS—combined. The World Health Organization puts the global number of people with this disease at 250 million. There is no cure. There is no approved drug therapy. And there are currently only three drug studies worldwide seeking a treatment. Psychosocially bruised by a disease that leaves us deformed, we do our best to hide our lymphedema.

Lymphedema is an equal opportunity disease, affecting women, men and children alike. Many are born with congenital or hereditary lymphedema. Others, like our veterans, get the disease as a result of physical trauma, bacterial infection, or as result of exposure to burn pits. Like seven million other Americans, one can develop lymphedema after being treated for cancer. Those with LE face a lifetime of time-consuming daily care regimens. These include manual lymph drainage massage, wrapping oneself in compression garments and using a pneumatic pump to control the swelling. Forever. Compression garments aren't even covered by Medicare. We are working to expand access through the Lymphedema Treatment Act, and we are hopeful this bill will pass this year. But it is clear that this community deserves more options.

Lymphedema is an ignored disease. A study concluded that physicians are currently getting an average of only 15–30 minutes of study on the lymphatic system in their entire medical training. This leaves them ill-prepared to diagnose the disease. Misdiagnosis leads to improper treatment. Those who are diagnosed find it difficult to find certified lymphedema therapists. Few medical centers exist that are prepared to address lymphatic diseases. Surgeons are experimenting with treatment that could alter the course of the disease. However, the necessary basic research is not being done to inform their procedures. And currently, Medicare and Medicaid do not cover some of the basic treatment needs of these patients—such as compression garments, which all must wear daily.

FISCAL YEAR 2021 APPROPRIATIONS RECOMMENDATIONS

It is time for a challenge worthy of our great country. We ask that within 20 years, we will make lymphedema a truly treatable disease. To reach this goal will require a commitment to important medical research. LE&RN joins the broader medical research community in thanking Congress for continuing to provide the National Institutes of Health with proportional and sustainable funding increases over the past several fiscal years, and we ask you all to continue to prioritize these activities by providing at least a $3 billion funding increase for fiscal year 2021 to bring NIH's budget up to $44.7 billion.

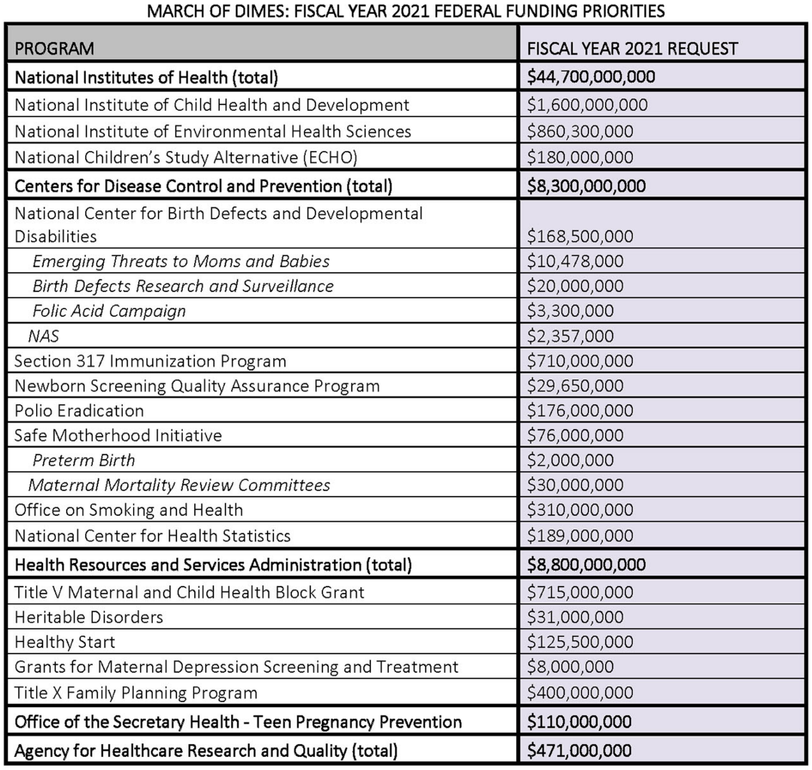
We continue to urge the Subcommittee to work to expand and advance the lymphatic disease portfolio at the NIH. In late 2015, the NIH hosted a Lymphatic Symposium, where experts in the field identified a scientific roadmap that could build the research portfolio up to a level of at least $70 million annually over subsequent years by funding meritorious grants on critical topics. In an effort to further support and enhance emerging lymphedema and lymphatic disease research activities, we ask the Subcommittee to encourage further collaboration among relevant institutes and centers conducting research in this area. We also call on the Subcommittee to work with your colleagues to establish a National Commission on Lymphatic Disease Research, which can thoroughly examine the portfolio and make recommendations on how best to advance this emerging scientific area under NIH's current structure. Currently, the National Institutes of Health spends approximately $25 million annually on lymphatic research, and only $5 million of this is dedicated to clinical lymphedema research. Experts state with confidence that there is no other disease affecting more Americans that receives so little attention. It must also be noted that study of the lymphatic system is poised to bring miracles for a host of diseases that are part of the lymphatic continuum: obesity, heart disease, diabetes, Rheumatoid arthritis, cancer metastasis, AIDS, Crohn's disease, lipedema, and a host of other diseases. Recent research discovered lymphatics surrounding the brain, which now has us studying its impact on Alzheimer's disease and multiple sclerosis. We appreciate the Subcommittee's continued support for the establishment of a National Commission on Lymphatic Diseases and ask that NIH be held accountable for the lack of progress on its establishment.

LE&RN also joins the public health community in asking Congress to provide the Centers for Disease Control and Prevention (CDC) with $8.3 billion through fiscal year 2021 and to establish funding to increase awareness, education, and surveillance of lymphatic diseases. The CDC's National Center for Chronic Disease Prevention and Public Health Promotion has programs dedicated to improving surveillance, physician education, and public awareness for several chronic diseases. We encourage the Subcommittee to establish a $5,000,000 merit-based programmatic activity in this area that will allow CDC to work with stakeholder organizations to expand important initiatives on chronic diseases such as lymphedema and lymphatic diseases. Formal study of the lymphatic system and of lymphatic diseases is virtually nonexistent in the current curricula of U.S. medical schools, and misinformation routinely leads to misdiagnosis and under-treatment. This delay and misdirection of treatment results in irreparable physical and psychosocial harm to patients suffering from these already debilitating diseases. CDC can help to address this lack of public and provider awareness.

Thank you for the opportunity to testify before you today. LE&RN looks forward to working with you all to advance medical research and public health activities that will improve patient outcomes for the members of our community suffering from these debilitating diseases.

[This statement was submitted by William Repicci, President and CEO, Lymphatic Education & Research Network.]

PREPARED STATEMENT OF MARCH OF DIMES



MARCH OF DIMES: FISCAL YEAR 2021 FEDERAL FUNDING PRIORITIES

PROGRAM	FISCAL YEAR 2021 REQUEST
National Institutes of Health (total)	**$44,700,000,000**
National Institute of Child Health and Development	$1,600,000,000
National Institute of Environmental Health Sciences	$860,300,000
National Children's Study Alternative (ECHO)	$180,000,000
Centers for Disease Control and Prevention (total)	**$8,300,000,000**
National Center for Birth Defects and Developmental Disabilities	$168,500,000
Emerging Threats to Moms and Babies	$10,478,000
Birth Defects Research and Surveillance	$20,000,000
Folic Acid Campaign	$3,300,000
NAS	$2,357,000
Section 317 Immunization Program	$710,000,000
Newborn Screening Quality Assurance Program	$29,650,000
Polio Eradication	$176,000,000
Safe Motherhood Initiative	$76,000,000
Preterm Birth	$2,000,000
Maternal Mortality Review Committees	$30,000,000
Office on Smoking and Health	$310,000,000
National Center for Health Statistics	$189,000,000
Health Resources and Services Administration (total)	**$8,800,000,000**
Title V Maternal and Child Health Block Grant	$715,000,000
Heritable Disorders	$31,000,000
Healthy Start	$125,500,000
Grants for Maternal Depression Screening and Treatment	$8,000,000
Title X Family Planning Program	$400,000,000
Office of the Secretary Health - Teen Pregnancy Prevention	**$110,000,000**
Agency for Healthcare Research and Quality (total)	**$471,000,000**

March of Dimes, the nation's leading nonprofit organization fighting for the health of all moms and babies, appreciates this opportunity to submit testimony for the record on fiscal year 2021 appropriations for the Department of Health and Human Services (HHS). March of Dimes leads the fight for the health of all mothers and infants through our research, community services, education, and advocacy. Our organization recommends the aforementioned funding levels for programs and initiatives that are essential investments in maternal and child health.

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD): March of Dimes recommends that Congress provide at least $1.6 billion for NICHD's groundbreaking biomedical research activities in fiscal year 2021. Increased funding will allow NICHD to sustain vital research on preterm birth, maternal mortality, maternal substance use, prenatal substance exposure and related issues through extramural grants, Maternal-Fetal Medicine Units, the Neonatal Research Network and the intramural research program. It will also ensure that NICHD can continue research on the impact of the 2019 novel coronavirus and coronavirus disease 2019 (COVID–19) on pregnant women, new mothers, and infants. March of Dimes is strongly supportive of NICHD's efforts to expand research identifying safe and effective therapies for pregnant and lactating women. The Task Force on Research Specific to Pregnant and Lactating Women (PRGLAC) laid the foundation for this important work by releasing recommendations in September 2018 as mandated by Congress in the 21st Century Cures Act (Public Law 114–255). March of Dimes is encouraged by PRGLAC's current work to develop an implementation plan for those recommendations. NICHD funding also supports research to address gaps in our understanding of the best way to treat mothers with opioid use disorder and the long-term impact of opioid exposure in utero. March of Dimes was pleased the President's fiscal year 2021 budget request included $50 million specifically for research to improve outcomes for infants born too soon or born with dangerous health conditions. We support the inclusion of this dedicated funding to address the nation's preterm birth crisis.

Title V Maternal and Child Health Block Grant Program: March of Dimes recommends funding the Title V Maternal and Child Health Block Grant Program (Title V Block Grant) at $715 million. States, territories and other jurisdictions use Title V Block Grant funds to support their most pressing maternal and child health needs. This increase in funding can be used to intensify state efforts to prevent maternal deaths and severe maternal morbidity, including supporting maternal mortality review committees, implementing the Alliance for Innovation on Maternal Health program, and continuing State Maternal Health Innovation Grants. We urge the Committee to increase funding for the Title V Block Grant in fiscal year 2021 to allow states to address maternal mortality while maintaining and expanding its work to improve maternal and child health across the nation and confronting emerging issues, such as COVID–19.

Safe Motherhood Initiative: The mission of the Safe Motherhood Initiative at the CDC's National Center for Chronic Disease Prevention and Health Promotion is to promote optimal reproductive and infant health. March of Dimes recommends funding of $76 million for the Safe Motherhood program, an increase of $18 million over fiscal year 2020. The increase would be used to scale CDC's efforts to address the nation's alarming number of maternal deaths by supporting state-based maternal mortality review committees in all 50 states. March of Dimes also strongly urges maintenance of the preterm birth sub-line at $2 million, as authorized in the PREEMIE Reauthorization Act of 2018 (Public Law 115–328), to maintain ongoing and essential preterm birth research at CDC.

National Center on Birth Defects and Developmental Disabilities (NCBDDD): NCBDDD is the lead Federal agency tasked with supporting vital surveillance, research, and prevention activities on birth defects and developmental disabilities. For fiscal year 2021, March of Dimes urges the Committee to provide at least $168.5 million for NCBDDD and apply this increase across the full range of NCBDDD activities. This increase aligns with March of Dimes' request to increase funding for the CDC by 22 percent by fiscal year 2022. We also urge the Committee to continue support for two new NCBDDD activities funded in fiscal year 2020, the Surveillance for Emerging Threats to Mothers and Babies Initiative and work to improve neonatal abstinence syndrome (NAS) surveillance. The Emerging Threats Initiative enables select states and jurisdictions to continue important work begun during the Zika virus response to identify and address new threats to mothers and infants. Currently, NCBDDD is working to utilize this infrastructure to monitor the impact of COVID–19 on moms and babies. NCBDDD's efforts to improve NAS surveillance are vital to addressing the opioid epidemic's short- and long-term impact on infants.

Newborn Screening: March of Dimes urges funding of $29.7 million for CDC's Newborn Screening Quality Assurance Program (NSQAP) and $31 million for the Health Resources and Services Administration's (HRSA) Heritable Disorders program, which play critical roles in assisting states in the adoption of additional screenings, educating providers and consumers, and ensuring coordinated follow-up care. These amounts are equal to the authorized levels in the Newborn Screening Save Lives Reauthorization Act of 2019 (H.R. 2507), which unanimously passed the U.S. House of Representatives in July 2019. HRSA's Heritable Disorders program also supports the work of the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC), which provides recommendations to the HHS Secretary for conditions to be included in the Recommended Uniform Screening Panel (RUSP). In recent years, the ACHDNC has added four new conditions to the RUSP, bringing the total number of recommended screens to 35. New funding for NSQAP and the Heritable Disorders program is crucial to ensure states have adequate funds and support to implement screening for these new additions to the RUSP.

Grants for Maternal Depression Screening and Treatment: Research shows that up to one in seven pregnant women or new mothers experience some sort of maternity-related depression, yet only about 15 percent of those affected receive treatment. The 21st Century Cures Act sought to address this gap by authorizing grants to states to improve screening for and treatment of maternal depression in pregnant and postpartum women. March of Dimes appreciates that Congress provided funding for this innovative grant program in fiscal year 2020 and urges the Committee to provide $8 million for the programs in fiscal year 2021.

Funding to Promote Optimal Birth Spacing and Improved Birth Outcomes: Research shows that appropriate birth spacing—waiting at least 18 months between pregnancies—can dramatically reduce the risk of poor birth outcomes. Additionally, we know that the youngest mothers have some of the worst birth outcomes. We can mitigate these risk factors by ensuring women have access to evidence-based counseling and education prior to pregnancy and access to all forms of contraception approved by the Food and Drug Administration. To support these important goals, March of Dimes recommends funding of $400 million for Title X Family Planning Program and $110 million for the Teen Pregnancy Prevention Program administered by the Office of the Assistant Secretary for Health.

Conclusion: March of Dimes looks forward to working with appropriators and all Members of Congress to secure the resources needed to improve our nation's health. Federal public health programs are essential to preventing preterm birth, ending preventable maternal deaths, and addressing the opioid epidemic's impact on mother, infants and families.

[This statement was submitted by Ariel González, Esq., Senior Vice President of Public Policy and Government Affairs, March of Dimes.]

PREPARED STATEMENT OF THE MARFAN FOUNDATION

THE FOUNDATION'S FISCAL YEAR 2021 L–HHS APPROPRIATIONS RECOMMENDATIONS

- —At least $44.7 billion in program level funding for the National Institutes of Health (NIH).
  - —Proportional funding increase for NIH's National Heart, Lung, and Blood Institute (NHLBI); National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS); National Eye Institute (NEI); and National Center for Advancing Translational Sciences (NCATS).

Chairman Blunt and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the heritable connective tissue disorder and aortic aneurysm syndrome community as you work to craft the fiscal year 2021 L–HHS Appropriations Bill.

About The Marfan Foundation

The Marfan Foundation's mission is to save lives and improve the quality of life of individuals with Marfan syndrome and other genetic aortic/vascular conditions.

- —We pursue the most innovative research and make sure that it receives proper funding.
- —We create an informed public and educated patient community to increase early diagnosis and ensure life-saving treatment.
- —We provide relentless support to families, caregivers, and healthcare providers.

The Foundation will not rest until we've achieved victory—a world in which everyone with these conditions receives a proper diagnosis, gets the necessary treatment, and lives a long and full life.

About The VEDS Movement

The mission of The VEDS Movement is to save lives and improve the quality of life of individuals with Vascular Ehlers-Danlos Syndrome (VEDS). By pursuing the most innovative research, educating the medical community, general public and affected individuals, and providing support to patients, families, and caregivers, we can charge forward and improve the outcomes for those living with VEDS.

About Genetic Aortic Aneurysm/Vascular Conditions

Connective tissue is found throughout the body. Consequently, heritable connective tissue conditions, like Marfan syndrome, Vascular Ehlers Danlos syndrome (VEDS), Loeys-Dietz syndrome, and familial aortic aneurysm syndrome, can affect many different parts of the body. Features of the conditions are most often found in the heart, blood vessels, bones, joints, lungs, eyes and intestines. All of these conditions are genetic conditions that have one common feature: the aorta (the main blood vessel that carries blood from the heart to the rest of the body) is prone to enlarge or rupture, a life-threatening problem that requires appropriate and timely medical intervention. In addition, people with Vascular Ehlers Danlos and Loeys-Dietz Syndrome are at high risk for ruptured arteries or organs throughout the body.

CENTERS FOR DISEASE CONTROL AND PREVENTION

People with heritable connective tissue disorders are born with them but features of the conditions are not always present right away. Some people have a lot of features at birth or as young children—including serious conditions like aortic enlargement. Others have fewer features when they are young and don't develop aortic enlargement or other signs of Marfan syndrome, vascular Ehlers Danlos, or Loeys-Dietz syndrome until they are young adults. Some features of these syndromes, like those affecting the heart and blood vessels, bones or joints, get worse over time. This makes it very important for people with such conditions to receive accurate, early diagnosis and treatment. Without it, they can be at risk for potentially life-threatening complications that could lead to a sudden early death. The earlier some treatments are started, the better the outcomes are likely to be. We are asking Congress to provide the Centers for Disease Control and Prevention (CDC) with $8.3 billion through fiscal year 2021 and to establish funding to increase awareness, education, and surveillance of connective tissue disorders. The CDC's National Center for Chronic Disease Prevention and Public Health Promotion has programs dedicated to improving surveillance, physician education, and public awareness for several chronic diseases. We encourage the Subcommittee to establish a $5,000,000 merit-based programmatic activity in this area that will allow CDC to work with stakeholder organizations to expand important initiatives on chronic diseases such as heritable connective tissue conditions, like Marfan syndrome, Vascular Ehlers Danlos syndrome (VEDS), Loeys-Dietz syndrome, and familial aortic aneurysm syndrome.

NATIONAL INSTITUTES OF HEALTH

NIH, specifically NIAMS and NHLBI, have worked closely with the Foundation to investigate the mechanisms of these conditions. In recent decades, this research has yielded significant scientific breakthroughs that have the potential to improve the lives of affected individuals. In order to ensure that the heritable connective tissue disorders research portfolios can continue to expand and advance, NIH requires meaningful funding increases to invest in emerging and promising activities.

PATIENT PERSPECTIVE

David Bowen was 13½ years old in February 1996 when he suddenly suffered a perforation of the sigmoid colon, which required a colostomy. His surgeon could not identify a cause and suspected David's parents of child abuse, despite David denying anything untoward. A full investigation was launched which removed that suspicion. Not one of his physicians ever considered the need to consult a geneticist. Instead, they led the family to believe that David was healthy and there was no reason to worry. While recovering he had other unusual symptoms, which should've sparked more investigation, but he was released from the hospital in early March. While at home slowly healing, all he wanted for his 14th Birthday was to roller blade around his driveway. In June, he had surgery to reverse the colostomy. It was filled with complications; fever, pain, vomiting, elevated blood pressure, and more bowel problems, but the doctors did not think they were serious and said it would take time. But David's condition worsened. The doctors and nurses were still not alarmed and did not consult a geneticist. David continued to go downhill and, by evening he collapsed in his mother's arms. His parents quickly arranged for a helicopter transport to a major trauma center. By the time he got there, he was in septic shock, bleeding, with infection throughout his body. He had surgery in the morning—the large colon was wide reopen, four perforations of the small bowel, abscesses, and blood clots. There were new complications over the next 10 days and, despite a valiant fight, David died on July 8, 1996.

For David, the diagnosis came too late to save him. Tragically, in 2020, this same story still continues to replay over and over due to the lack of medical knowledge of VEDS, including in the hospital emergency departments. People with VEDS rely on a handful of specialists to be available to their local doctors, especially in the case of emergency. In fact, 80 percent of people with VEDS have a major complication by the age of 40. And, the median life expectancy is 51 years. Education and awareness is needed. It's truly a matter of life and death.

[This statement was submitted by Michael Weamer, President and CEO, The Marfan Foundation.]

PREPARED STATEMENT OF MATTHEW SAVAGE OF VIRGINIA

Dear Chairman Blunt, Ranking Member Murray and distinguished members of the Subcommittee:

I write to you concerning the budget request of the Department of Education for fiscal year 2021. I write in opposition to Secretary Devos and President Trump's continuous budget cuts and request for consolidation of many of the grant programs the Congress has worked to build, beginning in 1965.

In a time of national emergency, when our school districts are being asked to cut costs in order to make up for a loss of revenue, when teachers are being laid off, and when our lower-income students who may not have access to a computer, high-speed Internet, or lunch outside of school are most at risk of falling behind in their educational careers, many Americans will find it difficult, as I do, to accept a tiny handful of billionaires proposing cuts to funding for our most vulnerable students.

We must fully understand the full implications of what Secretary Devos is really proposing in regards to the Elementary and Secondary Education for the Disadvantaged (ESED) block grant. Secretary Devos calls it putting students first; but in reality, this is nothing more than a tool for the richest of the rich to consolidate the power and the money that the Congress appropriates for the disadvantaged youth.

The justification for the ESED consolidation of these grant programs is that it allows the states and school districts to assert more control over the money they receive from the Federal Government. But the facts are that this consolidation proposal would not accomplish that goal. The facts are that consolidation of formula grants leads to more, not less, Federal power; and that power would be possessed by an even smaller group of people. This proposal would merely undermine the Congressional 'power of the purse' by allowing one individual to decide the fate of nearly twenty billion dollars of Federal funds. This proposal would allow states and individual school districts to use Federal money however they wish, without any substantive Federal regulation or Federal oversight.

Each of the almost 30 grant programs Secretary Devos proposes consolidating serve a different purpose. The largest is the Title 1 grant program to support schools with a large number of low-income residents, but they vary from support for migrant education, the homeless, the rural school population, English learners and neglected and delinquent children; and those are the students who are going to be impacted the worst if this ESED consolidation proposal is adopted. All of these grant programs serve a different purpose, and thus each must be apportioned with a different formula and governed by different Federal regulations and reporting requirements. Contrary to what Secretary Devos may believe, there is no one size fits all formula. As with the needs of every student, the needs of each individual school are completely different. And now as ever, we need the Department of Education's budget to recognize the unique needs of each classroom.

I am deeply concerned, further, that the ESED consolidation program would allow states to divert more and more into charter schools while the educational needs of the vast majority of students go unmet.

With warm regards.

PREPARED STATEMENT OF LINDA MAYO

Schizophrenia and bipolar disorder are among the most serious psychiatric disorders and play a disproportionate role among individuals who end up homeless, incarcerated, and who commit suicide. The cost of schizophrenia alone in the U.S. was estimated to be $155.7 billion [1].

As the mother of adult twin daughters, this issue is very personal. Both girls have been living with schizophrenia and bipolar schizo-affective disorders since their early twenties. Initially diagnosed and treated they lived independent and productive lives for over 10 years; working, going to college, socializing, dating, etc.

Over that time period they were in wellness treatment programs and taking meds. But a couple of times, their bodies developed a tolerance for the medication and they had to go through med changes to stabilize them once again. We are fortunate that substance abuse has never been an issue to deal with in their treatment. But there are those who choose to self-medicate with illegal drugs in order to drum out the voices in their heads.

Ten years ago, still in treatment and taking their medication, they began to spiral down. In today's mental health system the intervention they needed to prevent total decompensation is not permitted. They both decompensated to the point they were completely psychotic and one of them became homeless. Examples of their condition? One went to a house in which we had once lived in 20 years ago, pounded on the door screaming obscenities telling these people to get out of her "Fn**" house. The other believed she had transmitters under her skin and thought electricity was going through her body to the point she was pulling out electrical outlets and cutting electrical cords. I could cite many, many more similar and worse examples but I will move on.

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[1] Cloutier M, Aigbogun MS, Guerin A, et al. The economic burden of schizophrenia in the United States in 2013. J Clin Psychiatry. 2016;77:764–771.

Both eventually got into intensive treatment programs through the criminal justice system. One currently lives in a board and care facility and receives intensive treatment services and medication. The other lives in a subsidized apartment and receives intensive treatment services and medication. The kicker here is, even while being treated and medicated, they continue to battle the symptoms of their illness each and every day. My one daughter is now on Clozaril.

Today, Clozaril is the final medication that can keep her from falling into the abyss of total insanity. There are no other anti-psychotic medications for her to try. As a mother, I am terrified of the time when her body no longer responds to the medication.

I am begging you to do everything you can to support extensive research into more and better treatment options and a cure for my daughters and all those who share a similar story. I am not alone in this battle. PLEASE HELP US! Since 2006 Congress has been very generous by increasing NIMH budget by 35 percent, while at the same time, NIMH has reduced its support for drug treatment trials/research for cures by 96 percent.

I hope I have helped you understand the gravity of the situation for many who live with a serious mental illness. We are desperate for new medications. We are desperate for a cure. Please direct the NIMH to use the resources to save our loved ones lives and give them a chance to again live safe, productive, and happy lives.

Thanks for giving me the opportunity to express my fears and hope for resources to advance the research for our most vulnerable in our society today.

PREPARED STATEMENT OF AMY J. MCCLELLAN

I am the mother of two young adult daughters who live with serious mental illnesses—bipolar disorder and major depressive disorder (that has not responded to current treatments). Their lives were turned upside down with the onset of their mental illness in adolescence and profoundly affected our entire family. I still lay awake many nights praying that my daughter with treatment-resistant depression makes it through another day.

I also co-founded and am the board president of a mental health Clubhouse in Miami, which serves very low-income adults living with serious mental illness. Many of our members have told me their stories of homelessness, desperation and difficulty finding good treatment.

The National Institute of Mental Health (NIMH) is the main Federal Government agency for research into mental illness. The NIMH was authorized through the passage of the National Mental Health Act in 1946 to better help individuals with mental health disorders through better diagnosis and treatments. With a budget of almost $2 billion in 2020, the NIMH conducts research and funds outside investigators to better understand mental illness and develop new treatments to reduce the burden these disorders have on individuals.

I beg you to have NIMH prioritize research for the 5 percent of our population that has serious mental illnesses that include chronic depression (the leading cause of disability in the U.S.), schizophrenia (and schizoaffective disorder), and bipolar illness. This makes sense because it's the humane thing to do, but it also makes good fiscal smarts. The most severe mental illnesses account for the most dollars spent in hospitals, jails, prisons, emergency rooms, and services for the homeless. There hasn't been a new treatment for schizophrenia for decades, yet this illness alone destroys millions of lives each year and fills our streets and jails with people with untreated mental illness.

Dr. E. Fuller Torrey wrote in Psychiatric Times earlier this month:

> "Congress awarded the National Institute of Mental Health an additional $98 million as part of the National Institutes of Health budget resolution in December 2019, which brings the NIMH budget to just under $2 billion and represents a 35 percent increase since 2015, one of the largest increases in the history of the NIMH. Yet, during the 5 years from 2015 through 2019, NIMH funded a total of TWO new drug treatment trials for schizophrenia and bipolar disorder, according to clinicaltrials.gov. This contrasts with the 5-year period from 2006 through 2010 when NIMH funded 48 such trials . . ."

In December 2019, the NIMH released a draft of their five-year strategic plan for public comment. They reported receiving more than 6,000 responses identifying examples of research initiatives the NIMH could be pursuing today to help people with serious mental illness recover and live better lives. Despite this robust response, NIMH made no substantive changes to the research goals or objectives in the final version released to the public earlier this week.

The NIMH research goals for 2020–2025 heighten the existing imbalance in NIMH research. In doing so, they offer little hope for new or better treatments for individuals who are currently afflicted with a mental illness during their lifetime, especially a serious mental illness. This failure is inexcusable given the large increase in research funding given to NIMH in recent years.

Future NIMH funding must be used to correct the existing imbalance, not worsen it, especially now that the COVID–19 pandemic has upended the mental health treatment system and will likely result in an exacerbation of symptoms in people currently affected and an increase in serious mental illnesses among Americans. Those with the most severe forms of mental illness deserve to be prioritized.

Sincerely.

PREPARED STATEMENT OF MEALS ON WHEELS AMERICA

Dear Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee:

Thank you for the opportunity to submit testimony concerning fiscal year 2021 appropriations for the Older Americans Act (OAA) Nutrition Program, administered by the Department of Health and Human Services' (HHS) Administration for Community Living (ACL). On behalf of Meals on Wheels America, the national network of community-based senior nutrition providers and the individuals they serve, we are grateful for your enduring support for the program, particularly in response to the coronavirus (COVID–19) crisis in recent months. Despite crucial investments in annual appropriations and emergency supplemental funding, senior nutrition programs across the country face great challenges, existing prior to COVID–19, in addressing the growing demand for services with insufficient resources. Since the onset of the current national emergency, local Meals on Wheels programs have been responding on the front lines to deliver essential nutrition assistance to older Americans in need and are experiencing a dramatic increase in requests for meals, soaring costs and other unfamiliar challenges as they adjust their operations amid the pandemic. For this reason, we request a total of $1,028,753,000 for the OAA Nutrition Program—Congregate Nutrition Services, Home-Delivered Nutrition Services, and Nutrition Services Incentive Program (NSIP)—in fiscal year 2021. As older adults will most likely need to continue to stay at home and practice social distancing through the new fiscal year, our specific appropriations requests are:

—$510,342,000 for Congregate Nutrition Services (Title III C–1)
—$336,342,000 for Home-Delivered Nutrition Services (Title III C–2)
—$182,069,000 for Nutrition Services Incentive Program (Title III)

This fiscal year 2021 ask represents a $70,000,000 increase for Home-Delivered Nutrition Services and a $22,000,000 increase for Nutrition Services Incentive Program, both of which are necessary to meet the growing need for vital nutrition assistance and social connection to seniors, who remain among those at greatest risk of contracting and experiencing complications due to COVID–19. In total, this is a $92 million (10 percent) increase above fiscal year 2020-enacted funding levels and reflective of the total amount authorized for the OAA Nutrition Program in fiscal year 2021 by the Supporting Older Americans Act of 2020 (Public Law 116–131)—bipartisan legislation to reauthorize the OAA and its programs through fiscal year 2024. As our country strives to respond, recover and rebuild from this health and economic crisis, these nutrition programs and the services they provide must be continue to exist and expand because they are a lifeline for millions of our nation's most vulnerable.

The OAA Nutrition Program (i.e., Meals on Wheels) provides nutritious meals, opportunities for socialization and safety checks to adults age 60 and older—either in a group setting or directly in the home—and has been at the forefront of addressing senior hunger and isolation for nearly fifty years. Overseen by ACL's Administration on Aging (AoA) and implemented at the local level through more than 5,000 community-based providers, the services offered through the program are effective in promoting the health, independence and quality of life of seniors.

However, despite broad support from the public, policymakers and seniors themselves, the OAA Nutrition Program remains underfunded year after year and has experienced diminished growth and reach during a time when the country's older adult population is expanding. Due to COVID–19, older adults are now also facing an unprecedented threat to their health, autonomy and financial well-being. In a recent survey, four out of five Meals on Wheels programs reported demand for services had at least doubled since March 1, 2020.[1] Accordingly, additional Federal funding and flexibilities for utilizing OAA dollars are needed for senior nutrition providers to adequately adapt and scale operations to meet the rapidly growing and evolving needs of the communities they serve.

INSUFFICIENT FEDERAL FUNDING THREATENS A GROWING NUMBER OF SENIORS

With approximately 12,000 individuals turning 60 every day, the senior population is becoming increasingly endangered by hunger and isolation. Nationally, 9.5 million seniors are threatened by hunger (i.e., marginally food insecure)—and one in 13 individuals (7.7 percent) age 60 and older are food insecure or very low food secure.[2] Social isolation—which has been amplified throughout the current pandemic amid safety and social distancing measures—is another threat for the nearly 17.5 million (24 percent) seniors living alone, with one in five older adults reporting frequent feelings of loneliness prior to COVID–19.[3,4] Most older Americans possess at least one trait that puts them at increased risk of experiencing food insecurity, malnutrition, social isolation and/or loneliness, thereby increasing the likelihood of experiencing myriad negative and consequential health effects. Despite the wide recognition of the relationship between healthy aging and access to nutritious food and regular socialization, millions of seniors struggle to meet these basic human needs.

While the OAA Nutrition Program plays a pivotal role in addressing the growing issues of senior hunger and isolation, Federal funding for the program has not kept pace with demographic shifts or inflation, leaving a huge gap between seniors served and those who are in need of services but are not receiving them. Nationally, the OAA Nutrition Program network served 20 million fewer meals in 2018 than in 2005—a decline of more than 8 percent—despite the 60 and older population increasing over 45 percent in that same period.[5] Further underscoring the need for more funding, a 2015 Government Accountability Office study estimated that 83 percent of low-income, food insecure seniors do not receive the congregate or home-delivered meals that they likely need.[6]

Prior to the COVID–19 pandemic, nearly half of all Meals on Wheels America members representing every state and the District of Columbia reported maintaining an active waiting list due to insufficient resources to meet the need for services in their communities.[7] That sobering reality is even worse now, as revealed in a recent survey commissioned by Meals on Wheels America and conducted by Trailblazer Research, with over half of Meals on Wheels programs surveyed reporting that their existing waiting lists have grown by 26 percent, with 22 percent of them stating that their waiting lists have at least doubled. Furthermore, the survey results indicated that new requests for Meals on Wheels services have increased for nearly all programs, and as a result programs are serving 56 percent more meals and 22 percent more seniors each week since March 1 when concerns of COVID–19 and efforts to employ social distancing began.[1] The emergency funding provided in the Families First Coronavirus Response Act (FFCRA) and the Coronavirus Aid, Relief and Economic Security (CARES) Act provided a critical boost in resources to assist OAA nutrition programs in response to the need and demand for additional meals from both pre-existing and new clients as a result of the pandemic. While this emergency action was necessary, additional appropriations will be needed this coming fiscal year for the senior nutrition network, as well. As the country continues to combat the severe upsurge in food insecurity during this time of economic hard-

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[1] Meals on Wheels America. Survey of Meals on Wheels America Membership conducted by Trailblazer Research between April 22–28, 2020, https://www.mealsonwheelsamerica.org/learn-more/national/press-room/news/2020/05/07/new-survey-data-demand-on-meals-on-wheels-national-network-swells-and-wait-lists-grow-due-to-covid-19-pandemic.

[2] Ziliak & Gunderson. The State of Senior Hunger in America 2017, a report prepared for Feeding America, 2019, https://www.feedingamerica.org/sites/default/files/2019–05/state-of-senior-hunger-2017_full-report.pdf.

[3] U.S. Census Bureau, American Community Survey (ACS) Demographic Data, 2018, available on the Administration for Community Living's (ACL) Aging, Independence, and Disability Program Data Portal (AGID), https://agid.acl.gov/.

[4] Hawkley, Kozloski & Wong. A Profile of Social Connectedness in Older Adults, report prepared for AARP Foundation by Academic Research Centers, NORC at the University of Chicago, 2017, https://connect2affect.org/wp-content/uploads/2017/03/A-Profile-of-Social-Connectedness.pdf.

[5] ACL, Administration on Aging (AoA). State Program Report (SPR) 2005–2018, available on AGID, https://agid.acl.gov/.

[6] U.S. Government Accountability Office (GAO), Older Americans Act: Updated Information on Unmet Need for Services, June 2015, https://www.gao.gov/products/GAO-15-601R.

[7] Meals on Wheels America. The More Than a Meal Comprehensive Network Study, produced by Meals on Wheels America and conducted by Trailblazer Research (public report in publication), 2019.

ship, there are likely far more seniors that are currently in need of, but still not receiving, these critical nutrition and social services.

SERVING THOSE WITH THE GREATEST SOCIAL AND ECONOMIC NEED

The OAA exists to support seniors in the greatest social and economic need, and as such, effectively targets services and stretches limited financial resources accordingly. In 2018, the latest year for which data is available, the OAA Nutrition Program provided over 73 million congregate meals and 147 million home-delivered meals to 2.4 million seniors.[5] While impressive, it is still leaving too many in need behind. Further, for many program participants, the volunteer or staff member who delivers meals to their homes or serves them when it's safe for congregate dining facilities to be open, may be the only individual(s) she or he sees that day, and the meal may account for the majority of her or his daily food intake.

The profile of home-delivered meal clients reveals the high degree of vulnerability among recipients, with the majority being age 75 or older, female, living alone and/or having three or more chronic conditions. Among participants: 35 percent live at or below the poverty level; 25 percent live in rural areas; 15 percent are veterans; and 28 percent are a racial and/or ethnic minority.[8] Fortunately, the vital services financed by the OAA Nutrition Program enable seniors with these risk factors to remain safer, healthier and less isolated in their own homes and communities.

The results of a 2015 study commissioned by Meals on Wheels America found that seniors who received daily home-delivered meals were more likely to report improvements in mental health, self-rated health and feelings of isolation and loneliness, as well as reduced rates of falls and decreased concerns about their ability to remain in their home.[9] Additional studies have found home-delivered meal program participants to experience less healthcare utilization and lower expenditures than the non-participant controls, suggesting the program's potential to reduce costs among patients with high-cost or complex healthcare needs and help them remain independent in their communities.[10] As public spending on healthcare rises each year—largely attributable to a rapidly growing senior population with complex health needs (which can only be expected to increase amid the ongoing COVID–19 crisis), it is imperative that we invest in these cost-effective programs that promote health and independence, and reduce costly healthcare utilization.

As a long-established and trusted community-based service, Meals on Wheels is also a successful public-private partnership that, for decades, has leveraged Federal OAA grants to offer nutrition and social services with the help of millions of volunteers, who provide innumerable in-kind contributions to support daily operations. Through the delivery of these services, the program produces concrete results and saves significant taxpayer dollars by reducing other costly healthcare expenditures and providing a far more cost-effective and desirable alternative to traditional long-term care options, often paid for by Medicare and Medicaid.

DELIVERING A STRONG RETURN ON INVESTMENT FOR OUR NATION

We understand the difficult decisions you face with respect to annual appropriations bills, efforts to mitigate the immediate impact of the global pandemic and recovery from this prolonged national emergency. Providing a $92 million (10 percent) increase for the OAA Nutrition Program is a proven and efficient use of taxpayer dollars and critically needed at this time to ensure adequate resources are available to meet the nutritional and social needs of our nation's most frail seniors.

As the Subcommittee develops its fiscal year 2021 Labor-HHS-Education appropriation bill, we request you provide $1,028,753,000 for the OAA Nutrition Program so that local community-based Meals on Wheels programs can continue serving and safeguarding a growing number of seniors in need. As mentioned earlier, this funding level reflects the total provided by the Supporting Older Americans Act of 2020, which reauthorizes the OAA for 5 years and was signed into law in March 2020 after being passed unanimously, and is further evidence of the broad and bipartisan backing for this robust funding in Congress. Thank you, again, for your leadership,

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[8] Mabli et al. Evaluation of the Effect of the Older Americans Act Title III–C Nutrition Services Program on Participants' Food Security, Socialization, and Diet Quality, Mathematica Policy Research report prepared for ACL, April 2017, https://acl.gov/sites/default/files/programs/2017-07/AoA__outcomesevaluation__final.pdf.

[9] Thomas & Dosa. More Than a Meal Pilot Research Study, report commissioned by Meals on Wheels America, 2015, https://www.mealsonwheelsamerica.org/docs/default-source/News-Assets/mtam-full-report__march-2-2015.pdf?sfvrsn=6.

[10] Berkowitz et al. Meal Delivery Programs Reduce the Use of Costly Health Care in Dually Eligible Medicare and Medicaid Beneficiaries. Health Affairs (Vol. 37(4): 535–542; 2018), https://www.healthaffairs.org/doi/10.1377/hlthaff.2017.0999.

support and consideration. We are pleased to offer our assistance to you and your staff at any time throughout the appropriations process.

[This statement was submitted by Ellie Hollander, President and CEO, Meals on Wheels America.]

PREPARED STATEMENT OF THE MEDICAL LIBRARY ASSOCIATION AND ASSOCIATION OF ACADEMIC HEALTH SCIENCES LIBRARIES

I, Mary M. Langman, Director, Information Issues and Policy, Medical Library Association (MLA), submit this statement on behalf of MLA and the Association of Academic Health Sciences Libraries (AAHSL). MLA is a global, nonprofit, educational organization with a membership of more than 400 institutions and 3,000 professionals in the health information field. AAHSL supports academic health sciences libraries and directors in advancing the patient care, research, education and community service missions of academic health centers through visionary executive leadership and expertise in health information, scholarly communication, and knowledge management.

We thank the Subcommittee for the opportunity to submit testimony supporting appropriations for the National Library of Medicine (NLM), an agency of the National Institutes of Health (NIH), and recommend $479.7 million for NLM in fiscal year 2021, a 5 percent ($22.7 million) increase.

Working in partnership with the NIH and other Federal agencies, NLM is the key link in the chain that translates biomedical research into practice, making the data and other results of research readily available to all who need it. NLM is taking on additional responsibilities for NIH-wide efforts in data science and open science. As health sciences librarians who use NLM's programs and services every day, we can attest that NLM resources literally save lives. Therefore, investing in NLM is an investment in good health. NLM addresses Congressional priorities through rapid deployment of resources related to health emergencies including response to the COVID–19 pandemic and the opioid crisis, by providing clinical trial information, genomic sequencing data, and public access to research literature.

Leveraging NIH Investments in Biomedical Research

NLM's budget supports information services, research, and programs that sustain the nation's biomedical research enterprise. In fiscal year 2020 and beyond, NLM's budget must continue to be augmented to support modernization and expansion of its information resources, services, research, and programs which collect, organize, and develop new ways to make readily accessible rapidly expanding biomedical knowledge resources and data. NLM maximizes the return on investment in research conducted by the NIH and other organizations. It makes the results of biomedical information accessible to researchers, clinicians, business innovators, students, and the public, enabling such data and information to be used more efficiently and effectively to drive innovation and improve health. Rapid growth of data also necessitates funding that will ensure long-term sustainability of these valuable information resources.

NLM plays a critical role in NIH's data science and open science initiatives. NLM leads the development, maintenance and dissemination of key standards for health data interchange that are now required of certified electronic health records (EHRs). NLM builds, sustains, and augments a suite of almost 300 databases which provide information access to health professionals, researchers, educators, and the public. It supports the acquisition, organization, preservation, and dissemination of the world's biomedical literature. In fiscal year 2019, NLM made genomic sequence data available in the cloud. NLM's Sequence Read Archive (SRA) is the world's largest publicly available repository of next-generation genome sequence data, with more than 9 million records comprising 25 petabytes of data. To improve access and utility of SRA data, NLM uploaded the public access SRA data to two commercial clouds that have agreements with NIH's Science and Technology Research Infrastructure for Discovery, Experimentation, and Sustainability (STRIDES) Initiative. This transition significantly expands the discovery potential of the data. Freed from the limitations of local storage and computational resources, users are empowered to compute across the full corpus of SRA data without having to download and store large volumes of data. Moving to cloud platforms also makes it possible to develop customized tools and methods for asking research questions of the data.

Growing Demand for NLM's Information Services

Each day, more than 6 million people use NLM websites and download 115 terabytes of data. Thousands of researchers and businesses submit 15 terabytes of data daily. Annually, NLM information systems process more than six billion human requests and eight billion computer-to-computer interactions. NLM's information services help researchers advance scientific discovery and accelerate its translation into new therapies; provide health practitioners with information that improves medical care and lowers its costs; and give the public access to resources and tools that promote wellness and disease prevention. Every day, medical librarians across the nation use NLM's services to assist clinicians, students, researchers, and the public in accessing information to save lives and improve health. Without NLM, our nation's medical libraries would be unable to provide quality information services that our nation's health professionals, educators, researchers and patients increasingly need.

NLM's data repositories and online integrated services such as GenBank, dbGaP, Genetics Home Reference (GHR), PubMed, and PubMed Central (PMC) are revolutionizing medicine and ushering in an era of personalized medicine. GenBank is the definitive source of gene sequence information. Each month, 2.1 million users accessed consumer-level information about genetics from GHR, which contains more than 2,700 summaries of genetic conditions, genes, gene families, and chromosomes. PubMed, with more than 30 million references to the biomedical literature, is the world's most heavily used source of bibliographic information with almost 1.35 million new citations added in fiscal year 2019 and approximately 2.5 million users each day. NLM also launched a new PubMed platform for an improved user experience, including a new search algorithm with relevance rankings and better tools for citations. PubMed Central is NLM's digital archive which provides public access to the full-text versions of more than 6.1 million biomedical journal articles, including those produced by NIH-funded researchers. On a typical weekday more than 2.5 million users download more than 2.8 million articles.

NLM continually expands biomedical information services to accommodate a growing volume of relevant data and information and enhances these services to support research and discovery. NLM ensures the availability of this information for future generations, making books, journals, technical reports, manuscripts, microfilms, photographs and images accessible to all Americans, irrespective of geography or ability to pay, and guaranteeing that citizens can make the best, most informed decisions about their healthcare.

Improving Public Access to federally Funded Research Results

The Department of Health and Human Services (DHHS) continues to work with NLM to ensure free public access to the results of taxpayer-funded research. HHS operating divisions, and ten other Federal agencies, use NLM's PubMed Central (PMC) as a common repository to provide access to peer-reviewed publications resulting from their research. In fiscal year 2019, NLM added 600,000 full-text articles to PMC and continued linking articles to associated data by aggregating data citations, data availability statements, and supplementary materials. Since featuring these data links more prominently, daily downloads of supplementary material have increased by 30 percent. A subset of about 3 million articles in PMC is available for bulk retrieval for text mining and other research purposes.

Disseminating Clinical Trial Information

ClinicalTrials.gov, the world's largest clinical trials registry, now includes more than 320,000 registered studies and summary results for more than 39,000 trials. As health sciences librarians who fulfill requests for information from clinicians, scientists, and patients, we applaud NIH and NLM for implementing requirements for clinical trials registration and results submission consistent with the FDA Amendments Act of 2007, and for applying them to all NIH-supported clinical trials. These efforts increase transparency of clinical trial results and provide patients and clinicians with information to guide healthcare decisions. They also ensure biomedical researchers have access to results that can inform future protocols and discoveries.

Partnerships Ensuring Outreach and Engagement in Communities Across the Nation

NLM's outreach programs are essential to the MLA and AAHSL membership and to the profession. Through the National Network of Libraries of Medicine (NNLM), with over 7,000 members nationwide as of fiscal year 2019, NLM educates medical librarians, health professionals, and the general public about its services and provides training in their effective use. The NNLM serves the public by promoting educational outreach for public libraries, secondary schools, senior centers and other consumer settings, and its outreach to underserved populations helps reduce health disparities. NLM's "Partners in Information Access" provides local public health officials with online information that protects public health.

Since May 2018, the NNLM has partnered with the NIH All of Us Research Program to support community engagement efforts by United States public libraries and to raise awareness about the program. To date, 376 libraries and 101 community-based organizations across 33 states and the District of Columbia have held 1,135 events with more than 40,000 people. Via the NNLM All of Us Community Engagement Network, 654 libraries support health literacy, including offering health and wellness programming in their communities. To support public library staff in providing health programming to the community, NNLM has also provided 491 classes, training, and workshops that have served 11,188 library staff.

NLM's MedlinePlus provides consumers with trusted, reliable health information on 1,000 topics in English and Spanish. It attracts more than 1 million visitors daily. NLM continues to enhance MedlinePlus and disseminate authoritative information via the website, a web service, and social media. MedlinePlus and MedlinePlus en Español have been optimized for easier use on mobile phones and tablets. NIH MedlinePlus Magazine and NIH MedlinePlus Salud are available in doctors' offices nationwide, and NLM's MedlinePlus Connect enables clinical care organizations to link from their EHR systems to relevant patient education materials.

Strengthening Data Science and Open Science Capacity

NLM is a leader in data science and open science, including the acquisition and analysis of data for discovery and the training of biomedical data scientists. The library aims to strengthen its position as a center of excellence for health data analytics and discovery, and to spearhead the application of advanced data science tools to biological, clinical and health data. NLM is building a workforce for data-driven research and health by funding PhD-level research training in biomedical informatics and data science. The library also partners with NIH to ensure inclusion of data science and open science core skills in all NIH training programs, and is expanding training for librarians, information science professionals, and other research facilitators. NLM is participating in NIH-wide efforts to foster a culture that advances science and ensures the development and retention of a diverse, safe, and respectful workforce for data-driven research and health well into the future.

Responding to the Novel Coronavirus (COVID–19)

The health sciences library community thanks Congress for providing NLM with the $10 million supplemental appropriations to prevent, prepare for, and respond to the Coronavirus. NLM has been responding to COVID–19's rapidly evolving situation through its suite of tools and deep well of expertise in managing large and complex datasets and making them accessible to the public. Our frontline healthcare providers use NLM's databases to access the latest research datasets, literature publications, and scientific information about COVID–19. For example, NLM is:

—Making immediately available to the public in PubMed Central tens of thousands of coronavirus-related research publication and data contributed by major publishers

—Contributing to the COVID–19 Open Research Dataset (CORD–19), which represents the most extensive machine-readable coronavirus literature collection available for text mining to date, with more than 30,000 full-text scholarly articles from PMC as of mid-May 2020. The Text REtrieval Conference (TREC)-COVID Challenge makes use of the CORD–19 dataset to help search engine developers evaluate and optimize their systems in meeting the needs of the research and healthcare communities.

—Providing the biomedical community free and easy access to genome sequences from the coronavirus through the GenBank sequence database.

—Providing information about US clinical trials related to COVID–19 via ClinicalTrials.gov, which is also now making available information about trials listed in the World Health Organization's international clinical trial registry.

—Extending standard terminologies to include terms related to COVID–19, including codes for laboratory tests, chemical entities, and indexing terms.

—Applying machine learning techniques to research conducted at NLM to assist in identifying COVID–19 in X-rays and to identify and categorize relevant published literature.

Supporting Biomedical Informatics Research and Health Information Technology Innovation

NLM conducts and supports informatics research, training and the application of advanced computing and informatics to biomedical research and healthcare delivery. NLM's National Center for Biotechnology Information (NCBI) focuses on genomics and biological data banks, and the Lister Hill National Center for Biomedical Communications (LHC), is a leader in clinical information analytics and standards. Many of today's biomedical informatics leaders are graduates of NLM-funded informatics research programs at universities nationwide. A number of the country's exemplary electronic and personal health record systems benefit from findings developed with NLM grant support. A leader in supporting the development, maintenance, and free, nationwide dissemination of standard clinical terminologies, NLM partners with the Office of the National Coordinator for Health Information Technology to support the interoperability of EHRs. NLM also develops tools to make it easier for EHR developers and users to implement accepted health data standards and link to relevant patient education materials. In fiscal year 2019, NLM played a critical role in the development, usage, and utility of a data exchange standard to improve flow and availability of data, the Health Level Seven International (HL7) Fast Healthcare Interoperability Resources (FHIR(r)). NIH is encouraging funded investigators to use the FHIR standard to capture, integrate, and exchange clinical data for research purposes and to enhance capabilities to share research data. NIH has also announced to the small business communities its special interest in supporting applications that use FHIR in the development of health IT products and services. To support these efforts, NLM is managing the development and testing of FHIR tools that researchers can use to increase the availability of high-quality, standardized research datasets and phenotypic information for genomic research and genomic medicine.

We look forward to continuing this dialogue and thank you for your efforts to support funding of at least $479.7 million for NLM in fiscal year 2021, with additional increases in future years.

PREPARED STATEMENT OF THE MENTAL ILLNESS POLICY ORG.

I am writing on behalf of our nationwide membership to urge you to focus NIMH on serious mental illnesses. We urge the committee to require NIMH to allocate a minimum of 33 percent of it's budget to finding better medications for schizophrenia, bipolar disorder and other serious mental illnesses and specifically to supporting treatment trials for those disorders.

The lack of cures and treatments—as a result of the lack of attention from NIMH—is causing the seriously mentally ill to suffer, communities to deteriorate, and is bloating costs for everyone.

As I documented in *Insane Consequences: How the Mental Health Industry Fails the Mentally Ill*, in spite of $140 billion in Federal spending, 392,000 seriously mentally ill are incarcerated, 755,000 are on probation or parole, 40,000 seriously mentally ill go homeless, downtowns are being turned into homeless camps, psychiatric hospitals are closing, law enforcement is becoming a more dangerous profession, and even educated and wealthy families can't get care for seriously mentally ill loved ones.

This is largely because non-profit mental health organizations and Federal mental health programs no longer focus on the seriously ill. Mission-creep runs rampant. They wrap worthy social services such as bad grades, divorce, angst about gender identity, unemployment, and most recently, totally appropriate anxiety about COVID–19 in mental health narrative and divert funds to them. The seriously ill are left to suffer.

No agency is a better example of this than NIMH. The NIMH research portfolio is a hodge-podge of basic research without any attempt to prioritize the research that is most likely to lead to a cure or treatment for serious mental illness. Circa 1980, my own mentally ill family member was in a NIMH-sponsored inpatient research program at the St. Elizabeth's Hospital. Those types of programs no longer exist. If they were brought back we might be able to find a treatment or cure that would avoid future tragedies like those that befell President Ronald Reagan, Rep. Gabrielle Giffords, Rep. Steve Scalise, two capital guards, multiple contractors at the Washington Navy Yard and many others who were injured by persons with serious mental illness who didn't believe existing treatments were worth using.

Please require NIMH to replace its mission-creep with mission control and prioritize research on treatments, cures and medication trials for serious mental illness. Thank you for all you do. Let me know how I can help or if you need more information.

Sincerely.

[This statement was submitted by DJ Jaffe, Executive Director, Mental Illness Policy Org.]

PREPARED STATEMENT OF METAVIVOR

FISCAL YEAR 2021 APPROPRIATIONS RECOMMENDATIONS

—Please provide the National Institutes of Health (NIH) with an increase of at least a $3 billion for fiscal year 2021 to bring total agency funding up to a minimum of $44.7 billion annually.

—Please continue to support additional investment for the cancer "moonshot" as outlined by the 21st Century Cures Act and otherwise ensure the National Cancer Institute (NCI) has adequate resources.

—Please continue to emphasize the importance of Federal research activities focused on controlling and eliminating cancer that has already disseminated (Metastatic Cancer) through committee recommendations and timely oversight of ongoing activities.

—Please support emerging efforts to modernize the Surveillance, Epidemiology, and End Results Research Program (SEER) Registry to better capture the experience of metastatic cancer patients (as outlined by recommendations within the fiscal year 2020 House LHHS Appropriations Bill).

Chairman Blunt, Ranking Member Murray, and distinguished members of the Subcommittee, thank you once again for considering the views of METAvivor and the stage IV metastatic cancer community as you work on fiscal year 2021 appropriations for medical research. The community is deeply grateful for the $2.6 billion funding increase provided to NIH in fiscal year 2020. Please maintain this commitment to supporting innovative medical research moving forward.

ABOUT METAVIVOR

What is my involvement? I am President of METAvivor, a patient-founded, volunteer-led, grassroots organization that funds vital research to increase longevity and quality of life for metastatic breast cancer patients. It is our sincerest hope that one day efforts such as ours, efforts we hope you will also support, promote and undertake, will one day make a difference for the more than 500,000 patients who die annually of a metastasized cancer in the U.S. alone. Our disease is defined by the spread of cancer from its original location to other vital organs in the body, such as the bones, lungs, liver or brain. At present, the disease is fatal for 98 percent of those diagnosed. METAvivor was founded in 2009 by four terminally ill, metastatic breast cancer patients because everyone around them was dying. One of our founders learned there were metastasis researchers that had many research concepts, however, there was very little funding for the research projects. METAvivor founders decided something had to be done and began raising research funds for metastatic breast cancer. Within 12 months of organizing, two founders had died, and not long after a third founder died. Many more people joined to advocate for additional metastatic cancer research funding and the community pressed ahead. Today, we have one living founder, Dian "CJ"Corneliussen, and she along with the growing community of patient advocates, continue to raise funding for metastatic cancer research.

Since METAvivor's founding in 2009, METAvivor has awarded 106 metastatic cancer research grants totaling $13.6 million despite sustaining the deaths of 15 Board members. The organization continues to grow, but there are limits to what we can achieve alone. We need more funding for stage IV metastatic cancer research. Far more funding is needed; far more interest is needed; and far more research must be accomplished. After 10 years of doing this alone, it is high time other organizations; especially the NCI which has a national responsibility for all American citizens; even the terminally ill, does right by our greater community and adds to its portfolio a program of respectable size that addresses the issue and funds the research that will ultimately, significantly extend life with quality and hopefully end death for the metastatic cancer community as a whole.

THE FACTS ABOUT METASTATIC STAGE IV CANCER

Roughly 600,000 Americans die annually from cancer. Ninety percent of these deaths are caused by a metastasis. If we wish to lower the death rate, we must tackle metastasis. For more than 20 years, the primary focus has been on preventing cancer altogether and if that fails, catching it early. But aside from convincing people to stop smoking, forbidding smoke in common areas and removing colon polyps prior to malignancy, little progress has been made. For most cancers, it is believed there are multiple causes, few if any of which are known, making prevention a formidable goal. Improved equipment has allowed some cancers to be diagnosed as early as stage 0; however, stage 0 patients are also metastasizing. And although we are slowly adding drugs to the treatment repertoire, a treatment's effectiveness often runs out in 2–3 months. Thus, we empty our toolbox of drugs far too quickly and we, metastatic patients, die. Saving lives is an achievable goal but tragically is not being realized because the focus continues to be prevent and early detect. Those goals have been maximized. Backs have been turned to the metastatic community long enough. It is high time to include metastasis as a major focus area..

MY STORY

My name is Beth Fairchild. In my former life, I was an artist, a mother, a wife, a daughter, a friend. Now, while I may still be all of these, I have added fearless fighter and breast cancer advocate to the list of things that make me, me. This is my new, cancer life. At 34, my life was pretty normal. My husband and I were successful business owners. We were raising our daughter and preparing to adopt another. I was happy in my personal life and career, I worked out daily and ate healthy. Then, there it was: cancer. After months of complaining of intestinal discomfort and lack of energy, my doctors discovered my ovaries were the size of grapefruits and in danger of rupture. They had to come out and, because I had a family history (my mom was diagnosed with breast cancer at 44 and my paternal grandmother was dead and buried at 33), I decided on a total hysterectomy. My surgery was the day after Mother's Day. Tissue samples were sent off to pathology, and two days later, I was told I had breast cancer. After my diagnosis, I came home to die. I was in agony from the pain of surgery and my head was spinning. I couldn't see past that moment in time. But it got better. Every. Day. My body healed. I got stronger. I endured 18 weeks of chemo and survived! I was a 34-year-old, post-menopausal, bald-headed, terminal cancer patient, but I was alive and LIVING. I set out to take back control of my life.

My children were my first motivation. I saw the fear in their eyes. Mommy couldn't assure them that things would be ok, but I could show them I wasn't going to give up. I talked candidly with them about my condition and treatment. I got up every morning and took them to school, even the days I didn't feel like it. I was a mom first, and they kept me going. My job kept me going. I'm an artist. I make tattoos. My husband and I have five studios and I have made my career in the tattoo industry. My specialty is permanent cosmetics and areola restoration for breast cancer patients. Ironic, huh? On the days I had to see my breast cancer clients, I knew what the procedure meant to them, so I would leave chemo and go straight to the studio and help a woman feel whole again. It was therapy to me. Then, I found support groups. I had wanted to talk to and be with other women like me. There were several groups available in my town in North Carolina; however, I was the youngest person there by at least 20 or 30 years. I'm in no way minimizing the severity of cancer in older patients, but it was hard to hear others speak about not seeing their grandkids grow into adults when I felt like I wouldn't even see my daughter graduate from high school. When I was diagnosed with stage IV breast cancer, I was in the prime of my life. Cancer is a daily struggle in any season of life, but the under-40 demographic has to not only juggle surgeries and treatments, but oftentimes careers, new marriages, or maybe dating. Many have young kids already, but some women will never experience childbirth because their ovaries are suppressed from hormonal treatments or, like me, have had them removed in order to slow the cancer's progress. Realizing the sacrifices of these men and women, as well as myself, made, the lack of awareness about metastatic cancer was disturbing. I thought my condition was rare, but, turns out, not so much. There are 600,000 people with metastatic cancer. There are 41,000 with metastatic breast cancer that die every year, that is about 113 per day. We must increase research funding for new treatments. We must make sure that families like mine have hope and that my two little girls know that we are working toward life extending treatments.

Through local events and social media, I have tried to help spread the under-reported message of metastatic breast cancer. I started a social media movement on Facebook called Stomp Out BC using the hashtag #dontignorestageiv created by METAvivor. I am now the Immediate Past President of METAvivor and work alongside others to raise funds for and draw attention to metastatic breast cancer until my dying breath. No one can say for sure when my time will be up, or even for certain that this "thief of life" we call cancer will be the cause, but short of a miracle—and I do still believe in miracles—I will die with this cancer in my body. In the interim, I hope the lives of the more than 600,000 people with stage IV metastatic cancer is considered when making decisions about the future of cancer research and especially funding the stage IV metastatic cancer research. METAvivor has worked hard to fund research. Since 2009, we have funded over $10 million but we need more...stage IV metastatic cancer needs more research.

[This statement was submitted by Beth Fairchild, Immediate Past President, METAvivor.]

PREPARED STATEMENT OF THE MICHAEL J. FOX FOUNDATION

The Michael J. Fox Foundation for Parkinson's Research (MJFF) appreciates the opportunity to comment on fiscal year 2021 appropriations for the U.S. Department of Health and Human Services. Our comments focus on the importance of Federal investment in biomedical research at the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC). MJFF supports at least $44.7 billion for the NIH, as well as the continued appropriation of $5 million to proceed with the pilot of the National Neurological Conditions Surveillance System at the CDC.

In providing more than $900 million in Parkinson's disease (PD) research funding since our founding in 2000, our Foundation has fundamentally altered the trajectory of progress toward a cure. However, MJFF investments are a complement to, rather than a substitute for, federally funded research. Robust and reliable Federal funding is imperative to drive progress. There are many potential Parkinson's breakthroughs on the horizon, which are critically needed by the millions living with this disease and the many more who will age into Parkinson's risk.

NATIONAL INSTITUTES OF HEALTH RESEARCH FURTHERS PROGRESS TOWARD NEW TREATMENTS

Parkinson's is a chronic, progressive neurological disorder affecting approximately one million people (including 110,000 veterans) in the United States. Every year, Parkinson's costs Americans $52 billion—$25 billion of which is paid for by the Federal Government in Medicare, Supplemental Security Income and Social Security Disability Insurance costs. Without intervention, the prevalence of Parkinson's is expected to more than double by 2040. The financial impact and rising prevalence can be mitigated through research to treat and cure PD.

Investing in NIH research on the front end to develop innovative therapies and cures can lower back-end costs to the Federal Government. Ninety percent of the Parkinson's population relies on Medicare for healthcare coverage, and up to one-third of people with PD are dual-eligible for Medicaid due to their income or disability status. New treatments would relieve the burden on Medicare, Medicaid and the Department of Veterans Affairs. Additionally, NIH funds research in all 50 states, and every dollar of funding generates two dollars in local economic growth. This is important for the economic strength and vitality of cities and towns across America.

We appreciate the committee's continued support of NIH through increases over the past several years. However, those increases only helped NIH funding begin to catch up with inflation, and many good studies remain unfunded. In 2018, NIH funded just under 20 percent of investigator-initiated grants, leaving an untold number of breakthroughs undiscovered. Patients and the medical community deserve stable and reliable funding growth that allows for research progress and supports innovative projects that drive cures. It is time to fund the NIH in a robust way that allows for the National Institute of Neurological Disorders and Stroke and the National Institute on Aging at NIH to at least double its funding for Parkinson's disease research.

While industry and philanthropy have prioritized Parkinson's research, these investments are not enough. Researchers rely on federally funded basic research to make the discoveries from which come deeper understanding and therapeutic development. The biggest non-profit organizations and most generous philanthropists cannot come close to the resources or scope of a Federal agency committed to human health and economic strength such as NIH.

The following projects leveraged Federal dollars to push Parkinson's research forward in the past year:

Coordination of the Global Parkinson's Genetics Program

The Global Parkinson's Genetics Program (GP2) is a five-year study supported through the Aligning Science Across Parkinson's (ASAP) initiative, created by the Milken Institute Center for Strategic Philanthropy with support from the Sergey Brin Family Foundation. GP2 aims to create a resource of genetic data for scientists to analyze for greater understanding of the genetic architecture of PD, which could point to new measures and treatments for the disease. Led by NIH Distinguished

Investigator Andrew Singleton, PhD, GP2 will analyze samples from more than 150,000 people with Parkinson's worldwide.

GP2 is leveraging funding from ASAP—of which MJFF is the implementing partner, lending its grant-making infrastructure and business and scientific expertise—and NIH resources to gather samples and generate data from a diverse pool of participants around the globe. These efforts will significantly expand the understanding of the causes of Parkinson's disease and point to new ways scientists may intervene to stop or even prevent it.

Molecular Fingerprinting and Data Analysis across Parkinson's Studies

Launched in 2018, the Accelerating Medicines Partnership Parkinson's disease (AMP PD) program made strides in the past year toward greater use and generation of data toward new disease insights. AMP PD is a public-private partnership between the NIH, multiple biopharmaceutical and life sciences companies, and MJFF and ASAP. Managed through the Foundation for the NIH (FNIH), the program aims to identify and validate the most promising biological targets for therapeutics.

In 2019, AMP PD launched its Knowledge Portal harmonizing and offering data from across four MJFF- and/or NIH-funded studies for qualified researchers to compare toward novel disease insights and identification of biomarker candidates and therapeutic targets. The program also is funding protein profiling from study samples—generating more data from which to learn—and data analysis of that already in the AMP PD Knowledge Portal. This ambitious program is building infrastructure and financially supporting efforts toward breakthroughs.

Testing of New Treatments to Stop Parkinson's Disease

With supplemental MJFF funding, NIH scientists also are testing novel therapeutic approaches to slow or stop Parkinson's progression. For example, Richard Youle, PhD, at the National Institute of Neurological Disorders and Stroke, part of the NIH, is working on a project to boost breakdown of mitochondria (the cell's energy center). Mitochondria build-up may be toxic and lead to cell death. Ellen Sidransky, PhD, at the National Human Genome Research Institute, also part of the NIH, is testing activation of calcium channel TRPML1, which also may help the cell clear out impaired or excess cell parts. These projects are moving the field closer to new treatments that could protect cells, slow disease and ease symptoms.

CENTERS FOR DISEASE CONTROL AND PREVENTION SUPPORT HELPS GATHER VALUABLE DISEASE DATA

While there are rough estimates of the number of people diagnosed with PD, we do not currently have accurate and comprehensive information on how many people are living with the disease, who they are and where they are located. This lack of core knowledge makes it difficult to assess potential environmental triggers and other patterns of disease. This absence of data also slows Parkinson's research and drug development and makes it difficult to ensure healthcare services are allocated properly.

The National Neurological Conditions Surveillance System (NNCSS) was authorized by the 21st Century Cures Act, signed into law in December 2016 (Public Law 114–255) and received its first appropriation in fiscal year 2019. The CDC began its development and implementation work, ensuring that the NNCSS is an effective tool for all stakeholders—patients, researchers, Congress and the public. The NNCSS will be developed in three stages, which CDC will carry out in association with partners and stakeholders.

First, the agency is working on demonstrations using multiple sclerosis (MS) and Parkinson's disease, to determine how it can have the biggest impact by exploring complex data sources with innovative analytic methods, and capturing lessons learned. This stage will take 2 years. In fiscal year 2020, CDC will evaluate the newly purchased data sources and, as resources allow, will purchase and evaluate the final data sources.

Second, the agency will build out the NNCSS for MS and PD, as resources allow, using successful approaches from the demonstration projects, and checking methods, costs, and opportunities to determine which approaches will help efficiently extend the NNCSS to other neurological conditions.

Third, it will apply these model approaches to extend the NNCSS to other neurological conditions.

CONTINUED SUPPORT FOR RESEARCH IS CRITICAL TO DRIVE PROGRESS

Momentum in Parkinson's disease research is strong. While researchers are uncovering more about the causes and progression of Parkinson's and testing many new treatments, many questions remain, and more people are facing a PD diagnosis. We need the financial and data resources to find answers and slow or halt the disease. Robust investments in NIH and CDC will continue to propel research forward, leading to life-changing treatments and, ultimately, a cure.

Please allocate $44.7 billion for the NIH, as well as the fully authorized amount of $5 million to continue the work of the National Neurological Conditions Surveillance System at the CDC. Thank you for the opportunity to testify.

PREPARED STATEMENT OF KAREN MONTANA

The NIMH research goals for 2020–2025 offer little hope for advancements for those with severe mental illness including schizophrenia and bipolar disorder.

As a mother of a son with bipolar disorder and severe depression, I urge you to make sure the NIMH spends an adequate amount of its budget on helping people with these and others serious mental disorders. It is gut wrenching and heart breaking to see my son suffer, and the impact it has on our whole family, especially when I know there is money available for more research and testing to find more effective treatment for him.

Even after considerable response identifying new treatment initiatives, the final draft of the NIMH showed little change to their goals and objectives. This is a public agency being funding by our tax dollars. We need relief and help for our family members who suffer mental illness. The NIMH has an unprecedented budget for the next 5 years with which they could make a real impact on helping people with severe mental illness live better lives.

Please ensure that this funding will be used to help find more effective treatments for people with severe mental health disorders, including bi-polar disorder. Until you have seen your child suffer the ramifications with such an illness, you will never know the pain and suffering he goes through, and that our family lives through. It is gut wrenching and heartbreaking. We live in a constant state of anxiety and trauma, not knowing what the next day holds for our son, and thus for our family. Please, I beg you, make sure the NIMH does its job in finding treatments for these disorders.

Sincerely and Desperately.

PREPARED STATEMENT OF MOTHERS OF THE MENTALLY ILL

Dear Senators,

My son died by suicide March 18, 2019. His severe form of bipolar disorder, which included psychosis, was extremely hard to treat. Not knowing how to help, when I knew my son's brain was malfunctioning, was a horrible vantage point for a mother. I watched an antiquated and broken mental healthcare system fail. Medications that for decades have provided limited relief were the first choice of providers, and they created their own set of dangerous symptoms.

My son had a complicated brain disease, but no provider ever asked questions about what might be happening in his brain. They instead focused on his thoughts—using psychology to treat a psychiatric condition. Only a few providers even knew that genetic testing could provide clues about a person's metabolism and which prescriptions might not work as planned. One doctor called it "hocus pocus." That ill-informed attitude is one result of underfunded research.

I request that you commit more NIMH dollars to research about cause and treatment for the most serious forms of bipolar disorder and schizophrenia. Dollars for this critical area of research have shrunk desperately in the past 15 years, even as NIMH budgets have increased.

Severe brain impairment in a few individuals (about 2 percent of the population) is costing society disproportionately. Like my son, most individuals with the most debilitating psychiatric disorders end up incarcerated, homeless, impoverished and often dead from suicide. This is unconscionable in a society with sophisticated science that can do so much better.

The medications my son was offered made him miserable, pre-diabetic, and unable to think clearly. Before he got sick, he was a state champion in extemporaneous debate and a competitive swimmer. After he got sick, he struggled to remember which bus route would get him home and rarely had energy to participate in physical fitness.

We need research to uncover clues about what happens in the brain. When my son was 6, he had a bad Strep Throat with a fever of 105 degrees. After he began to recover, he developed an uncontrollable tic disorder and was diagnosed with Tourette's Syndrome. Some basic research led me to believe he suffered from Pediatric Autoimmune Neuropsychiatric Disorder Associated with Strep (PANDAS). This was a known, named condition and made sense for his diagnosis, but no one in the psychiatric community knew what to do with that information.

My son's Tourette's Syndrome included explosive anger and may have indicated a brain inflammation that ultimately made him susceptible to bipolar disorder. He had many unusual and significant bacterial infections throughout his life, and I believe his immune response to infection was a significant factor in his psychiatric condition. There was no pathway to investigate any of those possibilities because they are not being studied in any significant way within mainstream medical research.

I recently read Susannah Cahalan's book, Brain on Fire, an extraordinary telling of her personal experience with an autoimmune reaction to an illness that led to psychosis and other symptoms of serious mental illness. Traditional psychiatric approaches failed to help with old-school anti-psychotics. Cahalan's family sought help from well-resourced and clever doctors who determined that her brain was "on fire" from inflammation—a condition called anti-NMDA receptor encephalitis. She needed an entirely unique medical protocol, which enabled her to recover her mind and her life. Cahalan's diagnosis is called "rare," but I question whether it truly is. I wonder how many individuals sleeping in gutters, wasting away in prisons and jails, might have a condition like Cahalan's. Why does no one bother to investigate?

A dear friend has a son diagnosed with schizophrenia who has been in 5-point restraints in a state hospital for the better part of the past year. He is known to have epilepsy. He's had encephalitis. Medication seems to make him worse. Electro-Convulsive Therapy (ECT) sometimes helps, but it's controversial and hard to access. It seems clear that he has suffered from seizures his whole life and his brain is inflamed, yet psychologists and social workers have been tasked to talk him out of his illness.

In order for psychiatry to step into its critical role as a field of medicine that studies and treats the organ of its investigation—the brain—sophisticated research about the root causes and treatments for serious mental illness are a critical need.

Please require that significantly more NIMH dollars move toward vital research about the causes and treatments for schizophrenia and bipolar disorder. Thank you.

Sincerely.

[This statement was submitted by Jerri Clark, Director, Mothers of the Mentally Ill.]

PREPARED STATEMENT OF NAF

NAF is a national network of education, business, and community leaders who work together to ensure high school students are college, career, and future ready. NAF appreciates the opportunity to submit testimony to the Senate Labor, Health and Human Services, Education, and Related Agencies Appropriations Subcommittee on fiscal year 2021 report language for the Department of Labor and Department of Education addressing work-based learning for high school students.

For 40 years, NAF has been partnering with existing high schools in high-need communities to enhance school systems by implementing NAF academies—small learning communities within traditional high schools. We have partnered with hundreds of leading companies to provide work-based learning, career-relevant knowledge and hands-on experiences. Currently, NAF supports more than 110,000 students in 620 academies at 406 public high schools across 34 states, Washington, D.C., Puerto Rico, and the U.S. Virgin Islands.

NAF's educational design ignites students' passion for learning and provides employers in the students' local area the opportunity to shape America's future workforce by transforming the learning environment to include work-based learning experiences.

Work-based learning brings the classroom to the workplace and the workplace to the classroom. This instructional strategy provides students with a well-rounded skill set that goes beyond academics and includes the soft skills needed to succeed in college and the working world. Employers seek employees with workforce ready skills that include collaboration, attention to detail, effective communication, critical thinking, and active learning. NAF's approach to work-based learning is centered on a continuum of experiences beginning with career awareness, progressing to career exploration, and culminating in career preparation activities, including paid internships. Representatives from the employer community speak to classes, host college and career skills workshops, and take part in mock interviews. Students have the opportunity to tour worksites and network with and shadow business professionals. Work-based learning culminates in a paid internship that allows students to apply their classroom skills and learn exactly what it takes to succeed in the workplace.

Today, 65 percent of all jobs, and nearly all high-paying jobs, require some form of postsecondary education or training. Work-based learning gives students opportunities to apply academic and technical knowledge, while fostering workforce ready skills such as working in teams, professionalism, problem solving, and critical thinking. These skills can add up to 20 percent to a college graduate's earnings. Most importantly, work-based learning helps students build positive relationships with adults and grow their social capital.

Work-based learning is a winning solution for high school students, employers, and their communities. It is imperative, especially to the employers struggling to fill positions with skilled and diverse employees, to encourage deeper and wider inclusion of this real-world, time-tested, skills-based workforce development program into the community. Together, the schools and employers create a talent pipeline and a pool of future leaders.

There are more than 15.3 million high school students in the United States, according to the U.S. Department of Education. High school graduation is the pathway to the continued growth and development of our youth and our communities. The potential long term impact of students not graduating spreads beyond the lives of those students and their families. For example, according to the report "By the numbers: Dropping out of High School" (Breslow, 2012), a youth who drops out of high school can expect to earn $10,386 less annually than a high school graduate, and $36,424 less annually than a college graduate. In addition, the report showed that a youth who does not graduate from high school could cost taxpayers an average of $292,000 over a lifetime.

Engaging high school students in work-based learning experiences ensures these students graduate college, career, and future ready, which is essential, especially for students who fail to see the connection between high school academics and future careers. In a recent study, students enrolled in a NAF program in grade 9 and were identified as at-risk of not graduating were 5 percentage points more likely to graduate from high school than their non-NAF counterparts. NAF academy students have a 99 percent graduation rate.

Showing students the connection between school and careers is critical. Work-based learning engages students in school; so they are more likely to graduate and are prepared with the necessary skills. This act of prevention benefits employers and the community at-large. NAF urges the subcommittee to include the requested fiscal year 2021 report language as outlined below.

DEPARTMENT OF LABOR

NAF encourages communities to include experts in work-based learning, particularly those with an expertise at the secondary level, on local workforce boards. NAF urges the subcommittee to support and advocate for the inclusion of the following report language in the fiscal year 2021 Appropriations bill.

Research shows that participation in work-based learning during high school has a positive impact on students and helps them secure higher-quality jobs, boosting equity and economic opportunity. The Committee urges the Department to encourage local secondary educational authorities with expertise in work-based learning to be included as part of the required education and training organization representatives on local Workforce Development Boards to provide guidance on work experience, including summer employment opportunities.

DEPARTMENT OF EDUCATION

NAF encourages work-based learning included as a quality indicator in state and local education accountability programs. NAF urges the subcommittee to support and advocate for the inclusion of the following report language in the fiscal year 2021 Appropriations bill.

To further support work-based learning and future career preparedness for high school students, the Committee encourages the Department to support including work-based learning and paid internships in state and local education accountability programs as a quality indicator. This will help ensure that decision makers can monitor which student populations are or are not receiving access to these opportunities.

CONCLUSION

Thank you for your attention to the importance of including work-based learning experiences for high school students. NAF appreciates the opportunity to share its expertise; and thanks you for your consideration of these requests that will help improve secondary education for our nation's students and embolden their future success.

[This statement was submitted by JD Hoye, CEO, NAF.]

Prepared Statement of the National Alliance for Eye and Vision Research

NAEVR, which serves as the "Friends of the National Eye Institute," is a 501(c)4 non-profit advocacy coalition comprised of 50 organizations involved in eye and vision research, including professional societies in ophthalmology and optometry, patient and consumer groups, private funding foundations, and industry. NAEVR thanks Congress, especially the House and Senate Appropriations Subcommittees on Labor, Health and Human Services, and Education (LHHS), for the strong bipartisan support for National Institutes of Health (NIH) funding increases from fiscal years 2016 through fiscal year 2020. The $11.6 billion NIH increase has helped the agency regain some of the ground lost after years of effectively flat budgets.

NAEVR is grateful for the recent bipartisan agreements to provide supplemental appropriations for NIH and other key health programs as the healthcare and research community responds to the COVID–19 pandemic. To maximize our country's ability to develop countermeasures against COVID–19 and to sustain the research momentum, NAEVR urges Congress to appropriate $44.7 billion for the NIH, a $3 billion or 7.2 percent increase, over the fiscal year 2020 program level and allowing for: meaningful growth above inflation in the base budget to support promising science across all Institutes and Centers (ICs); funding from the Innovation Account established through the 21st Century Cures Act which would supplement NIH's base budget, as intended, through dedicated funding for specific programs; and support for early-stage investigators.

Additionally, due to the strain COVID–19 is placing on the research infrastructure and strict limits of the fiscal year 2021 discretionary spending caps, NAEVR supports bipartisan proposals to exempt key health programs, including NIH, from the fiscal year 2021 caps. NAEVR also requests that the LHHS bill is structured to facilitate emergency funding, as necessary, to maintain the momentum of research emerging from past NIH investment such that the return on that investment is fully realized with new diagnostics and therapies.

NAEVR also urges Congress to appropriate $875 million for the NEI, a $51 million or 6.2 percent increase over enacted fiscal year 2020. The NEI is the world leader in sight-saving and vision-restoring research. Congress must ensure robust NEI funding to address the challenges of The Decade of Vision 2010–2020—as recognized by Congress in S. Res. 209 in 2009—which include an aging population, disproportionate risk/incidence of eye disease in fast-growing minority populations, and the impact on vision from numerous chronic diseases and their treatments/therapies.

Despite the total fiscal year 2016–2020 funding increases of $146 million, NEI's enacted fiscal year 2020 budget of $824.1 million is just 21 percent greater than the pre-sequester fiscal year 2012 budget of $702 million. Averaged over the eight fiscal years, the 2.6 percent annual growth rate is less than the average annual biomedical inflation rate of 2.8 percent, thereby eroding purchasing power, which in fiscal year 2019 was below that of fiscal year 2012 and equivalent to that in fiscal year 2000. Maintaining the momentum of vision research is vital to vision health, as well as overall health and quality of life. Since the U.S. is the world leader in vision research and training the next generation of vision scientists, the health of the global vision research community is also at stake.

With the COVID–19 pandemic, the NEI also faces additional challenges, as both the working age population and students may potentially rely exclusively on electronic communications devices and e-learning platforms into the future. Since increased rates of myopia, dry eye, and eye strain are associated with lengthy exposure to these communications tools, the NEI will play a pivotal role in research that ensures eye health along the continuum of life—and especially as it relates to the vision care that children receive during their developmental years.

NEI LEADS IN GENETIC AND REGENERATIVE MEDICINE RESEARCH

As recently as the March 21, 2018, NEI 50th Anniversary Congressional Reception, NIH Director Francis Collins, MD, PHD said the following about NEI:

"Due to the architecture, accessibility, and the elegance of the eye, vision research has always been a few steps ahead in biomedical research. Understanding the genetic basis of eye diseases has led the way for understanding the genetic basis of many common diseases."

The NEI has been a leader in genetics/genomics research and regenerative medicine.

—*Genetics/Genomics:* Vision researchers worldwide participating in NEI's Glaucoma Genetics Collaboration Heritable Overall Operational Database (NEIGHBORHOOD) Consortium have identified 133 genetic variants that predict within 75 percent accuracy a person's risk for developing glaucoma related to elevated intraocular pressure (IOP). Among the 133 variants, 68 had not been previously linked to IOP, and their loci point to cellular processes, such as lipid metabolism and mitochondrial function, that contribute to IOP. By understanding these cellular processes that can increase IOP and cause optic nerve damage, clinicians may be able to make an earlier diagnosis and researchers may be able to develop neuroprotective therapies to potentially halt disease progression.

—NEI-funded research has also made discoveries of dozens of rare eye disease genes possible, including the discovery of RPE65, which causes congenital blindness called Leber congenital amaurosis (LCA). As of late 2017, NEI's initial efforts led to a commercialized, Food and Drug Administration (FDA)-approved gene therapy for this condition. These gene-based discoveries are forming the basis of new therapies that treat the disease and potentially prevent it entirely.

—*Regenerative Medicine:* NEI is at the forefront of regenerative medicine with its Audacious Goals Initiative (AGI) for Regenerative Medicine, which launched in 2013 with the goal of restoring vision. Initially asking a broad constituency of scientists within the vision community and beyond to consider what could be done if researchers employed this new era of biology, the AGI currently funds major research consortia that are developing innovative ways to image the visual system. Researchers can now look at individual nerve cells in the eyes of patients in an examination room and learn quite directly whether new treatments are successful. Another consortium is identifying biological factors that allow neurons to regenerate in the retina. And the AGI is gathering considerable momentum with current proposals to develop disease models that may result in clinical trials for therapies within the next decade.

—In late 2019, NEI began a first-in-human clinical trial that tests a stem cell-based therapy from induced pluripotent stem cells (iPSC) to treat geographic atrophy, also known as the "dry" form of Age-related Macular Degeneration (AMD), the leading cause of vision loss among people age 65 and older. This trial converts a patient's own blood cells to iPS cells which are then programmed to become retinal pigment epithelial (RPE) cells, which nurture the photoreceptors necessary for vision and which die in geographic atrophy. Bolstering remaining photoreceptors, the therapy replaces dying RPE with iPSC-derived RPE.

CONGRESS MUST ROBUSTLY FUND THE NEI AS IT ADDRESSES THE INCREASING BURDEN OF VISION IMPAIRMENT AND EYE DISEASE

NEI's fiscal year 2020 enacted budget of $824.1 million is less than 0.5 percent of the $167 billion annual cost (inclusive of direct and indirect costs) of vision impairment and eye disease, which was projected in a 2014 Prevent Blindness study to grow to $317 billion—or $717 billion in inflation-adjusted dollars—by year 2050. Of the $717 billion annual cost of vision impairment by year 2050, 41 percent will be borne by the Federal Government as the Baby-Boom generation ages into the Medicare program. A 2013 Prevent Blindness study reported that direct medical costs associated with vision disorders are the fifth highest -only less than heart disease, cancers, emotional disorders, and pulmonary conditions. The U.S. is spending only $2.50 per-person, per-year for vision research, while the cost of treating low vision and blindness is at least $6,680 per-person, per-year. [http://costofvision.preventblindness.org/]

In a May 2016 JAMA Ophthalmology article, NEI-funded researchers reported that the number of people with legal blindness will increase by 21 percent each decade to 2 million by 2050, while best-corrected visual impairment will grow by 25 percent each decade, doubling to 6.95 million people-with the greatest burden affecting those 80 years or older. [http://jamanetwork.com/journals/jamaophthalmology/article-abstract/2523780?resultClick=1]

In an August 2016 JAMA Ophthalmology article, the Alliance for Eye and Vision Research (AEVR, NAEVR's educational foundation) reported that a majority of Americans across all racial and ethnic lines describe losing vision as having the greatest impact on their day-to-day life. Other studies have reported that patients with diabetes who are experiencing vision loss or going blind would be willing to trade years of remaining life to regain perfect vision, since they are concerned about their quality of life. [http://jamanetwork.com/journals/jamaophthalmology/article-abstract/2540516?resultClick=1]

Investing in vision health is an investment in overall health. NEI's breakthrough research is a cost-effective investment, since it leads to treatments and therapies that may delay, save, and prevent health expenditures. It can also increase productivity, help individuals to maintain their independence, and generally improve the quality of life—as vision loss is associated with increased depression/accelerated mortality.

In summary, NAEVR requests fiscal year 2021 NIH funding of at least $44.7 billion and NEI funding of $875 million. NAEVR thanks the Subcommittee for the opportunity to submit this written testimony, especially as it grapples with the challenges now and into the future from the COVID–19 pandemic.

For more information, visit NAEVR's Web site at www.eyeresearch.org.

[This statement was submitted by James Jorkasky, Executive Director, National Alliance for Eye and Vision Research.]

Prepared Statement of the National Alliance for Public Charter Schools

Mister Chairman and Members of the Subcommittee, I am pleased to present the views of the National Alliance for Public Charter Schools on the fiscal year 2021 appropriation for the Charter Schools Program (CSP), which is administered by the U.S. Department of Education. I thank the Subcommittee for maintaining strong support for the CSP, including by providing a significant funding increase to $440 million fiscal year 2019 and continuing that level in 2020. The CSP continues to play a critical role in expanding educational opportunities for families and in improving public school outcomes nationwide. As the Subcommittee begins consideration of the fiscal year 2021 Labor, Health and Human Services, Education and Related Agencies appropriations legislation, we request an increase in funding for the CSP to at least $500 million, with a reservation of 30 percent for the replication and expansion of high-quality charter schools. We strongly urge the Subcommittee to maintain a specific appropriation for the CSP and to reject the Administration's education block grant proposal. The President's proposal would jeopardize the ability of community leaders to start new schools. We also urge you to continue your strong support for Title I and the Individuals with Disabilities Education Act, both of which provide critical funding for public schools, including charter schools.

THE GROWTH AND SUCCESS OF CHARTER SCHOOLS

Over the last year or so, and notwithstanding charter schools' achievements, we have seen a number of misconceptions about those schools put forward in the media and in other public discourse. So let's be clear on what charter schools are: they are public schools, supported by taxpayers and open to all students, without entrance requirements. Each State decides who may authorize its charter schools and how they are to be held accountable for meeting the goals laid out in their charters. Moreover, while charter schools typically have more flexibility than non-charter schools—in setting the curriculum, hiring teachers and other staff, determining the school calendar, and adapting to meet the needs of their students-they are required to meet the same academic testing requirements as other schools.

Most importantly, although there is variety in the performance of charter schools, in the main they are delivering for their students. The 2015 Urban Charter School Study, from the Center for Research on Education Outcomes (CREDO) at Stanford University, found that students in urban charter schools gained an average of 40 additional days of learning per year in math and 18 days in reading, compared to their non-charter-school peers. Moreover, the study found that the longer a student attends an urban charter school, the greater the gains; four or more years of enrollment in such a school led to 108 additional learning days in math and 72 in reading. Research in individual States and communities, such as 2019 studies of North Carolina, Boston, and Newark charter schools, provides additional evidence backing up these national findings. Charter schools have succeeded in offering high-quality options to students, particularly in low-income urban districts where those options are most sorely needed and particularly for African American and Hispanic students as well as students from low-income families.

THE IMPORTANCE OF THE FEDERAL CHARTER SCHOOLS PROGRAM

The CSP was first authorized in 1994, as a bipartisan effort of President Clinton and leaders of both parties in Congress. The program was originally created to support the start-up of new schools, but now also funds the expansion and replication of successful charter schools and helps charter schools gain access to school facilities. It has continued to receive bipartisan support over more than two and a half decades.

Since its inception, the CSP has awarded some $3.9 billion to States, charter management organizations (CMOs), and other entities. To put that number in context, it's about 1 percent of the appropriation for ESEA Title I LEA Grants over that time period. The result: the number of charter schools has grown from only a handful in the early 1990s to more than 7,500 today. Many of those schools have relied on the CSP to get off the ground because, while States and localities have provided per-pupil funding to their public schools, they have not provided new charter schools with funds for planning, staff training, equipment and materials, renovations, recruitment, and other necessary start-up activities. In addition, State appropriations have often not given charter schools the same level of per-pupil support as non-charter schools, and often have not addressed their facilities needs.

Unfortunately, with States now facing severe resource constraints because of the COVID–19 crisis, insufficient State support for charter schools could become even more of a problem over the next few years. Charter schools more typically serve communities with low property tax revenues, and thus depend more heavily than the average school on State funding. When States experience reductions in income, sales, and other taxes and thus have to cut funding for public education, charter schools will be particularly affected.

Charter school enrollment—now at nearly 3.3 million students—has grown rapidly, but it has not kept up with the demand for seats in charter schools. Surveys indicate that 5 million additional students would attend a charter school if space were available at a convenient location. Many of those are students who attend schools identified as in need of support and improvement under Title I, that is, schools that are not meeting State performance targets either for the school as a whole or for one or more student subgroups. The increase we are recommending would enable the creation of charter schools to serve more of the students and families who want them.

FISCAL YEAR 2021 REQUEST

As I noted at the beginning of my statement, our request for fiscal year 2021 is $500 million, including 30 percent ($150 million) for grants to CMOs for the replication and expansion of high-quality charter schools. Although we understand that the amount of funding available to the Subcommittee will be tight, because of the budget caps and COVID–19 relief efforts, we strongly believe that this requested increase would be a wise investment. As schools across the nation grapple with the challenges of distance learning, charter schools have shown incredible resilience and leadership. Charter school autonomy, and the flexibility that it affords, allowed charter schools to pivot very quickly to rise to the challenges presented by the closing of school buildings. Schools like Common Ground in New Haven Connecticut deliver free fresh produce directly to the doors of those in need weekly; Impact Public Schools in Tukwila, Washington built partnerships to provide their students with Wi-Fi hotspots, laptops and free meals; and Springs Charter Schools in Florida offered their online learning curriculum for free to all, reaching more than 5,000 students today.

An increase of $60 million would allow States and CMOs to support the creation of new charter schools, reducing the waiting lists and providing high-quality educational options to more families, particularly those in communities where those opportunities are not commonly available. In many cases the very communities hit hardest by the virus and its economic fallout.

Our request would also enable more CMOs to replicate and expand the charter schools they operate or manage. A study by CREDO found that the schools funded through the Replication and Expansion competition have made impressive growth in reading and math: more than half of the grants have supported CMOs that outpaced non-charter schools in academic growth in both subjects.

Finally, our request would help charter schools meet their very significant school facilities needs. Charter schools generally do not have the same access to the funding sources that support the facilities needs of other public schools, such as municipal bonds, property tax revenues, and State school facilities programs. They have had to scrape by in buildings not designed for learning or use funds that should have been available for instruction to cover facilities needs, or simply not open at all for lack of an adequate building. The two small facilities programs included in the CSP, Credit Enhancement for Charter School Facilities and the State Facilities Grants, help fill some of this unmet need.

CONCLUSION

The National Alliance for Public Charter Schools takes great pride in the growth and accomplishments of public schools over the last quarter century. Our schools' enrollments continue to climb, and more and more studies have found that charter schools are succeeding, that they increase achievement and meet the other needs of a diverse and often very needy student populations. Indeed, at a very critical time in our nation's history, when innovative approaches to educating all students are needed, charter schools stand ready to offer that innovation and have a track record of doing so successfully. The flexibility granted by their charters makes it feasible for them to adopt to new operational challenges and succeed with the student populations that are at the greatest risk of educational failure because of the disruptions resulting from COVID–19. But they cannot do so with insufficient funding.

This success of charter schools could not have been achieved without the CSP, which continues to be a vital source of support. We ask that you continue that support and accept our recommendation for fiscal year 2021.

[This statement was submitted by Nina Rees, President and CEO, National Alliance for Public Charter Schools.]

PREPARED STATEMENT OF THE NATIONAL ALLIANCE ON MENTAL ILLNESS

Chairman Blunt, Ranking Member Murray and distinguished members of the Subcommittee, the National Alliance on Mental Illness (NAMI) would like to offer our views on the Subcommittee's fiscal year 2021 bill. NAMI is the nation's largest grassroots mental health organization dedicated to building better lives for the millions of Americans affected by mental illness. NAMI advocates for improved research and innovation, increased access to care, and comprehensive services and supports for individuals living with mental health conditions.

HIGH COST OF MENTAL ILLNESS IN AMERICA IN THE U.S.

Approximately one in five Americans live with a mental health condition—approximately 46.6 million people in 2017.[1] Individuals who live with mental health conditions are our neighbors, family members, and friends. They contribute to all sectors of the U.S. economy—yet the social and economic costs associated with mental health conditions is devastating. In 2013, mental illness topped the list of the costliest conditions in the U.S. at $201 billion, according to a 2016 study.[2] While this financial cost is an incredible burden on U.S. healthcare spending, the personal cost of untreated mental illness to individuals and families is much more devastating. At NAMI we hear from countless individuals who share their own stories of a family member or friend who couldn't reach their full potential because of a lack of necessary, innovative treatment. Some also carry the burden of someone lost to suicide. In fact, 47,173 Americans die by suicide annually, and it's currently the tenth leading cause of death in the United States.[3] Additionally, suicide and self-injury cost the U.S. $69 billion in 2015 alone.[4] As you can see, the work of this Subcommittee and your commitment to adequate investment in innovative mental health research, and first-class treatments and supports is vitally important to keep America strong and save American lives.

FISCAL YEAR 2020 LABOR-HHS APPROPRIATIONS BILL

NAMI would like to thank the Chairman, Ranking Member, and Subcommittee for the bipartisan effort on the fiscal year 2020 enacted bill, and the critical investments that were made for mental health research and treatment. We are especially grateful for the $2.6 billion budget increase for the National Institutes of Health (NIH), and the $98 million increase for the National Institute of Mental Health (NIMH). NAMI is also very appreciative of the additional $200 million for the ongoing Certified Community Behavioral Health Clinics (CCBHCs).

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[1] Gordon, J. (2018, May 15). National Institute of Mental Health. Prevalence of Mental Illness. Retrieved from: https://www.nimh.nih.gov/health/statistics/mental-illness.shtml. Date: 3 April 2019.

[2] Roehrig, C. Mental Disorders Top The List of The Most Costly Conditions in The United States: $201 Billion, Health Affairs, 2016. DOI:10.1377/hlthaff.2015.1659

[3] Suicide Statistics. American Foundation for Suicide Prevention. Retrieved from: https://afsp.org/about-suicide/suicide-statistics/. Date: 2 April 2019.

[4] Ibid.

NAMI FISCAL YEAR 2021 FUNDING PRIORITIES FOR THE NATIONAL INSTITUTE OF MENTAL HEALTH

NAMI endorses the goal of at least $44.7 billion for the National Institutes of Health (NIH), a $3 billion increase in base funding for the agency. Additionally, NAMI supports the current NIMH strategic plan and its high-level strategic objectives.

Advancing Services and Intervention Research & Investing in Early Psychosis Prediction and Prevention (EP3)

Approximately 100,000 young Americans experience a first episode of psychosis (FEP) each year.[5] Intervening early is critical to altering the downward trajectory associated with psychosis. Accordingly, NAMI prioritized support for the NIMH Recovery After an Initial Schizophrenia Episode (RAISE) Project, which developed Coordinated Specialty Care (CSC) programs that are helping people experience recovery. We urge further investment into maintaining CSC's positive treatment and quality-of-life outcomes over the long-term. NAMI also supports NIMH's Early Psychosis Prediction and Prevention (EP3) initiative, which shows promise in detecting risk for psychotic disorders and reducing the duration of untreated psychosis in adolescents who have experienced early psychosis.

Advancing Precision Medicine

NAMI remains supportive of the NIMH Research Domain Criteria (RDoC) and its efforts to build a classification system based on underlying biological and behavioral mechanisms, rather than on symptoms. Through continued development, we believe RDoC will provide the precision currently lacking in traditional diagnostic approaches to mental health conditions.

NAMI FISCAL YEAR 2021 FUNDING PRIORITIES FOR SAMHSA PROGRAMS

NAMI supports programs at the Center for Mental Health Services (CMHS) at SAMHSA that are focused on replication and expansion of effective, evidence-based interventions to serve children and adults living with mental health conditions. We are grateful for increases in recent years for the Community Mental Health Services Block Grant (MHBG) to its current level of $722.6 million.

Additionally, NAMI strongly supports the 10 percent set-aside in the MHBG for evidence-based programs that address the needs of individuals with early serious mental illness. As noted above, NAMI endorses the Coordinated Specialty Care (CSC) model for collaborative, recovery-oriented care. This evidence-based approach emphasizes shared decisionmaking and should be the priority program for receiving funding from this set-aside.

Request for Consideration of additional Set-Aside for Crisis Care Services

As the Subcommittee is aware, there is an increased need for mental health crisis care services to improve our nation's mental health and combat the suicide and opioid epidemics. As such, NAMI supports a funding increase for an additional $35 million to the MHBG to fully fund a 5 percent set-aside for Crisis Care Services—as was included in the House Labor-HHS Subcommittee's fiscal year 2020 bill. If funded, we request the array of crisis care services to include centrally deployed 24/7 mobile crisis units, short-term residential crisis stabilization programs, the implementation of evidence-based protocols for treating individuals at risk of suicide, and regional or statewide crisis call centers coordinating in real time.

Additional NAMI Fiscal Year 2021 Funding Priorities at CMHS

We support continued funding for all current programs at CMHS, including $125 million for Children's Mental Health Services, $6.3 million for Criminal and Juvenile Justice Programs, $102 million for Project AWARE state grants, $64.6 million for the Projects for Assistance in Transition from Homelessness (PATH) program, $36.4 million for the Treatment Systems for Homeless portfolio, and $19 million for the continuation of the Assisted Outpatient Treatment (AOT) pilot program and $7 million for the Assertive Community Treatment (ACT) program. NAMI respectfully requests the Subcommittee consider a $68 million increase to the National Suicide Prevention Lifeline, for a total of $80 million and fully fund all Garrett Lee Smith (GLS) suicide prevention grants consistent with fiscal year 2020, enacted. Additionally, NAMI remains concerned about the proposed elimination of the Primary and Behavioral Health Care Integration (PBHCI) program in the fiscal year 2021 Presi-

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[5] Fact Sheet: First Episode Psychosis. National Institutes of Mental Health. Retrieved from: https://www.nimh.nih.gov/health/topics/schizophrenia/raise/fact-sheet-first-episode-psychosis.shtml. Date: 21 May 2020.

dent's Budget (PB) Request. The PBHCI is a critical program which supports collaboration and infrastructure that increases primary and wellness care for children and adults with serious mental health conditions, and we strongly encourage the restoration of funding at $51.9 million.

Health Resources and Services Administration (HRSA)

NAMI recognizes the important work of HRSA, and therefore requests $36.9 million for Mental and Behavioral Health, $102 million for the Behavioral Health Workforce, and $10 million for Increasing Access to Pediatric Mental Health Care—all level to fiscal year 2020, enacted funding. These programs are crucial to supporting development of the mental health workforce.

Fully Funding the 21st Century Cures Act

The Helping Families in Mental Health Crisis Act as included in the 21st Century Cures Act, Public Law 114–255, was a landmark piece of legislation and represented a substantial leap forward for Americans who live with mental illness. NAMI respectfully asks the Subcommittee to fully fund all programs authorized including $6 million for Adult Suicide Prevention programs and $2.5 million for Strengthening Community Crisis Response Systems. These programs, if funded, will ensure that we can capitalize on the advancements put forth in this bill, and help more Americans living with mental health conditions to realize that recovery is possible.

CONCLUSION

NAMI would like to express our gratitude to the Chairman, Ranking Member and the Subcommittee for your investments in the necessary research, treatments, services and supports for Americans living with mental health conditions.

PREPARED STATEMENT OF THE NATIONAL ALOPECIA AREATA FOUNDATION

THE FOUNDATION'S FISCAL YEAR 2021 L–HHS APPROPRIATIONS RECOMMENDATIONS

- —At least $44.7 billion for the National Institutes of Health (NIH).
  - —Proportional funding increases for National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), National Institute of Allergy and Infectious Diseases (NIAID) and the National Center for Advancing Translational Science (NCATS).

Chairman Blunt and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the alopecia areata community as you work to craft the fiscal year 2021 L–HHS Appropriations Bill.

ABOUT ALOPECIA AREATA

Alopecia areata is a prevalent autoimmune skin disease resulting in the loss of hair on the scalp and elsewhere on the body. It usually starts with one or more small, round, smooth patches on the scalp and can progress to total scalp hair loss (alopecia totalis) or complete body hair loss (alopecia universalis).

Alopecia areata affects approximately 2.1 percent of the population, including more than 6.5 million people in the United States alone. The disease disproportionately strikes children and onset often occurs at an early age. This common skin disease is highly unpredictable and cyclical. Hair can grow back in or fall out again at any time, and the disease course is different for each person. In recent years, scientific advancements have been made, but there remains no cure or indicated treatment options.

The true impact of alopecia areata is more easily understood anecdotally than empirically. Affected individuals often experience significant psychological and social challenges in addition to the biological impact of the disease. Depression, anxiety, and suicidal ideation are health issues that can accompany alopecia areata. The knowledge that medical interventions are extremely limited and of minor effectiveness in this area further exacerbates the emotional stresses patients typically experience.

ABOUT THE FOUNDATION

NAAF, headquartered in San Rafael, California, supports research to find a cure or acceptable treatment for alopecia areata, supports those with the disease, and educates the public about alopecia areata. NAAF is governed by a volunteer Board of Directors and a prestigious Scientific Advisory Council. Founded in 1981, NAAF is widely regarded as the largest, most influential, and most representative foundation associated with alopecia areata. NAAF is connected to patients through local support groups and also holds an important, well-attended annual conference that reaches many children and families.

NAAF initiated the Alopecia Areata Treatment Development Program (TDP) dedicated to advancing research and identifying innovative treatment options. TDP builds on advances in immunological and genetic research and is making use of the Alopecia Areata Clinical Trials Registry which was established in 2000 with funding support from the National Institute of Arthritis and Musculoskeletal and Skin Diseases; NAAF took over financial and administrative responsibility for the Registry in 2012 and continues to add patients to it. NAAF is engaging scientists in active review of both basic and applied science in a variety of ways, including the November 2012 Alopecia Areata Research Summit featuring presentations from the Food and Drug Administration (FDA) and NIAMS.

NAAF is also supporting legislation to provide coverage for cranial prosthetics under Medicare. This bill will grant increased access to cranial prosthetics and therapies for patients with alopecia areata and other forms of medical hair loss. Many patients living with medical hair loss suffer from a variety of diseases, including cancer. With no known cause or cure, alopecia areata is an autoimmune skin disease affecting approximately 6.8 million Americans, many of whom are children.

NATIONAL INSTITUTES OF HEALTH

NIH hosts a modest alopecia areata research portfolio, and the Foundation works closely with NIH to advance critical activities. NIH projects, in coordination with the Foundation, have the potential to identify biomarkers and develop therapeutic targets. In fact, researchers at Columbia University Medical Center (CUMC) have identified the immune cells responsible for destroying hair follicles in people with alopecia areata and have tested an FDA-approved drug that eliminated these immune cells and restored hair growth in a small number of patients. This huge breakthrough has led to NIAMS providing a research grant to the researchers at Columbia to continue this work. In this regard, please provide NIH with meaningful funding increases to facilitate growth in the alopecia areata research portfolio.

PATIENT PERSPECTIVE

Rosie's mother explains their family's experience with alopecia areata:

> "As we struggled to understand the diagnosis of alopecia areata and what it might mean for our two-and-a-half-year-old daughter Rosie, the last of her remaining hair fell out. In the meantime, we sought answers from books, from second (and third) opinions, and genetic testing. We read medical journal articles, sometimes in the middle of the night when we were up with Rosie's little sister, looking for signs of hope that a cure was just around the corner. We scoured the Internet for miracles and success stories, for the magic bullet that would return those soft brown curls back to Rosie's smiling face. We tried countless treatments; ointments, creams, steroids, herbal medicines, special diets, and even lifestyle changes designed to reduce any stress a three-year-old might feel. We searched Rosie's scalp daily, sometimes with a flashlight, for any sign of new hair growth. Our hope that this would be a temporary condition, even a funny story someday, slowly faded. The next few months were filled with ups and downs. Sympathetic smiles were far rarer than stares, and the stares were often paired with inquisitive finger-pointing from younger children. Parents would shush their children, 'Shhh—don't stare. Stop pointing. It's not polite,' while we just kept right on grocery shopping or waiting in line at Starbucks. When Rosie asked why they were pointing, we'd explain they were simply curious, all the while whisking her away from the pointers with a pit in our stomach.
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> One particular type of public comment bothered Rosie more than any other; 'Hey little guy, how are you today?' or, 'Great scootering, buddy!' She'd frown and tell people she wasn't a boy, and usually she'd be too annoyed to explain further. She began to ask, 'Why do they think I'm a boy, I'm wearing pink? Boys don't wear pink!' Of all the answers we'd had to provide, this one was the toughest. By the end of the discussion, we found ourselves explaining to our teary-eyed Rosie that sometimes things happen to us that we can't control. So, instead of focusing on fixing her baldness, we shifted to raising a little girl who loves herself unconditionally, hair or no hair."

Thank you for the opportunity to testify before you today. NAAF looks forward to working with you all to advance medical research and public health activities that will improve patient outcomes for the members of our community suffering from alopecia.

[This statement was submitted by Dory Kranz, Chief Executive Officer, National Alopecia Areata Foundation.]

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION FOR STATE COMMUNITY SERVICES PROGRAMS

As Executive Director of the National Association for State Community Services Programs (NASCSP), I am pleased to submit testimony in support of the Department of Health and Human Services' (HHS) Community Services Block Grant (CSBG). We are seeking a fiscal year 2021 appropriation level of $775 million for CSBG. NASCSP believes that this funding level will ensure that states and local communities have the resources they need to lead the fight against poverty through innovative, effective, and locally tailored anti-poverty programs that help communities, individuals, and families achieve economic security.

NASCSP is the member organization representing the State CSBG Directors in all 50 states, Washington D.C., and 5 U.S. territories on issues related to CSBG and economic opportunity. NASCSP also provides training and technical assistance to help State Offices implement program management best practices and develop evidence-based policy. The State Offices represented by our organization would like to thank the members of this committee for their support of CSBG over the years, particularly for the increase to CSBG in the fiscal year 2020 Labor-HHS Bill and for recognizing the role of CSBG in response to the COVID–19 pandemic through supplemental funding provided by the CARES Act.

CSBG is a model example of a successful Federal-State-Local partnership, a fact I can personally attest to having worked for over 20 years in various roles within the CSBG network. However, CSBG is arguably one of the most misunderstood programs within the Federal Government. This is evident in the Administration's justification for eliminating CSBG in its budget. The administration claims that "CSBG funding is poorly targeted and not allocated based on performance." They also claim that "CSBG also funds some services that are duplicative of those supported by other Federal programs." My testimony will illustrate that this could not be further from the truth. I would like to highlight three main points in my testimony:

1. The structure of CSBG empowers states and local communities to take the lead on reducing poverty, giving states wide discretion to target and tailor funding as they see fit for their unique conditions.
2. The robust local, state, and Federal accountability measures of the CSBG Performance Management Framework are unique and bold compared to other Federal programs, preventing duplication and fostering continuous improvement.
3. CSBG creates impact in communities across the country by leveraging additional private, local, state, and Federal investments to fight poverty, serving as the thread that weaves together and coordinates both private and public antipoverty efforts.

STRUCTURE

Critics of Federal anti-poverty programs emphasize the need for state and local leadership to address poverty, asserting that state and local leaders are best equipped to tackle the challenges facing their communities. CSBG embodies this very principle. CSBG is a block grant administered and managed by states, which distribute funds to a nationwide network of over 1,000 local CSBG Eligible Entities, also known as Community Action Agencies or CAAs. The CSBG network serves every corner of America, touching urban, rural, and suburban communities. In some rural counties, the CAA is the only human services organization working to promote economic security in that community.

Community Action Agencies utilize CSBG funds to address specific local needs, which may include services and programs that address one or more of the core domains in which we work: employment, education and cognitive development, income, infrastructure and asset building, housing, health and social behavioral development, and civic engagement and community involvement. The CSBG Act also requires that the work of Community Action Agencies must be shaped by a community needs assessment performed at least every 3 years. This process ensures that CAA programs and services are evidence based and tailored to unique community needs, rather than a one-size-fits-all solution. The needs assessment prevents duplication and incorporates community feedback in the strategic planning process. Furthermore, the CSBG Act requires at least one-third of a Community Action Agency's board to be composed of people with low-incomes or their representatives, ensuring that local needs are accurately reflected in the priorities of the organization.

In addition to low-income representation, the CSBG Act also requires Community Action boards be comprised of local elected officials or their representatives and community stakeholders which include local businesses, other helping organizations, professional groups, or community organizations. This unique tripartite structure assures that the Community Action Agency not only properly identifies the needs of a community, but also identifies the available resources and opportunities that can be leveraged to maximize outcomes and impact. The tripartite structure of Community Action boards calls on all sectors of society to join in the fight against poverty.

ACCOUNTABILITY

In addition to a structure that empowers states and local communities, CSBG is bolstered by a Performance Management Framework to ensure accountability at all levels of the network. This federally established Performance Management Framework includes state and Federal accountability measures, organizational standards for Community Action Agencies, and a Results Oriented Management and Accountability (ROMA) system. Under the Performance Management Framework, the CSBG Network reports outcomes through the CSBG Annual Report. Within this reporting mechanism, National Performance Indicators are used across the network to track and manage progress, ensuring CAAs have the data they need to improve and innovate. The ROMA system allows local communities to strengthen their impact and achieve robust results through continuous learning, improvement, and innovation. Furthermore, CSBG State Offices monitor local agency performance and adherence to organizational standards, providing training and technical assistance to ensure high quality delivery of programs and services.

IMPACT

CSBG is a sound Federal investment that produces tangible results. Federal CSBG dollars are used to support and strengthen the anti-poverty infrastructure of our communities. In fiscal year 2017,[1] for every $1 of CSBG, CAAs leveraged $7.36 from non-Federal sources. This leveraging of funds allowed CAAs to expand and maintain highly successful programs. Including all Federal sources, non-Federal sources, and volunteer hours valued at the Federal minimum wage, the CSBG Network leveraged $20.22 of non-CSBG dollars per $1 of CSBG. Without CSBG, many rural communities across America would not be able to implement critical programs that address poverty at both the community and family levels. Terminating CSBG would be detrimental to the lives of the over 15.3 million people with low-incomes who the CSBG network served in fiscal year 2017. Here is just a snapshot of the impact of CSBG:

—173,775 unemployed, low-income people obtained a job as a result of Community Action.

—52,220 low-income people with jobs obtained an increase in income and/or benefits.

—38,947 low-income people achieved "living wage" employment and/or benefits.

—425,445 low-income participants obtained healthcare services for themselves or a family member.

—360,909 low-income families in CAA tax preparation programs qualified for a Federal or state tax credit. (The expected total amount of tax credits was $459,277,981).

—134,109 low-income people completed Adult Basic Education (ABE) or General Educational Development (GED) coursework and received a certificate or diploma.

Looking beyond the data, we can see that the CSBG Network is delivering innovative, comprehensive, and effective programs across the country that put individuals and families on a path out of poverty:

—*Nationwide Pandemic Response and Recovery:* As the COVID–19 crisis has swept across America, Community Action Agencies are trusted local partners implementing programs that provide support and stability in these unprecedented times. CAAs have adapted processes and procedures to continue operating and expand programs such as emergency food distribution, energy assist-

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[1] Fiscal year 2017 data is the latest publicly available from the Office of Community Services (OCS) within the Department of Health and Human Services (HHS).

ance, housing support, and other efforts in response to the immediate impacts of the pandemic. Many CAAs have also utilized technology to innovate and continue to provide Head Start early childhood education and home visits virtually. INCA Community Services in Oklahoma has delivered over 430 care packages to seniors and other homebound individuals, providing not only physical necessities, but also emotional support. The CSBG network has also been recognized by Governors across the nation as a critical partner in the recovery ahead. In Kentucky, the state's Community Action Agencies have been called on by the Governor to help direct and distribute the Team Kentucky Fund. In Georgia, Community Action Agency leaders have been tapped to serve on the Governor's community outreach task force.

—*Two Generation Housing Solutions in Washington:* The Second Chance Center (SCC) Rapid Engagement and Empowerment Project is an initiative of the Benton-Franklin Community Action Committee. The SCC is targeted to meet the needs of families with children who are experiencing homelessness as well as those at-risk of homelessness. The target populations and goals are two-fold; first, to reduce the recidivism rate of families with children, returning to homelessness, living doubled-up, or in imminent danger of becoming homeless, and second to provide a safe family-oriented day shelter with services to educate, encourage, and assist in this process that works to promote self-sufficiency, including job search skills, Life Skills, and financial literacy. The initiative is on track to serve 120 people in its first year, helping families achieve greater self-determination and self-sufficiency through solutions for both children and parents.

—*Economic Self-Sufficiency & Bundled Services in Mississippi:* Washington, Warren, Issaquena, Sharkey Community Action Agency (WWISCAA) operates a comprehensive case management program to help members of the community reach their full potential. The main pillars of the program include: (1) Assistance with job placement, employability skills training and soft skill such as resume writing; (2) GED placements, work skill training and vocational skills training for young adults; (3) intern placement and job shadowing for low-income men of color; and (4) Coordinated referrals for economic assistance and healthcare from the county department of human services. The outcome indicators used to measure success were the number of jobs gained and maintained for 90 days, the number of GEDs obtained, completion of vocational skills training programs, attainment of Career Readiness Certifications, attainment of professional licenses, and increase in the number of youth attending post-secondary education. Results included over 2,600 measurable outcomes across employment, education, and income management.

In closing, we ask the committee to fund CSBG at no less than $775 million for fiscal year 2021, the funding level necessary to grow and sustain this nationwide network with an over 50-year record of success. The structure of CSBG empowers states and local communities to take the lead on reducing poverty, while prioritizing locally determined solutions. CSBG is subject to the extensive accountability mechanisms of the Performance Management Framework, ensuring effective and responsible stewardship of funds at the Federal, State, and local level. CSBG is producing concrete results, serving millions of vulnerable Americans each year and implementing strategies that move communities, individuals, and families toward economic security and independence. Additionally, in the months ahead, the need for CSBG programs and services will only increase due to the impact of COVID–19. Community Action Agencies have a robust record of success helping Americans to get back to work. In addition to helping hundreds of thousands of Americans obtain employment every year, the CSBG network played a critical role in the economic recovery from the last recession 10 years ago.

NASCSP looks forward to working with Committee members to ensure that CSBG continues to help families achieve outcomes that strengthen our communities and make a difference in the lives of our most vulnerable neighbors. Thank you.

Respectfully submitted.

[This statement was submitted by Jenae Bjelland, Executive Director, National Association for State Community Services Programs.]

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF COUNCILS ON DEVELOPMENTAL DISABILITIES

Chairman Blunt, Ranking Member Murray and members of the committee, the National Association of Councils on Developmental Disabilities (NACDD), a national membership organization for the State Councils on Developmental Disabilities (DD

Councils), appreciates the opportunity to present this testimony. NACDD respectfully requests that Congress appropriate $80 million for the DD Councils within the Administration for Community Living (ACL) in the Labor-HHS-Education appropriations bill for fiscal year 2021 and clarify in report language that not less than $700,000 of that amount be provided for technical assistance and training for the DD Councils.

Authorized by the bipartisan Developmental Disabilities Assistance and Bill of Rights Act (DD Act), DD Councils work collaboratively with the University Centers for Excellence in Developmental Disabilities (UCEDDs) and Protection and Advocacy program for Developmental Disabilities (P&As), to "assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life, through culturally competent programs."[1] The DD Act design threads these three distinctly different programs together to ensure a well-trained cadre of experts provide services to individuals with DD and their families, protect the rights of individuals with DD, and ensure that people with DD are fully included in the work to improve services and systems to make them fully inclusive. Working within this Federal framework, the role of the DD Councils is to promote person-centered and family-centered system improvements with and for people with developmental disabilities.

For the past fifty years, Congress has recognized that DD Councils are in a strategic position in each state and territory to invest in dynamic and innovative programs that improve services and systems that help people with developmental disabilities live in the community. Appointed by Governors and comprised of at least 60 percent people with DD and their families, DD Councils assess problems or gaps in the system and design solutions. Innovative solutions from the DD Councils often bring about public-private partnerships that make real changes to systems such as employment, transportation, education, healthcare, housing and more.

This year, DD Councils were quick to respond to the COVID–19 pandemic to advise governors and state agencies and fill gaps in emergency services for people with I/DD and families. Expert council staff and trusted local organizations provided concrete resources to respond to emerging needs of individuals with developmental disabilities and their families who have been impacted by the COVID–19 pandemic. For example, one of the thirty-three projects by the Illinois DD Council supported direct care staff to be able to continue their work under these unusual circumstances to provide the supports needed for the people they serve. The Missouri DD Council established a COVID–19 Scholarship Fund, which will provide opportunities for individuals and/or family members to apply for one-time funding to use technology as a way to address today's unique barriers to community living (e.g. accessing telehealth and other supports during quarantine). The Washington State DD Council's Informing Families Project worked with self-advocates to create and disseminate accessible information about the pandemic to people with I/DD in accessible formats (e.g. "plain language") that has been downloaded by hundreds of people and shared across the country.

This fiscal year 2021 funding request reflects the need for DD Councils to direct resources through partnerships with local non-profits, businesses and state and local governments, to address obstacles to community living for people with DD that they encounter every day as well as those that emerge unexpectedly during disaster and public health emergencies, such as the recent pandemic. Community living provides opportunities for children and adults with DD to live their life to the fullest extent possible. People with DD are living longer and contributing to the social and economic growth of our country at historic levels. States and territories rely on DD Councils to turn fragmented approaches into innovative and cost-effective strategies to increase the percentage of individuals with DD who become independent, self-sufficient and integrated into the community. DD Council programs and funding helps people with DD realize competitive and integrated employment, access to qualified direct support workers, successfully transition to independent living, access affordable housing, build leadership and advocacy skills, and more. DD Council members also provide a critical and unique role in educating state and local policymakers by directly participating in the design of state and local government-funded supports and services affecting their lives.

DD Councils promote community living in the states through narrowly tailored, state-specific initiatives. For example, even though persons with developmental disabilities want to go to work and continue to be contributing members to the workforce, national statistics indicate that persons with developmental disabilities expe-

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[1] 42 U.S.C. 15001(b).

rience significantly higher unemployment rates than their peers without disabilities. To address this disparity, the Missouri DD Council invested funds for people with I/DD to get and keep competitive jobs in integrated work settings, improve transportation options and create homeownership opportunities. The "Show-Me-Careers" project scaled up evidence-based practices in eight pilot communities using approaches developed with their local community in mind, including skill-building of youth, career planning, and development of partnerships with the local business community. The DD Council also partnered with three Regional Planning Commissions and leveraged funding with the Missouri Department of Transportation (MODOT) to launch MO–RIDES, a referral service that connects riders to transportation providers. MO–RIDES works with existing transportation providers to find affordable, accessible and flexible transportation for people with DD who need a ride to work, appointments or shopping, thus improving their quality of life, by giving them greater access to their community. Finally, recognizing that people with disabilities, including people with intellectual and developmental disabilities (I/DD) face a severe housing crisis, the Missouri DD Council supported the Home of Your Own (HOYO) project for low-income (below 50 percent median) people with significant disabilities. The HOYO program has helped over 30 Missourians with developmental disabilities obtain homes throughout the state and continues beyond the grant period as Missouri Inclusive Housing Development Corporation (MoHousing).

Another example of local solutions stemming from DD Council efforts comes from Washington. The popular understanding of Autism spectrum disorder focuses primarily on children and the importance of early detection and intervention. However, Autism is a lifelong condition and supports and treatments change as people grow older. The Washington State DD Council is leading a five-year Community of Practice to explore different ways of supporting families with individuals with Autism across his or her lifespan. Some of their work includes developing strategies to address the needs of aging caregivers, establishing an adult sibling support network, educating parents with intellectual and developmental disabilities about parenting support services, and more.

The Georgia DD Council is another great example of Councils applying state-based solutions to obstacles to community living. Individuals with disabilities should have the opportunity to live full, self-determined lives in the community. That is why the Georgia Council on DD is the lead supporter of the UNLOCK! Coalition. UNLOCK! works to rebalance the state system of long-term services and supports, so that fewer dollars are spent on institutional care and more dollars are invested into home and community-based supports. Because of UNLOCK!, self-advocates, their families, providers, and other allies successfully advocated to bring additional resources for long term supports and services for people with disabilities to their state.

The 56 DD Councils require continuous support in order meet the requirements of the DD Act. The DD Act provides funding for technical assistance to DD Councils on how to implement the DD Act.[2] Previously funded through Projects of National Significance within the Administration for Community Living, starting in fiscal year 2018, Congress authorized the same technical assistance within the appropriation for DD Councils. Unlike previous years, the fiscal year 2018 and fiscal year 2019 legislation did not contain report language to protect technical assistance funding at levels that reflect the need for these services. Unfortunately, for both fiscal year 2018 and 2019, the Secretary of Health and Human Services reduced funding both through a departmental transfer as well as for other administrative needs in the department. For that reason, NACDD respectfully requests that the committee include report language reflecting minimum levels of funding of not less than $700,000 for technical assistance and training.

Please contact Erin Prangley, NACDD Director, Policy, at eprangley@nacdd.org if you require additional information. Thank you for consideration of this request.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF COUNTY AND CITY HEALTH OFFICIALS

The National Association of County and City Health Officials (NACCHO) is the voice of the nearly 3,000 local health departments-including city, county, metropolitan, district, and tribal agencies-across the country. As we are currently seeing with our nation-wide response to the novel coronavirus (COVID–19), local health departments are on the front lines of the response to any public health crisis. However,

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[2] The Information and Technical Assistance for Councils on Developmental Disabilities is a federally funded technical assistance project authorized by Section 129(b) of PL 106–402.

years of underfunding have left them without the workforce and funding to respond most effectively to this and other challenges. Therefore, NACCHO requests that Congress include in its fiscal year 2021 spending bill at least $200 million to establish a public health workforce loan repayment program at the Health Resources and Services Administration (HRSA), as well as $8.3 billion in overall funding for the Centers for Disease Control and Prevention.

Local health departments prepare and respond to all types of public health emergencies. In recent weeks and months, public health professionals in these departments have rapidly mobilized to serve on the front lines of the COVID–19 crisis. The nation is seeing the troubling result of years of funding cuts and stagnation. Today, our system is under intense stress with frontline public health workers diverting their attention to the COVID–19 response while trying to continue the ever-important daily work of defending against chronic and long-term disability and disease, keeping our food and water safe, and addressing persistent challenges like substance misuse-problems that do not disappear simply because a greater threat is present. The lack of investment in the public health workforce and infrastructure is exacerbated in local health departments that serve smaller populations with smaller staffs who may not even have the workforce to remove from regular duties to help coordinate the outbreak response in their communities. Now is the time to better fund our public health infrastructure, including our workforce.

PUBLIC HEALTH WORKFORCE

NACCHO is requesting a $200 million appropriation to establish a public health loan repayment program at HRSA. This program—modeled off the success of the National Health Service Corps in bringing healthcare providers to communities in need—will help health departments across the country recruit and retain staff who can tackle 21st Century challenges and increase health departments' capacity to keep the public healthy and safe.

Governmental public health was hit hard by the Great Recession, and while much of the rest of the public sector workforce has recovered or grown, local and state health departments have not. In fact, local and state health departments have lost nearly a quarter of their workforce since 2008, shedding over 50,000 jobs across the country. A first step to address the public health workforce shortage is enacting and implementing a loan repayment program for public health professionals who agree to serve 2 years in a local, state, or tribal health department, in order to help recruit and retain trained staff. New staff and volunteers are being brought into the field for the COVID–19 response. This program would provide an incentive to keep them long term and help ensure that their experience is harnessed and available before the next crisis hits. The COVID–19 emergency has shown the holes in the public health infrastructure and the lack of surge capacity for responding to an emergency at the same time as meeting other public health needs. Structural investments are needed to be better prepared before the next outbreak.

CENTERS FOR DISEASE CONTROL AND PREVENTION

NACCHO appreciates the increase in funding for the Centers for Disease Control and Prevention (CDC) in fiscal year 2020 and urges the subcommittee to support a top line of at least $8.3 billion for CDC in fiscal year 2021. This is in line with the 22×22 campaign, to raise the CDC's budget 22 percent by 2022, which was started in 2019 with support from NACCHO. The need for core support for CDC is much greater than this; however, this funding request takes into account limitations due to budget caps.

In addition to rebuilding the workforce, investment in the CDC is critical for local health departments to successfully implement programs which keep our communities healthy and prepared to respond to the ever-growing list of public health emergencies such as the current COVID–19 outbreak. The CDC plays an important role in support of local health departments in many ways, including: supporting local health departments' ability to detect and respond to infectious disease and outbreaks through national surveillance systems and alerts, providing important subject matter expertise in the event of an outbreak of an emerging infectious disease, providing logistics, communication, analytics and other support functions during an emergency response. Congress should support CDC as an agency and the individual programs that it funds.

A few cities and counties receive funding directly from CDC; however, much of CDC's funding for local health departments goes through state health departments as the primary grantee. It is critically important that the necessary amount of Federal funds is allocated to local health departments who merge public health expertise with thorough understanding of local conditions to keep all communities healthy and safe. In addition, we ask the committee to ask CDC for greater visibility as to how much funding provided to state health departments reaches local communities through subgrants.

While emergency funds have been authorized to help respond to the COVID–19 emergency, public health departments need predictable, robust support to address health needs across the spectrum of infectious disease, chronic disease and emergency preparedness. Whether the department is responding to a measles outbreak, trying to solve their community's substance abuse crisis, or investigating vaping related illnesses, these funds go towards life-saving planning and response efforts in each Senator's state.

The response to COVID–19 shows that robust Federal investment in public health is needed to help people be safe and healthy. Thank you for your attention to these recommendations to strengthen public health.

[This statement was submitted by Lori Tremmel Freeman, MBA, Chief Executive Officer, National Association of County and City Health Officials.]

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF DRUG COURT PROFESSIONALS

Chairman Blunt, Ranking Member Murray, and distinguished members of the subcommittee, I am honored to have the opportunity to submit my testimony on behalf of this nation's more than 4,000 drug treatment courts and the 150,000 people they will connect to lifesaving addiction and mental health treatment this year. Given the unprecedented success of drug treatment courts and the growing need in communities around the country for solutions to the addiction epidemic, I am requesting Congress maintain level funding of $70 million for the fiscal year 2021 Drug Treatment Court Program at the Department of Health and Human Services, Substance Abuse and Mental Health Services Administration (SAMHSA).

In 2011, I graduated from the Stone County DWI Court in Stone County, Missouri. After my eighth DWI arrest, I was looking at 7 years in prison but was offered DWI court instead. The Stone County DWI court provided me with the treatment, structure, accountability, and social skills I needed to find my path to recovery. Today, I am a substance use disorder counselor and part of the same DWI court team that helped me achieve recovery. I am also the founder and director of Peeps in Recovery and the first alumnus on the Missouri Association of Treatment Court Professionals board of directors.

I have first-hand knowledge of the importance of combining treatment with accountability. DWI courts and other treatment courts hold offenders accountable for their actions while connecting them with evidence-based drug treatment to address the underlying cause of the crime so it doesn't happen again. Stone County's drug treatment court program expanded to include models for adults, DWI offenders, and veterans. The work of all three is ending the cycle of individuals coming in and out of our justice system and committing crimes in service to their addiction or mental health disorder.

Stone County receives funding from SAMHSA which allows our drug treatment court programs to expand capacity, offering more evidence-based treatment for more people in the justice system. SAMHSA dollars allow the drug treatment court programs to partner with Drury University in Springfield, Missouri for ongoing, independent evaluations of our program, giving us the statistics that show our Federal, state, and local funding is a positive investment in the future of our community.

The Government Accountability Office finds drug treatment courts reduce crime by up to 58 percent. Further, in what is widely regarded as the most comprehensive study on drug treatment courts to date, the Department of Justice, National Institute of Justice Multi-Site Adult Drug Court Evaluation (MADCE) confirmed drug treatment courts significantly reduce both drug use and crime, and found cost savings averaging $6,000 for every individual served. The MADCE further found drug treatment courts improve education, employment, housing, and financial stability for nearly all participants. They are proven to promote family reunification, reduce foster care placements, and increase the rate of addicted mothers delivering babies who are born drug-free.

But beyond these numbers, drug treatment courts are bringing hope to so many. I started drinking when I was 11 years old. I told myself that I would never act like my other family members when I was drinking. There would be no violence, no turmoil, no trauma, and no sickness. But learned behaviors have a way of repeating themselves when you do not know any other way, and I made the same mistakes as my family. My continuous drinking led to arrests, multiple jail sentences, and combined two-and-a-half years in prison.

In 2010, I woke up handcuffed in a Stone County jail. I'd been arrested on my eighth DWI charge, just shy of my 40th birthday. At that moment, I conceded that, like my other family members before me, I would die from this disease. When they brought me into the courtroom, the judge called me by name and said something I'd never heard a judge say he was going to help me. For the first time, I left a courtroom with hope, something I'd longed to feel for years. After five days in medical detox, I spent thirty days in inpatient treatment before starting the DWI court program because I was that sick. My treatment also included intensive outpatient services and medication-assisted treatment.

The Stone County DWI Court not only provided treatment services and accountability, they taught me the skills I needed to maintain meaningful, healthy relationships. The court provided family counseling for my adult son and me, showing us healthy ways to deal with anger and pain without alcohol. The program broke our cycle of generational addiction. I am proud my grandchildren have never seen me drink.

I strongly urge this committee to recommend level funding of $70 million to the Drug Treatment Court Program so people like me, and the 1.5 million others served by drug treatment courts in the last 30 years, continue to receive lifesaving treatment and accountability.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF RSVP DIRECTORS

The National Association of RSVP Directors (NARSVPD) appreciates the opportunity to submit testimony recommending an fiscal year 2021 funding level of $63 million for the RSVP program, administered by the Corporation for National and Community Service (CNCS).

This additional $12 million will help programs cope with the effects of the Coronavirus pandemic, bring successful programs to scale, enable more seniors live independently, support veterans and military families, and meet other local needs.

Volunteer Match reports a nationwide need for 624,300 volunteers of whom 223,700 are specifically to aid communities affected by the Coronavirus. Many of these activities can be done by RSVP volunteers.

RSVP deploys more than 200,000 volunteers in more than 600 programs to support the efforts of thousands of community organizations across the nation. It provides opportunities for people 55 and over to make a difference in their communities through volunteer service. It offers maximum flexibility and choice to its volunteers by matching the personal interests and skills of volunteers with opportunities to help solve community problems.

The funds that we request will also help compensate for the loss of non-Federal revenues as sponsors have suffered financially. Programs' own fundraising events have been cancelled or delayed indefinitely.

The pandemic has changed the landscape for RSVP. NARSVPD conducted a survey during the week of May 5–May 10. Most respondents report that no more than about 30 percent of their volunteers are serving at the present time, although it is clear that more volunteers could serve if CNCS provided additional funding and administrative relief that gave programs more flexibility.

Our survey revealed that senior volunteers are playing an important role in combatting the pandemic and could do even more with increased support.

Today, RSVP volunteers are doing grocery shopping, serving in food pantries and Meals on Wheels programs preparing and delivering food to those in need. They have instigated Pen Pal programs with school students, nursing home residents, veterans, and others. Volunteers are virtually tutoring and mentoring for students in need of reading assistance. They are helping low-income people with income tax preparation. They are planting community gardens. They are doing state health insurance counseling by phone. They are conducting telephone/Virtual Reassurance Programs. They are helping homebound individuals who have limited access to transportation. Finally, they are participating in phone banking and other emergency management activities and providing medical transportation with appropriate safeguards.

Respondents to our survey believe that getting back to original numbers of volunteers will take time but is achievable if programs are able to develop sample plans that insure that volunteer stations are safe for volunteering; if they are able to put volunteers at ease by providing hand sanitizer, gloves, and masks; if they can receive funds for technology like Zoom to expand virtual volunteering; and, if CNCS allows for budget flexibility for new and different supplies.

Among other ideas, programs would like the flexibility to recruit volunteers below the age of 55, develop volunteer opportunities during non-conventional hours, and expand virtual volunteer opportunities. They also seek funds and training to use social media as a recruitment tool.

We contemplate a "hybrid" volunteer culture that combines traditional volunteering with new platforms and new technology and serving both physically and virtually. This new approach to serving will require funds for technologies that enable virtual volunteering and for training volunteers. Further, if staff needs to work remotely, it will need laptops to replace phones.

It will also require flexibility at the program level to meet evolving local needs including changing outcome and performance measures to reflect new realities, providing safety measures for volunteers and offices, encouraging volunteer safety measures to reassure older volunteers, counseling for volunteers to address their concerns and fears, and help to integrate older volunteers who are computer illiterate into virtual volunteering.

Programs could clearly benefit from sharing best practices about virtual volunteering.

With Congressional support, the Corporation can facilitate the transition to the post-Corona world. It can lower age of eligibility to 45, administer liability waivers as needed, and develop contingency plans if there is a winter resurgence of the virus. CNCS should allow RSVP Directors to provide mileage reimbursement to existing volunteers unable to volunteer because of a state Stay at Home Order. CNCS could develop and disseminate strategies to address the specific concerns of older volunteers, purchase gloves, masks and other PPE equipment to distribute to programs. It can work with IRS to relax rules on tax preparation to enable preparers to be more efficient as drop off sites. It could develop a blanket MOU that would allow programs to operate in other service areas as long as they are not competing to perform the same service.

In short, the additional appropriation we seek can bring about a new era for RSVP in which volunteers perform virtual as well as traditional forms of volunteering.

The pandemic has exacerbated several trends affecting seniors. Older Americans are facing higher costs for assisted living and healthcare and are facing greater social isolation. In many parts of the country-especially counties in the rural Midwest-older Americans are "aging in place" because disproportionate shares of young people have moved elsewhere. This leaves seniors dependent on a frayed social safety net and dependent on volunteers for needed services.

According to the Population Reference Bureau, "The aging of the baby boom generation could fuel a 75 percent increase in the number of Americans ages 65 and older requiring nursing home care, to about 2.3 million in 2030 from 1.3 million in 2010. Demand for elder care will also be fueled by a steep rise in the number of Americans living with Alzheimer's disease, which could nearly triple by 2050 to 14 million, from 5 million in 2013." The need for RSVP has never been greater.

Volunteers improve the quality of life for volunteers and those they help.

According to an article published on April 22, 2018 in the Wall Street Journal, a study of 2,705 volunteers age 18 and older from found that 75 percent of those who volunteered in the past 12 months said volunteering made them feel physically healthier. A much larger study-one involving more than 64,000 subjects age 60-suggests that volunteering slows the cognitive decline of aging. The author of that study reported, "The effect is significant. It's consistent." Further, she said, "we find that as people volunteer, their cognitive health scores improve. If they don't volunteer, their cognitive scores decline faster." The reasons behind volunteering's boost to cognitive health have to do with the unique characteristics of such activity. Unlike paid work, there is a "different subjective well-being" or "warm glow" that a volunteer experiences from helping people. Volunteering is also unique "because it supplies mental, physical and social stimulation in one package." "You have to move around, you interact with people, you think about activities."

Baby boomers are also particularly susceptible to loneliness, which undermines health and is linked to early mortality, and has been found to shorten lives as much as smoking or drinking. Being lonely may be worse than being obese. A study of recently widowed older adults found that "higher intensity volunteering may be a particularly important pathway for alleviating loneliness among older adults."

A recent study of more than 64,000 subjects age 60 and older suggests that volunteering slows the cognitive decline of aging. The study found that volunteers score on average about 6 percent higher in cognitive testing than non-volunteers. The author concludes, "We find that as people volunteer, their cognitive health scores improve. If they don't volunteer, their cognitive scores decline faster."

RSVP is a valuable resource because it is not means tested and recruits volunteers without regard to income. Usually, most serve between 10 and 40 hours a week, but there is no set schedule. RSVP is flexible allowing volunteers improve the lives of their neighbors and friends every day.

RSVP is cost-effective and an excellent investment. The average Federal RSVP grant is about $80,000. This is less than the $90,156, which was national annual median cost of a semi-private room in a nursing home in 2019. In many states, it costs more to put one senior in a nursing home for a year than it does to support an entire RSVP program. Using Independent Sector's estimate of the value of an hour of volunteer service, RSVP volunteers provide more than $1 billion worth of service to the nation each year.

RSVP is a "destination" for retiring "baby boomers." Before the Coronavirus hit, some 10,000 "baby boomers" retired every day and will do so every day for the next 20 years. RSVP is the only national program able to place large numbers senior volunteers in high quality volunteer positions. CNCS reported that RSVP has increased the number of baby boomers in the program and provides those volunteers with high quality activities

RSVP helps other seniors to live independently. RSVP volunteers help keep seniors in their homes.

RSVP volunteers support veterans and military families.

We believe that restoring funding for RSVP to $63 million will help RSVP transition into a more flexible and adaptable program that will result in significant benefits to both the volunteers and the communities they serve.

For additional information, contact: Betty Ruth, NARSVPD President, at bruth@al-rsvp.com or Gene Sofer at eugenesofer@gmail.com.

[This statement was submitted by Betty M. Ruth, President, National Association of RSVP.]

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF STATE HEAD INJURY ADMINISTRATORS

Dear Chairman Blunt and Ranking Member Murray:

On behalf of the National Association of State Head Injury Administrators (NASHIA), thank you for this opportunity to submit testimony regarding the fiscal year 2021 appropriations for programs authorized by the Traumatic Brain Injury (TBI) Program Reauthorization Act of 2018 administered by the U.S. Department of Health and Human Services (HHS); and the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) program authorized by the Workforce Innovation and Opportunity Act (WIOA) of 2014. WIOA transferred NIDILRR from the Department of Education to HHS and is Administered by the Administration for Community Living (ACL). For fiscal year 2021 NASHIA is requesting:

—$19 million for HHS' Administration for Community Living's (ACL) TBI State Partnership Grant Program to provide funding to all states, territories and District of Columbia;

—$6 million for the ACL Protection & Advocacy (P&A) Grant Program to increase the amount of the awards to each state P&A program;

—$6.727 million for the Centers for Disease Control and Prevention's (CDC) TBI program authorized by the TBI Act of 2018 and administered by the National Center for Injury Prevention and Control (NCIPC)

—$5 million additional funding for the NCIPC to establish and oversee a national concussion surveillance system authorized by the TBI Program Reauthorization Act of 2018.

—$15 million over 5 years to expand NIDILRR research, administered by ACL, with the additional funding to expand the number of NIDILRR TBI Model Systems from 16 to 18.

In addition, NASHIA supports funding for CDC's and ACL's older adult falls prevention program ($2.05 million and $5 million) and the injury control research centers ($9 million).

In 2013, 2.8 million Americans sought treatment for or died from a TBI as the result of a car crash, fall, sporting or recreational injury, an assault or other contributing factor, impacting how a person is able to return to school, work, home and community due to the resulting cognitive, emotional, physical problems. It is a complex disability that challenges states' ability to provide the right services at the right time. As no two people with brain injury are alike, no two states are alike in how they provide services, supports and resources.

The HHS' ACL Federal TBI State Partnership Grant Program is the only program that assists states in addressing the complex needs of individuals with TBI. Two years ago, ACL awarded 3-year grants to 24 states at either $300,000 or $150,000 annually to improve and expand service delivery. Last year, the ACL awarded grants to three more states in the amount of $150,000 each year for 2 years. Considering the number of individuals who sustain a TBI each year and the number who are living with a TBI, this amount is certainly inadequate for states to address the extensive needs to assist individuals to live as independently as possible.

Current state grantees have identified and are assisting high risk populations, which include youth and adults with TBI in juvenile justice and criminal justice systems; older adults with fall-related TBIs; returning servicemembers and veterans; and young children in pre-school programs through screening, training, and linking individuals to services. Some states are also addressing such issues as TBI and opioid misuse; improved linkages from hospital to home and community; and improving and expanding state and Federal funding streams that may be available for home and community-based services in lieu of nursing facility level of care. At the end of each grant funding cycle, states have found it difficult to continue these activities without increased and sustainable funding to help to continue this important work.

Over the course of recovery, there are many entities involved that are difficult for those with a TBI and their families to negotiate. These entities include emergency departments; medical and rehabilitative facilities and programs, such as trauma designated hospitals; post-acute rehabilitation programs; education, if school aged; vocational rehabilitation, if returning to work; therapies to maintain physical and cognitive functioning; and community services and supports to enable the individual to return to the community to live as independently as possible. Payers for these type of services include private health insurance, Workers' Compensation; Medicaid; Medicare; state revenue; private pay; and public assistance programs. Navigating this path to recovery is overwhelming for individuals and their families. To assist with the coordination of rehabilitative care, services and supports, many states administer service coordination or case management systems supported by Medicaid, state funding or dedicated funding from fines or fees, referred to as trust fund programs. Not all states, however, have this resource and those states that do, may not have adequate provider networks throughout the state.

States primarily incur the burden of TBI with regard to individuals who need ongoing, crisis or short-term services and supports that are not paid for through private healthcare insurance plans. About half of the states have enacted legislation to establish a trust fund program for such purposes; a few state legislatures appropriate general revenue to fund services; about half of the states have implemented brain injury Medicaid Home and Community-Based Services (HCBS) waiver programs; and some state programs use a combination of these funding sources to support the array of needs. These services include post-acute rehabilitation; personal care; service coordination or case management; assistance with activities of daily living; in-home accommodations and modifications; transportation; and therapies, including behavioral, cognitive, speech-language and physical therapies. With limited state resources to address these needs, many individuals, particularly those with behavioral issues, addiction problems, and poor judgment, will find themselves homeless or in correctional facilities. The Federal grant program provides additional resources to address these issues.

The ACL's Administration on Intellectual and Developmental Disabilities, which administers the TBI State Protection & Advocacy (PATBI) grant program, awards grants to each state and territory at a minimum of $50,000. The requested amount will increase the amount awarded to state and PATBI grantees.

The requested $5 million for the CDC's National Center for Injury Prevention and Control to establish and oversee a national concussion surveillance system will greatly assist states as they target their resources to better meet and understand the needs of individuals who sustain a concussion. States also benefit from research conducted by the TBI Model Systems funded by NIDILRR), also housed in the ACL, to assist with "best practices" to ensure good outcomes.

In keeping with our mission, NASHIA, a nonprofit organization, works on behalf of states to promote partnerships and build systems to meet the needs of individuals with TBI with the goal of all states having resources to assist individuals with TBI to return to home, community, work and school after sustaining a brain injury, as well as assistance to family members who often serve as primary caregivers.

Federal funding is needed to help states to address injury prevention, including high risk populations such as older adult falls, and to help states to better determine and address needs through ACL TBI grants. Should you wish additional information, please do not hesitate to contact Becky Corby, NASHIA Government Relations, at (rcorby@ridgepolicygroup.com) or Susan L. Vaughn, Director of Public Policy, at (publicpolicy@nashia.org). Thank you for your continued support.

[This statement was submitted by Susan L. Vaughn, Director of Public Policy, National Association of State Head Injury Administrators.]

Prepared Statement of the National Association of State Long-Term Care Ombudsman Programs

Chairman Blunt and Ranking Member Murray, I present this testimony on behalf of the nearly 71,000 residents in Washington State's long-term care facilities and in collaboration with the National Association of State Long-Term Care Ombudsman Programs (NASOP). As you know, we are immersed in our work to serve the residents of long-term care facilities under the terrible cloud of the COVID–19 pandemic. Therefore, this testimony has not been updated since last year. Our requests, however, are still relevant to our current needs. Thank you for your past support of State Long-Term Care Ombudsman Programs (SLTCOPs) and the vulnerable citizens that it serves, particularly in the CARES Act. I submit this statement and the funding recommendations for the fiscal year 2021 for SLTCOPs administered through the Administration for Community Living, in the Department of Health and Human Services to include:

—$20 million for assisted living ombudsman services under Title VII of the Older Americans Act;
—$35 million for our current core funding under Title VII of the OAA; and
—$5 million under the Elder Justice Act for training and services to address increasing abuse, neglect, and exploitation, including related to staff that are part of the opioid crisis.

Long-term care ombudsmen help older adults and people living with disabilities have a good quality of life, receive quality care, and be treated with dignity. LTC Ombudsmen are paid professionals who recruit, train and oversee teams of local volunteers who want to give back to their communities. The advocacy we provide is the first line of protection for thousands of elders living in licensed long-term care facilities. Last year, volunteers in Washington donated approximately 34,002 hours of their time and skill to resolve complaints made to the program with a success rate of nearly 90 percent. We save the State resources by resolving complaints at the lowest level keeping them out of the expensive regulatory and legal systems. However, like our sister program's across the nation, we are not able to keep up with consumer needs and growing costs which is of concern giving the aging of the baby boomer generation in the U.S.

In Washington and other states, the number of Assisted Living Facility residents has grown tremendously. By the end of 2019, Washington will have 2,000 additional assisted living facility beds but no expansion in ombudsman services. The growing number of long-term care residents makes it financially and resources to provide the cost saving advocacy services provided by LTC Ombudsman Programs.

To alleviate the effects of diminished budgets and expanding long-term care populations, we respectfully request the following funding to support all SLTCOPs.

First, we request $20,000,000 to support SLTCOP work with residents of assisted living, board and care, and similar community-based long-term care settings. While the mandate to serve residents in assisted living facilities was added to our mission Act, there have been no appropriations for this function. Assisted living and similar businesses have boomed, but SLTCOP funding has not increased to meet the demand and respond to the industry boom.

Washington State has demonstrated leadership by reducing costs in their Medicaid system, while improving consumer choice in community based long-term. Assisted living has proven to be a viable option for those who qualify for more costly nursing home care, but wish to exercise their choice to live in assisted living. Assisted living residents have complex medical needs, very much like the nursing home residents of 20 years ago. Growth in the number of assisted living facilities, in conjunction with complex needs of consumers and diminished funding, threatens our nation's Long-Term Care Ombudsman Programs. These challenges to State Programs hinder our ability to meet program requirements to provide regular and timely access to all residents wanting long-term care ombudsman services. Current funding levels preclude SLTCOPs from quickly responding to complaints and monitoring facilities. Without our eyes and ears in these buildings, residents are at risk of abuse, neglect, and serious financial exploitation, and any number of violations to their rights.

Our second request is for $35,000.000, which is needed to provide core program funding for the program under Title VII of the Older Americans Act. These funds must be allocated to all fifty states. In addition to improving the quality of life and care for millions of vulnerable long-term care residents, our work saves Medicare and Medicaid funds by avoiding unnecessary costs associated with poor quality care, unnecessary hospitalizations and expensive procedures and treatments. Furthermore, nationally in 2016, nearly 7,331 volunteers served in the SLTCOP. For every one staff ombudsman, six volunteer ombudsmen serve residents. Ombudsman staff and volunteers investigated 199,493 complaints made by 129,559 individuals. Ombudsmen were able to resolve or partially resolve 74 percent—or an ombudsman resolved three out of every four complaints investigated.

In 2018, Washington State had 3,818 long-term care facilities with approximately 71,000 residents. Our state program includes myself, and two other full time staff, which has not changed much since 1989. Thankfully, we have great partnerships with other not-for-profits to operate local ombudsman programs, extending our reach into the most isolated of nursing home residents in our rural communities. These partners include seven Area Agency on Aging entities and three Community Action Programs and in total, we employ 17.51 full-time staff. Two national studies about the effectiveness about the LTC Ombudsman Program (the Institute of Medicine, and the Bader Report) have recommended that best practice be to employee one full-time paid staff ombudsman for every 2,000 long-term care residents or licensed beds. Washington State falls short of that goal at having only 49 percent of the needed paid staff.

Although we have a great team of paid and volunteer ombudsmen, our program is still not able to cover every facility in our state. Nearly half of the licensed facilities in our state never receive routine visits by an ombudsman, which is the hallmark activity of the Program and vital to building trusting and effective working relationships. We are so busy responding to complaints and phone calls that we are not able to conduct regular outreach, build presence in all facilities, and make our services known to isolated residents and their family members. We are overwhelmed with complaints about unwanted and unlawful discharges, also known as, “resident dumping” by residents, their loved ones and by hospitals, which involves expensive legal issues, interactions with multiple health and long-term care community systems, state entities and the courts.

Third, we request $5,000,000 to support the work of SLTCOPs under the Elder Justice Act (EJC). This appropriation would allow states to hire and train staff and recruit more volunteers to prevent abuse, neglect, and exploitation of residents and investigate complaints. However, the funds have been authorized since 2010, to date no EJC funds have been appropriated for SLTCOPs. Currently, Federal Older Americans Act funding comprises about a third of the total funding required to maintain the Washington Long-Term Care Ombudsman Program, at its current level, with the majority of funding coming from our State General Funds. We understand that this subcommittee faces a strained financial situation, but a continued commitment to SLTCOPs protects the health and safety of millions of older adults living in nursing homes and assisted living facilities. I believe their protection should remain a high priority.

Demand for our services is growing. The number of complex and very troubling cases that long-term care ombudsmen investigate has been steadily increasing. In addition, there continues to be a disturbing increase in the frequency and severity of citations for egregious regulatory violations by long-term care providers that put residents in immediate jeopardy of harm, which, unfortunately, is true for nursing homes in my state. Ombudsmen are needed now more than ever in nursing homes, assisted living, and similar care facilities where we are required to serve.

The people who operate long-term care facilities have recognized the value and benefit of having ombudsmen assist with staff training and consultation. In order to improve advocacy and services available to residents, our office and NASOP respectfully request the aforementioned funding levels. We also appreciate that the testimony of the Elder Justice Coalition also calls for these increases.

Thank you for your ongoing support.

[This statement was submitted by Patricia L. Hunter, MSW, Washington State Long-Term Care Ombudsman.]

PREPARED STATEMENT OF THE NATIONAL COALITION OF STD DIRECTORS

Chairman Blunt, Ranking Member Murray, and Subcommittee Members:

I am providing this testimony on behalf of the National Coalition of STD Directors (NCSD), a national membership organization representing STD programs at health departments in all 50 states, seven large cities or counties, and eight U.S. territories, to request funding for the Division of STD Prevention at Centers for Disease Control and Prevention (CDC) at no less than $1.6 billion, no less than $20 million for a special initiative to end congenital (mother to child) syphilis, and no less than

$1.8 billion in COVID–19 supplemental funding to support STD programs in their response to the novel coronavirus . This testimony reflects the voices and perspectives of STD programs across the U.S. who are overwhelmed, underfunded and fighting a losing battle against sexually transmitted diseases (STDs).

I have a very simple message for you and that is that STD prevention is core public health work. STD programs have been leaders in quickly responding to outbreaks for years. Fighting the coronavirus pandemic has shown how important contact tracing is to prevent the spread of viruses or infections. The unsung heroes on the front lines of contact tracing and keeping Americans safe every day are Disease Intervention Specialists (DIS). After an individual tests positive for an STD, DIS are responsible for identifying their partners and ensuring that exposed individuals are connected to testing and treatment. In the United States today there are 2,000 DIS, 75 percent of whom are trained in emergency response. We've heard from our membership that DIS are being reassigned to support with coronavirus response, including training and supervising the hiring of new contact tracing teams. This means while DIS are performing vital investigations related to COVID–19, it comes at the cost of preventing more STD infections. DIS are often the first to be deployed in assisting with outbreak response, but for years have been underfunded. Now, in a time of increased need, DIS are stretched thin. We need to invest in them now, not only to support any future crisis, but to support them in addressing STDs, which are currently at the highest levels ever.

STD program staff are highly trained in interviewing, blood draws, and implementing culturally sensitive care, which are all essential skills needed for outbreak response. DIS and STD epidemiologists are first on-the-scene when there is an infectious outbreak, but for more than 15 years, the STD programs that support them have been flat-funded. Without resources to hire and train new staff, STD programs have been hallowed out. Coronavirus response has shown us how crucial these workers are and will continue to be in the future. U.S. Congress must invest in STD programs to protect the current and future health of Americans.

Furthermore, as our woefully unprepared medical and public health systems respond to COVID–19, STD clinics have also been on the front lines to combat the outbreak. To respond to COVID–19 STD clinics have reduced or suspended services and clinics have become de facto COVID–19 testing sites. Patient access to STD services across the country has been disrupted tremendously, and the barriers to care are insurmountable indefinitely as we await the trajectory of the virus.

As we work to bring COVID–19 under control, we want to also look ahead to help states and clinics train and expand STD programs so they are prepared for other contagious disease outbreaks while still maintaining their focus on STDs. A supplemental increase of $1.8 billion, $1.3 billion to hire and train DIS and $500 million to support clinics will help STD programs and providers in their response to coronavirus while also maintaining their regular workload and public health operations.

With STDs at epidemic levels, and in a field that is already woefully underfunded, there must continue to be dedicated resources for identifying and testing new cases, otherwise rising STD rates will continue unabated. Data released in October 2019 by the Centers for Disease Control showed that after 5 years of dramatic increases, combined cases of syphilis, gonorrhea, and chlamydia reached all-time highs in the U.S. These historic increases have created a public health emergency with devastating long-term health consequences including infertility, cancer, transmission of HIV, and infant and newborn death. This number is expected to drastically increase due to years of limited resources, and the much-needed redistribution of STD resources to fight the novel coronavirus. Supporting an increase of $1.6 billion to STD prevention at CDC in fiscal year 2021 is an important investment in our public health infrastructure, and for keeping Americans healthy.

Did you know that last year over 1,000 infants were born with congenital syphilis in the United States? Congenital syphilis occurs when syphilis is passed from a mother to her baby during pregnancy or delivery. Congenital syphilis increased by more than 40 percent between 2017 and 2018, resulting in a 22 percent increase in newborn deaths. Congenital syphilis is completely preventable with early prenatal care and STD testing. Unfortunately, during coronavirus response, some DIS have had to reduce the number of syphilis case investigations to assist with COVID–19 contact investigations. We cannot let mothers with potential syphilis infections slip during the cracks in the midst of another infectious disease outbreak. It is critical that we provide adequate funding in order to eliminate syphilis in our lifetime. Are you aware that in 2018 congenital syphilis cases surpassed the number of perinatal HIV cases? This is largely thanks to the Federal investment in innovative approaches dedicated to HIV, resulting in the number of reported perinatal HIV cases to decrease. With your support we can achieve similar results for congenital syphilis. The Senate must invest $20 million in direct service funding for congenital syphilis prevention and treatment.

In summary, supporting STD programs is supporting public health. For the past 15 years the Federal STD program at CDC has been level funded resulting in a crumbling infrastructure and inadequate tools for preventing new cases of STDs. It is times like these that showcase the importance of our public health workforce. If the Senate does not invest in STD programs now, not only will there not be enough workers for future outbreaks, but the United States will continue to see STD rates skyrocket, and newborns die. In order to ensure that STD programs have the support they need to fight coronavirus, and bounce back once the outbreak response is completed, the United States Senate must:

- —Support a supplemental increase of $1.8 billion to respond to the novel coronavirus
  - —$500 million for STD clinics
  - —$1.3 billion to hire and train DIS to conduct contract tracing
- —Increase STD funding at CDC by $1.6 billion in fiscal year 2021
- —Invest $20 million in ending Congenital Syphilis

By taking these small steps, the Senate will show its support for this crucial public health program, and avert STD consequences including infertility, newborn death, new HIV cases, and cancer.

If you have any questions or would like additional information, please contact NCSD's Taryn Couture, associate director of policy government relations, at tcouture@ncsddc.org.

Sincerely.

[This statement was submitted by David Harvey, Executive Director, National Coalition of STD Directors.]

PREPARED STATEMENT OF THE NATIONAL CONGRESS OF AMERICAN INDIANS

On behalf of the National Congress of American Indians (NCAI), the oldest, largest, and most representative national organization comprised of American Indian and Alaska Native tribal nations, thank you for the opportunity to provide written testimony regarding fiscal year 2021 appropriations on funding for tribal and related programs in the Departments of Education, Health and Human Services, Labor, and Related Agencies.

U.S. DEPARTMENT OF EDUCATION

It is imperative that American Indian/Alaska Native (AI/AN) students receive a quality education. However, in Indian Country, daunting challenges are preventing this from becoming a reality for all AI/AN students, including aging school facilities, limited access to broadband, ruralness and remoteness impacting school attendance, difficulty recruiting and retaining teachers, and a lack of culturally appropriate educational opportunities. These challenges have led to a graduation rate of 72 percent for AI/AN students compared to an 85 percent graduation rate for the rest of the country.

There are approximately 620,000 (93 percent) Native students enrolled in public schools in both urban and rural areas, while 45,000 (seven percent) attend schools within the Bureau of Indian Education. Effectively reaching all Native students requires a concentrated and sustained effort from multiple partners: tribal nations, the Federal Government, state and local education agencies, Native parents and families, and communities. Accordingly, NCAI requests the following levels of programmatic support.

U.S. DEPARTMENT OF EDUCATION FISCAL YEAR 2021 REQUESTS

Department Education Programs	NCAI Fiscal Year 2021 Request
Title 1, Part A (Local Education Agency Grants)	$20,000,000,000
Student Assessment Systems under the Every Student Succeeds Act (ESSA)	$35,000,000
State-Tribal Education Partnership (STEP) Program	$5,000,000
Title VII funding, ESEA (Impact Aid Funding)	$2,000,000,000
Title VI funding, Every Student Succeeds Act (ESSA)	$198,000,000
Native Hawaiian Student Education (Title VI, Part B)	$42,000,000
Alaska Native Education Equity Assistance Program (Title VI, Part C)	$42,000,000
Indian Education Language Immersion Grants (Title VI)	$18,000,000
Special Programs for Native Student, Including Native Youth Community Projects	$68,000,000

U.S. DEPARTMENT OF EDUCATION FISCAL YEAR 2021 REQUESTS—Continued

Department Education Programs	NCAI Fiscal Year 2021 Request
Title III–A Grants under the Higher Education Act for Tribal Colleges and Universities	$81,696,000
Tribal Colleges and Universities: Adult/Basic Education	$8,000,000
Tribally Controlled Post-Secondary Career and Technical Institutions and Technical Institutions	$12,000,000
Native American-Serving, Non-Tribal Institutions (Higher Education Act, Title III–F)	$10,000,000
Tribal Education Departments (Dept. of Ed)	$10,000,000
Total	$22,529,696,000

Indian Education: Alaska Native Education Program (Title VI, Part C) and Native Hawaiian Education Program (Title VI, Part B): NCAI is concerned that the President's fiscal year 2021 budget eliminates funding for the Alaska Native Education Program and the Native Hawaiian Education Program. These programs fund the development of curricula and education programs that address the unique educational needs of Alaska Native and Native Hawaiian students, as well as the development and operation of student enrichment programs. NCAI recommends funding these two programs, each at $42 million for fiscal year 2021.

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

The health and wellness of tribal communities depends on a network of healthcare, education, wellness service providers, prevention coordination, and tribally-driven initiatives. Despite the Federal government's trust responsibility to provide healthcare, the Indian Health Service, Tribal Health Programs, and Urban Indian Organizations (collectively known as the I/T/U) system face significant funding disparities, notably in per capita spending between the Indian Health Service (IHS) and other Federal healthcare programs. The I/T/U system is critical to securing the health and wellness of tribal communities. To meet the Federal Government's fiduciary responsibility and the health needs of tribal communities, NCAI requests the following levels of programmatic support.

DEPARTMENT OF HEALTH AND HUMAN SERVICES FISCAL YEAR 2021 REQUESTS

Department of Health and Human Services Programs	NCAI Fiscal Year 2021 Request
Total Fiscal Year 2021 Indian Health Service Funding	$9,145,000,000
Services	$6,825,000,000
Contract Support Costs	$922,300,000
Facilities	$1,398,000,000
Special Diabetes Program for Indians (SDPI)	$200,000,000
On the TRAIL (Together Raising Awareness for Indian Life) to Diabetes Prevention Program	$1,000,000
HRSA Native Hawaiian Healthcare Systems Program	$25,000,000
Ending HIV Epidemic/Hepatitis C Initiative	$25,000,000
Head Start	$10,810,000,000
TCU Head Start Partnership Program	$8,000,000
Native Languages Preservation (NLP), with Esther Martinez Program (EMP)	$15,000,000 for NLP, W/$6,000,000 for EMP
Promoting Safe and Stable Families, Title IV–B, Subpart 2 Discretionary Funds (3 percent tribal allocation reserved from this amount)	$110,000,000
Tribal Court Improvement Grant Program (authorized under Title IV–B, Subpart 2)	$3,000,000
Child Abuse Discretionary Activities, Innovative Evidence-Based Community Prevention Program	$38,000,000
Community-Based Child Abuse Prevention	$60,000,000
Maternal Infant and Early Childhood Home Visiting Program	$420,000,000
Child Welfare Services, Title IV–B, Subpart 1 (tribal allocation reserved from this amount)	$280,000,000
SAMHSA Programs of Regional and National Significance, Child and Family Programs	$8,000,0000
SAMHSA Garrett Lee Smith Grants, State/Tribal Youth Suicide Prevention and Early Intervention Grant	$40,000,000
SAMHSA Garrett Lee Smith Grants, Campus Suicide Prevention Program	$9,000,000 +
SAMHSA American Indian and Alaska Native Suicide Prevention	$5,000,000
SAMHSA Tribal Behavioral Health Programs (Mental Health and Substance Abuse Programs)	$50,000,000
Older Americans Act (Title VI-Part A,B)	$43,000,000
Older Americans Act (Title VI-Part C)	$12,100,000
Older Americans Act (Title VII-Subtitle B)	5 percent tribal set-aside

DEPARTMENT OF HEALTH AND HUMAN SERVICES FISCAL YEAR 2021 REQUESTS—Continued

Department of Health and Human Services Programs	NCAI Fiscal Year 2021 Request
Low Income Home Energy Assistance Program (LIHEAP)	$4,700,000,000 with $51,000,000 allocated to tribes and tribal organizations
Total	$26,085,400,000

Substance Abuse Mental Health Services Administration: These funds are critical to supporting mental health services and substance abuse prevention activities aimed at high-risk American Indian and Alaska Native youth and their families. NCAI requests $50 million in total for SAMHSA Tribal Behavioral Health Programs ($25 million for Mental Health and $25 million for Substance Abuse Programs).

Low-Income Home Energy Assistance Program (LIHEAP): NCAI requests $4.7 billion for LIHEAP, with $51 million directly allocated to tribal nations and tribal organizations. LIHEAP helps low-income households and seniors with their energy bills, providing vital assistance during both the cold winter and hot summer months.

U.S. DEPARTMENT OF LABOR

Workforce development success in Indian Country depends on the ability of tribal nations, Native organizations, and Tribal Colleges and Universities (TCUs) to craft innovative, customized solutions designed for the particular capacity building needs of their tribal communities. To that end, the appropriate role of the Federal Government is to support governance freedom, programmatic flexibility, training and technical assistance, and resources that Indian Country needs to design and implement bold strategies capable of advancing each community's workforce development priorities. The Federal Government must work closely with tribal communities to identify and address obstacles that currently obstruct tribal innovation and create new opportunities for tribal ingenuity to flourish. The Federal Government must endow its systems, programs, and funding protocols with the ease and adaptability that tribal nations need to effectively build their human capacity in accordance with their cultural values and in furtherance of their community and economic development goals. The following fiscal year 2021 budget requests set forth appropriation levels that are essential to empowering tribal efforts to advance the economic security of tribal nations.

DEPARTMENT OF LABOR FISCAL YEAR 2021 REQUESTS

Department of Labor Programs	NCAI Fiscal Year 2021 Request
YouthBuild Program	$89,000,000
Division of Indian and Native American Programs (DINAP)	$60,500,000
Native American Employment and Training Council	$125,000
Older Americans Act (Title V), Senior Community Service Employment Program	$434,371,000
Total	$583,996,000

Senior Community Service Employment Program (SCSEP): NCAI urges Congress to fund SCSEP at $434 million. This program is the only Federal job training program focused exclusively on helping older Americans return to the workforce. Through the program, low-income job-seekers (55 years of age or older) update their skills and contribute to their communities through paid, on-the-job training at schools, hospitals, senior centers, tribal facilities, and other non-profit or public facilities.

CORPORATION FOR PUBLIC BROADCASTING (CPB)

The ability to communicate keeps communities safe and promotes trade and commerce. Tribal access to modern communications networks supports economic development, tribal governance, healthcare, education, and public safety in tribal and surrounding communities. NCAI requests the following levels of programmatic support.

CORPORATION FOR PUBLIC BROADCASTING (CPB) FISCAL YEAR 2021 REQUESTS

Corporation for Public Broadcasting	NCAI Fiscal Year 2021 Request
American Indian and Alaska Native Radio Station Grants	$7,000,000
Native Public Media	$500,000
Native Public Media and Koahnic Broadcast Corporation	$500,000
Total	$8,000,000

CONCLUSION

NCAI appreciates the opportunity to share these recommendations. For more information, please contact Fatima Abbas, Director of Policy and Legislative Counsel, at fabbas@ncai.org or Nicholas Courtney, Policy Analyst, at ncourtney@ncai.org.

PREPARED STATEMENT OF THE NATIONAL CONSUMER LAW CENTER [1]

The Federal Health & Human Services' Low Income Home Energy Assistance Program (LIHEAP) [2] is the cornerstone of government efforts to help low-income seniors and families afford essential home energy services.[3] LIHEAP is a particularly important safety net program for the record number of unemployed and underemployed households struggling with lost jobs and diminished wages in the wake of the devastating economic disruption due to the COVID–19 pandemic.[4] We respectfully request that the subcommittee fund LIHEAP at the full authorized amount of $5.1 billion and note the need is likely to be greater.

The United States is the midst of unprecedented times as the world addresses a novel coronavirus pandemic (COVID–19). Public heath directives in most states led to the closure of non-essential businesses to slow the spread of COVID–19, hitting lower-wage service economy workers, low-income families and black and Hispanic workers particularly hard.[5] The CBO predicts unemployment in Q3 2020 could

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[1] Since 1969, the nonprofit National Consumer Law Center(r) (NCLC(r)) has worked for consumer justice and economic security for low-income and other disadvantaged people in the U.S. through its expertise in policy analysis and advocacy, publications, litigation, expert witness services, and training.

[2] 42 U.S.C. §§ 8621 et seq.

[3] Stories about the value of LIHEAP:

"*Justine of Missouri:* I work for a nonprofit that helps keep low-income, medically vulnerable St. Louisans safe in their own homes from extreme temperatures. So many of the people we serve rely on LIHEAP to keep their utilities on and their homes habitable. We consider ourselves, in part, a homelessness prevention organization. Without the ability to heat their homes in winter, our clients will not be able to age in place but will have to move in with family (if they even have any). Our donors are incredible and we're able to do so much, but we can't do it alone. Our community, like many others, needs LIHEAP."; and,

"*Raylene from California:* I am living again in my central California hometown because of the relatively low cost of living here. I rent a low cost senior apartment and have minimal insurance for my 13 year old car. I have the lowest cost medicare supplemental insurance I can find and all my other expenses are as low as I can keep them. I had to drop my renter's insurance and the newspaper because I just can't afford them. My $1103 in Social Security has stretched as far as I can manage. Without the HEAP program I would not be able to run the air conditioner during the 3 months of summer when temperatures are close to 100. We have a lot of seniors with the same concerns; please envision yourself in our shoes and keep this program for us. Thank you." For more stories, see LIHEAP Stories available at https://neuac.org/advocacy/save-liheap/liheap-stories/.

[4] See e.g., Sarah Hansen, 2.4 Million Workers Filed For Unemployment, Bringing Total to More Than 38 Million, Forbes (May 21, 2020), available at: https://www.forbes.com/sites/sarahhansen/2020/05/21/24-million-workers-filed-for-unemployment-last-week-bringing-total-to-more-than-38-million/#56c4ada9eb91.

[5] See e.g., Board of Governors of the Federal Reserve System, Report on the Economic Well-Being of U.S. Households in 2019, Featuring Supplemental Data from April 2020 (May 2020) at p.53, available at https://www.Federalreserve.gov/publications/files/2019-report-economic-well-being-us-households-202005.pdf (39 percent of workers with household incomes under $40,000 have lost their jobs); see also, CBO, Interim Economic Projections for 2020 and 2021 (May 2020) at p.4, available at https://www.cbo.gov/publication/56368 (employment between February and April 2020 declined by 16 percent overall, but by 21 percent for Hispanic workers and 18 percent for black workers).

reach15.8 percent.[6] Economists predict the United States could experience an economic downturn as severe as, or worse than the Great Recession caused by the housing market collapse.[7] Federal Reserve Chairman Powell warns that an economic recovery could take more than a year and that a full recovery might not be possible without a vaccine.[8] This caution is echoed by the CBO[9] and the former director of the Centers for Disease Control and Prevention (CDC).[10]

In most states, governors, state public utility commissions and private utility companies have implemented consumer protections from utility disconnections during the crisis.[11] These disconnection moratoria have been vital to protecting the health and safety of households, helping to slow the transmission of the virus by facilitating physical distancing by allowing people to safely stay at home. However, we estimate that many millions of low-income and newly low-income households will face the start of the fiscal year 2021 heating season already disconnected or in danger of utility disconnection. While the shut-off moratoria allow households to continue to receive utility service, they will also continue to receive utility bills and we anticipate that, due to the high unemployment rate, unpaid utility arrearages will climb during the crisis. These utility arrearages, combined with other financial hardships, will likely drive a surge in demand for LIHEAP benefits in fiscal year 2021.

The longer the shut-off moratoria are in place, the larger the arrearages for these households, for multiple essential utility services and other debt obligations. Conservative estimates of residential electricity customers in arrears during the COVID–19 disconnection moratoria range from $6 billion to $14 billion.[12]

For decades, LIHEAP has been a reliable safety net program specifically tailored to help low-income households stay warm and avoid hypothermia in the winter, as well as stay cool and avoid heat stress (even death) in the summer. The program is currently funded at $4.64 billion ($3.74 billion through the fiscal year 2020 appropriation[13] along with an additional $900 million through the CARES Act).[14]

Fiscal year 2019 funding for LIHEAP at $3.74 billion was estimated to help 6 million households maintain essential home energy service.[15] Yet, at a time when the U.S. economy was far more robust, only an estimated one in five eligible households was served by LIHEAP in fiscal year 2019.[16] Before COVID–19, there was already a large percentage of the population living on the edge of financial hardship. According to the U.S. Department of Energy's data, about one-third of U.S. households report struggling with energy affordability.[17] In 2019, the Federal Reserve reported

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[6] See CBO, Interim Economic Projections for 2020 and 2021 at p.1 (May 2020) available at https://www.cbo.gov/publication/56368.

[7] See Peter Cohan, COVID–19's Worst Case? 10.6 percent Jobless Rate, $1.5 Trillion GDP Drop, Forbes (Mar. 21, 2020), available at: https://www.forbes.com/sites/petercohan/2020/03/21/covid-19s-worst-case-106-jobless-rate-15-trillion-gdp-drop/#3ab4a19a10a2.

[8] See Sarah Hansen, Full Economic Recovery Unlikely Without Coronavirus Vaccine: Fed Chair Powell, Forbes (May 18, 2020) available at https://www.forbes.com/sites/sarahhansen/2020/05/18/full-economic-recovery-unlikely-without-coronavirus-vaccine-fed-chair-powell/#d7fa3f76f586.

[9] See CBO, Interim Economic Projections for 2020 and 2021 at p.2 (May 2020) available at https://www.cbo.gov/publication/56368 ("The persistence of social distancing will keep economic activity and labor market conditions suppressed for some time.").

[10] See Dr. Tom Frieden, Former CDC director: There's a long war ahead and our Covid–19 response must adapt, CNN Health (Updated 9:33 AM, Mar.21, 2020). Available at: https://www.cnn.com/2020/03/20/health/coronavirus-response-must-adapt-frieden-analysis/index.html (cautions the American public that this is going to be a long crisis, and because COVID–19 is so contagious we may need to maintain social distancing for an extended period of time).

[11] See National Assoc. of Regulatory Utility Commissioners, State Response Tracker, at https://www.naruc.org/compilation-of-covid-19-news-resources/state-response-tracker/ ; Energy and Policy Institute tracker at https://www.energyandpolicy.org/utilities-disconnect-coronavirus/.

[12] See John Howat, Skyrocketing Utility Arrears during COVID–19 Crisis: The Need for Substantial Federal Support, NCLC (April 2020) available at https://www.nclc.org/images/pdf/special__projects/covid-19/IB__Electric__Service__Arrearage__Narrative.pdf (very optimistic scenario of 20 percent of residential customers with a 60-day arrearage balance versus realistic scenario of 40 percent of residential customers with a 90-day arrearage balance).

[13] Further Consolidated Appropriations Act, 2020 (Public Law 116–94).

[14] Coronavirus Aid, Relief, and Economic Security (CARES) Act (Public Law 116–136).

[15] Testimony of the National Energy Assistance Directors' Association, House Subcommittee on Labor, Health and Human Services and Education and Related Agencies (April 8, 2019).

[16] See Katrina Metzler, National Energy and Utility Affordability Coalition's House Subcommittee on Labor, Health and Human Services and Education and Related Agencies fiscal year 2021 LIHEAP testimony (Mar.23, 2020).

[17] See U.S. Energy Information Administrations, Residential Energy Survey, "One in three U.S. households faced challenges in paying energy bills in 2015" (Sept. 2018), at https://www.eia.gov/consumption/residential/reports/2015/energybills/.

that 4 in 10 households would have difficulty with an unexpected expense of $400 and that 3 in 10 households would be unable to pay their bills.[18] A growing body of research has documented the rise in household income volatility (the dramatic fluctuation of income over time) and the impacts on household well-being.[19] Pre-COVID–19, approximately one-third of households experienced income volatility[20] with irregular work schedules as the leading cause of volatility.[21] Analysis of material hardship for low and moderate income consumers experiencing income volatility found much higher rates of inability to afford bills, medical care, housing payments and food,[22] and a higher likelihood to resort to expensive payday loans to pay for basic living expenses.[23] Thus, pre-COVID, too many households experienced economic fragility and energy insecurity. Now, with the economic devastation of COVID–19, a bold governmental response is necessary to keep struggling families connected to essential home energy service.

LIHEAP protects the health and safety of the frail elderly, the very young, and those with chronic health conditions that increase susceptibility to temperature extremes. LIHEAP is an administratively efficient and effective targeted health and safety program that works to bring fuel costs within a manageable range for vulnerable households.

For the reasons discussed in this testimony, we anticipate an unprecedented need for fiscal year 2021 LIHEAP funding. We respectfully request that the subcommittee fund LIHEAP at $5.1 billion for fiscal year 2021 and note that the need is likely to be even greater.

[This statement was submitted by Olivia Wein, Staff Attorney, National Consumer Law Center.]

PREPARED STATEMENT OF THE NATIONAL COUNCIL OF SOCIAL SECURITY MANAGEMENT ASSOCIATIONS

On behalf of the National Council of Social Security Management Associations (NCSSMA), thank you for the opportunity to submit this testimony regarding the Social Security Administration's (SSA's) fiscal year 2021 Appropriation. NCSSMA respectfully requests that Congress provide at least $13.904 billion in fiscal year 2021 for SSA's Limitation on Administrative Expenses (LAE) account. SSA's LAE account provides resources for general operations, continued support for much-needed Information Technology (IT) modernization and reducing the disability hearings backlog. While previous funding has certainly helped improve service to the Amer-

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[18] See Board of Governors of the Federal Reserve, "Report on the Economic Well-Being of U.S. Households in 2018 (May 2019) at p.21, available at https://www.Federalreserve.gov/consumerscommunities/files/2018-report-economic-well-being-us-households-201905.pdf.

[19] See e.g., Federal Reserve Survey of Household Economics and Decisionmaking reports available at https://www.Federalreserve.gov/consumerscommunities/shed.htm; The Aspen Institute Expanding Prosperity Impact Collaborative (EPIC) series on the issue of income volatility available at http://www.aspenepic.org/epic-issues/income-volatility/; see also, Pew Charitable Trusts, How Income Volatility Interacts with American Families; Financial Security (Mar 2017) available at https://www.pewtrusts.org/en/research-and-analysis/issue-briefs/2017/03/how-income-volatility-interacts-with-american-families-financial-security.

[20] See Daniel Schneider and Kristen Harknett, Income Volatility in the Service Sector: Contours, Causes and Consequences (July 2017) at p.3, available at http://www.aspenepic.org/epic-issues/income-volatility/issue-briefs-what-we-know/issue-brief-income-volatility-service-sector/; see also, Board of Governors of the Federal Reserve, Report on the Economic Well-Being of U.S. Households in 2018 (May 2019) at p.2, available at https://www.Federalreserve.gov/consumerscommunities/files/2018-report-economic-well-being-us-households-201905.pdf.

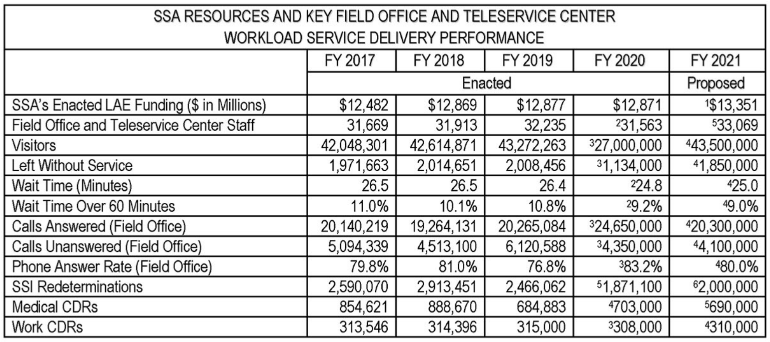
[21] See Income Volatility: A Primer(May 2016) The Aspin Institute Financial Security Program and EPIC at p.5, available at https://www.aspeninstitute.org/publications/income-volatility-a-primer/; see also, Daniel Schneider and Kristen Harknett, Income Volatility in the Service Sector: Contours, Causes and Consequences (July 2017) at p.3, available at http://www.aspenepic.org/epic-issues/income-volatility/issue-briefs-what-we-know/issue-brief-income-volatility-service-sector/; see also Asset Funders Network, Income Volatility: Why it Destabilizes Working Families and How Philanthropy Can Make a Difference at p.6m available at https://assetfunders.org/resource/afn-income-volatility-2017/.

[22] See Stephen Roll, David S. Mitchell, Krista Holub et al., Responses to and Repercussions from Income Volatility in Low- and Moderate-Income Households: Results from a National Survey, Aspen Institute EPIC, Center for Social Development, Intuit Tax & Financial Center (Dec. 2–17) at pp 6–7, available at https://www.aspeninstitute.org/publications/responses-repercussions-income-volatility-low-moderate-income-households-results-national-survey/.

[23] See Daniel Schneider and Kristen Harknett, Income Volatility in the Service Sector: Contours, Causes and Consequences (July 2017) at p. 9, available at http://www.aspenepic.org/epic-issues/income-volatility/issue-briefs-what-we-know/issue-brief-income-volatility-service-sector/(almost a quarter of consumers reporting week-to-week volatility report using payday lenders).

ican public, SSA must still replace frontline staff to address field office backlogs, answer telephones, and assist those who request our help. This level of funding will help ensure the agency can continue to build on the improvements currently underway.

We recognize the current fiscal constraints facing legislators, but we are concerned that the enacted level of $12.871 billion for SSA for fiscal year 2020 was slightly below the fiscal year 2019 enacted level of $12.877 billion. In contrast, for fiscal year 2020, NCSSMA had recommended an increase of at least $640 million over the fiscal year 2019 funding level to ensure progress continues in the areas listed below. This included an additional $300 million to improve frontline services and increase hiring in SSA field offices, $240 million to address hearing office and program service center backlogs, and $100 million to continue the agency's efforts in modernizing its systems infrastructure and software.



SSA RESOURCES AND KEY FIELD OFFICE AND TELESERVICE CENTER
WORKLOAD SERVICE DELIVERY PERFORMANCE

	FY 2017	FY 2018	FY 2019	FY 2020	FY 2021
	Enacted				Proposed
SSA's Enacted LAE Funding ($ in Millions)	$12,482	$12,869	$12,877	$12,871	[1]$13,351
Field Office and Teleservice Center Staff	31,669	31,913	32,235	[2]31,563	[5]33,069
Visitors	42,048,301	42,614,871	43,272,263	[3]27,000,000	[4]43,500,000
Left Without Service	1,971,663	2,014,651	2,008,456	[3]1,134,000	[4]1,850,000
Wait Time (Minutes)	26.5	26.5	26.4	[2]24.8	[4]25.0
Wait Time Over 60 Minutes	11.0%	10.1%	10.8%	[2]9.2%	[4]9.0%
Calls Answered (Field Office)	20,140,219	19,264,131	20,265,084	[3]24,650,000	[4]20,300,000
Calls Unanswered (Field Office)	5,094,339	4,513,100	6,120,588	[3]4,350,000	[4]4,100,000
Phone Answer Rate (Field Office)	79.8%	81.0%	76.8%	[3]83.2%	[4]80.0%
SSI Redeterminations	2,590,070	2,913,451	2,466,062	[5]1,871,100	[6]2,000,000
Medical CDRs	854,621	888,670	684,883	[4]703,000	[5]690,000
Work CDRs	313,546	314,396	315,000	[3]308,000	[4]310,000

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[1] President's FY 2021 LAE Request
[2] As of May 1, 2020
[3] NCSSMA Projection Based on August 2020 Field Office Reopening
[4] NCSSMA Projection
[5] Deputy Commissioner for Operations' Operating Plan
[6] FY 2021 Congressional Justification

The President's fiscal year 2021 budget request includes $13.351 billion for SSA's administrative expenses. As part of the fiscal year 2021 Budget Appendix, the Commissioner of Social Security expressed the following resource needs in fiscal year 2021:

> "... The Commissioner's budget includes $14,004 million for total administrative discretionary resources in 2021. This represents $13,804 million for SSA administrative expenses, $79 million in research, and $121 million for the Office of the Inspector General."

We are gravely concerned that the current coronavirus crisis and its accelerating threat to the health, economic security and well-being of our nation will have an untold negative impact on not only those seeking assistance from our agency, but on our own staff and their loved ones as well. NCSSMA appreciates that the CARES Act included $300 million for SSA's LAE account to prevent, prepare for and respond to the coronavirus. This funding will help ensure our agency can continue its mission during these unprecedented times. Because of the many unknowns associated with COVID–19, our request includes an additional $100 million above the Commissioner's budget request to support field office and teleservice telework and the processing of critical work during a crisis that is estimated to affect the American public and SSA well into fiscal year 2021.

COMMUNITY-BASED SERVICE

Adequate resources for SSA positively affect the agency's ability to deliver vital services to the American public and fulfill the agency's stewardship responsibilities. The following are examples of why it is vital SSA receives adequate resources, in a timely manner, to provide excellent service in its field offices:

> Earlier this year, our office had two Supplemental Security Income (SSI) recipients walk into our office looking for assistance. Both individuals were homeless and from outside our service area. They had no idea where to go for help and, in both cases, had no money, and did not know where they were going to spend

> the night. It was too late in the day to get them on a bus to our local Department of Social Services (DSS). Our staff made phone calls to various community agencies, found both individuals a place to sleep for the night, and arranged for transportation to the DSS office the next morning. These two individuals would have spent the night in the cold and on the street if we had not been here to assist.—*Ogdensburg, NY*
>
> A transient man arrived in the office near closing during a severe rainstorm. He came into the office requesting to file for disability benefits. Upon further development, it was discovered that the man had terminal colon cancer. The man was then referred to a CS where his claim was taken and completed after we closed to the public. During the interview, the man mentioned to the CS that he did not have any place to stay for the night. In addition to getting the claim off to DDS, the CS contacted the local Adult Protective Services and we were able to find him suitable shelter during the storm.—*Ada, OK*
>
> We had a customer who, according to our records, had filed for retirement in 2013. She received a letter that her Direct Express card was being canceled and became alarmed. She recalled signing up neither for benefits or receiving a check, nor was she in possession of a Direct Express card. Our employee reviewed the record, contacted Direct Express, and found out 6 years of benefits, approximately $50,000, was sitting untouched on her Direct Express card. The employee was able to retrieve the funds for our customer. The customer truly appreciated our help and said that we “made her Christmas”. Having adequate staff allows employees to serve the public and take the time to investigate this unusual situation and resolve it without sacrificing service to the other 200 people, on average, that our office serves in person daily.—*Spokane, WA*

While we understand the budget constraints facing legislators, when SSA’s administrative resource needs are unmet, it results in deterioration in key service areas and stewardship workloads. SSA continues to experience a large number of customers requesting assistance from field offices as members of the baby boom generation retire or become disabled. In fiscal year 2019, the national 800 number call center and field offices handled over 48 million calls from the public. Meanwhile, over 14 percent of callers received a busy signal in our teleservice centers and over 6 million calls went unanswered in the field. In fiscal year 2019, the national 800 number call wait time was 20 minutes. In addition to the almost 90 million face-to-face and telephone contacts made last year, the agency continues to have over 5 million actions pending in the program service centers. As of May 1, 2020, there were 455,304 hearings pending, down from 575,421 at the end of fiscal year 2019. Disabled individuals are waiting an average of 404 days for a hearing, down from 506 just 8 months ago. The additional resources provided in fiscal year 2018 and fiscal year 2019 have cut the number of pending hearings by more than half since fiscal year 2016 and reduced the average processing time by 201 days. These are positive steps, but progress must continue to be made. We must not lose sight of the fact that those filing for disability have conditions that worsen over time, without adequate treatment, and many experience financial hardship as they wait more than a year to have their case heard in front of an Administrative Law Judge. If SSA’s administrative funding is not adequate, these backlogs will remain, and public service levels will continue to be compromised.

FISCAL YEAR 2021 FUNDING

Resource allocations in fiscal year 2021 must be sufficient to address deficit-reducing program integrity work, as well as the massive hearings backlog, increases in other workloads, visitors, and telephone calls in field offices and to the national 800 number. In addition, resources are also necessary to advance SSA’s ongoing Information Technology (IT) Modernization project that will significantly enhance the agency’s systems and improve productivity.

To ensure a long-term solution, NCSSMA strongly believes that we must explore mechanisms for creating a more robust and predictable funding stream for SSA’s administrative expenses. NCSSMA recommends and/or endorses the following: exclude SSA’s administrative funding from any cap that sets an arbitrary ceiling on discretionary spending; remove SSA’s administrative funding from the discretionary budget caps and provide a separate limit in the Budget Resolution; establish multi-year funding for critical systems investments and expenditures; and expand the definition of program integrity funding to include critical systems investments and expenditures that facilitate completion of program integrity initiatives.

CONCLUSION

NCSSMA respectfully requests that Congress provide adequate funding for the Social Security Administration's (SSA) fiscal year 2021 administrative funding needs. We respectfully request that Congress consider funding of at least $13.904 billion for SSA's administrative expenses to ensure progress continues to be made in addressing the disability hearings backlog, the agency's IT modernization efforts and additional resources for frontline services in SSA's field offices and teleservice centers. Our request includes the Commissioner's budget request of $13.804 billion and at least $100.0 million towards continued efforts related to the coronavirus crisis and its accelerating threat to the health, economic security and well-being of our nation. In addition, NCSSMA respectfully requests that Congress explore mechanisms for creating a more robust and predictable funding stream for SSA's administrative expenses. SSA must have the necessary resources and front-line staffing to provide quality service to the American public. This includes addressing program integrity workloads that reduce improper payments and save taxpayer dollars. SSA must continue investments in IT modernization that will improve quality and efficiency and help address the high volumes of initial claims and post-entitlement work.

[This statement was submitted by Peggy Murphy, President, National Council of Social Security Management Associations.]

PREPARED STATEMENT OF THE NATIONAL FAMILY PLANNING & REPRODUCTIVE HEALTH ASSOCIATION

Chairman Blunt, Ranking Member Murray, and Subcommittee Members:

As the chief executive officer of the National Family Planning & Reproductive Health Association (NFPRHA), I thank you for this opportunity to provide testimony in support of increased Title X funding and critical program language in the fiscal year 2021 appropriations bill. I am deeply concerned by the administration's continued attacks on the integrity of the Title X program, as demonstrated by the devastating rule that the Department of Health and Human Services finalized in 2019.[1] Today, more than one million people no longer have access to Title X-supported services at the health center they used in 2018 due to the rule. I urge Congress to use the fiscal year 2021 Labor, Health and Human Services, Education, and Related Agencies appropriations bill to make a strong statement in support of high-quality, evidence-based, and patient-centered family planning care and against the Title X rule by including language to block the rule and reverse the damage done in communities across the country. With that language in place, we urge Congress to appropriate $400 million for the program, the funding level the House proposed in fiscal year 2020.

NFPRHA is a non-partisan 501(c)3 membership association that advances and elevates the importance of family planning in the nation's healthcare system and promotes and supports the work of family planning providers and administrators, especially in the safety net. Representing close to 1,000 members that operate or fund more than 3,500 health centers in the United States, NFPRHA conducts and participates in research; provides educational subject matter expertise to policy makers, healthcare providers, and the public; and offers its members capacity-building support aimed at maximizing their effectiveness and financial sustainability as providers of essential healthcare. Prior to the grantee shifts caused by the 2019 Title X rule, NFPRHA represented more than 70 percent of Title X grantees and more than 90 percent of Title X service sites.

Title X has served as the nation's sole Federal program dedicated to family planning since its inception in 1970, 50 years ago. In 2018, Title X helped close to 4 million people access family planning and related health services at nearly 4,000 health centers around the country.[2] Title X-funded health centers include a diverse array of providers, such as freestanding family planning centers, federally qualified health centers, hospitals, school- and university-based health centers, and other entities.[3] For many individuals, particularly those who have low incomes, are under- or un-insured, or are adolescents, Title X has been their main access point to

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[1] Department of Health and Human Services. Final Rule. "Compliance with Statutory Program Integrity Requirements." Federal Register 84 (March 4, 2019): 7714–7791.

[2] Christina Fowler et al, "Family Planning Annual Report: 2018 National Summary," RTI International (August 2019). https://www.hhs.gov/opa/sites/default/files/title-x-fpar-2018-national-summary.pdf.

[3] Prior to implementation of the 2019, many Planned Parenthood affiliates participated in the program. Planned Parenthood withdrew from the program in August 2019.

affordably and confidentially obtain contraception, cancer screenings, sexually transmitted disease testing and treatment, complete and medically accurate information about their sexual health and family planning options, and other basic care. In fact, a study found that in 2016, six in ten women seeking contraceptive services at a Title X-funded health center saw no other healthcare providers that year,[4] and in 2016 Title X-supported contraceptive services helped patients prevent an estimated 755,000 pregnancies.[5] In addition to that direct clinical care, Title X supports important health center efforts that are not reimbursable under Medicaid or private insurance, including staff training and community-based sexual and reproductive health education programs.

Despite this compelling data, and in spite of the critical importance of equitable access to family planning services for all people, the Trump administration pushed forward a rule that has decimated the Title X network and made it harder for providers to offer high quality, comprehensive preventive services to patients. I urge you to include both a prohibition on the rule's implementation and a new pathway to allow providers that left the program rather than comply with the rule a way to reenter the program and serve the millions of patients who rely on them for care. This language is also critical for the providers that have remained in the program in order to ensure that patients are left with some access to family planning services.

Furthermore, I urge you to fund the program at $400 million, as the House proposed in fiscal year 2020. These funds will allow Title X providers to maintain existing services and provide a down payment on the resources needed to restore Title X's capacity to serve the millions of people who could benefit from its services. As you know, Title X has been funded at just over $286 million for the past 7 years. In 2016, researchers from the Centers for Disease Control and Prevention, the Office of Population Affairs, and George Washington University estimated that Title X would need $737 million annually to deliver family planning care to all uninsured, low-income women in the United States.[6] This estimate understates the true need for Title X, as it does not include an estimate of costs for men (who made up 13 percent of patients in the network in 20180,[7] does not address Title X's trans and nonbinary patients, and does not include an estimate for the insured patients who rely on Title X's confidentiality protections.

The gap between the funds appropriated and the funds needed has only grown in recent years. From 2010 to 2016 the number of women who needed publicly funded family planning services increased by 1.5 million,[8] but Congress cut Title X's funding by $31 million over that period. That decrease unfortunately corresponds to dramatic decreases in the number of patients served at Title X-funded sites; the numbers dropped from 5.22 million in 2010[9] to just under four million in 2018.[10] NFPRHA and its members are deeply concerned about diminishing access to high-quality family planning care and urge Congress to take an initial step to reverse this devastating trend by appropriating $400 million for Title X in fiscal year 2021.

The need for the Title X program and its network of providers is even more critical as the coronavirus affects communities across the country. Family planning and sexual health services are often time-sensitive, and the need for these services does not stop during a pandemic. In fact, recent public opinion polling shows that a majority of US adults (65 percent) think now is a bad time for individuals and couples to try to get pregnant, and only 5 percent of adults would consider it "less essential" for individuals to have that access to birth control during the coronavirus pan-

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[4] Megan Kavanaugh, Mia Zolna, and Kristen Burke, "Use of Health Insurance Among Clients Seeking Contraceptive Services at Title X-Funded Facilities in 2016," Perspectives on Sexual and Reproductive Health 50.3 (September 2018). https://onlinelibrary.wiley.com/doi/full/10.1363/psrh.12061.

[5] Jennifer Frost et al, "Publicly Supported Family Planning in the United States: Likely Need, Availability and Impact, 2016," Guttmacher Institute (October 2019). https://www.guttmacher.org/report/publicly-funded-contraceptive-services-us-clinics-2015.

[6] Euna August, et al, "Projecting the Unmet Need and Costs for Contraception Services After the Affordable Care Act," American Journal of Public Health (February 2016): 334–341.

[7] Christina Fowler et al, "Family Planning Annual Report: 2018 National Summary," RTI International (August 2019). https://www.hhs.gov/opa/sites/default/files/title-x-fpar-2018-national-summary.pdf.

[8] Jennifer Frost, Lori Frohwirth and Mia Zolna, "Publicly Supported Family Planning Services in the United States: Likely Need, Availability, and Impact, 2016," Guttmacher Institute (October 2019). https://www.guttmacher.org/report/publicly-supported-FP-services-US–2016.

[9] Christina Fowler et al, "Family Planning Annual Report: 2010 National Summary," RTI International (August 2019). https://www.hhs.gov/opa/sites/default/files/title-x-fpar-2018-national-summary.pdf.

[10] Fowler et al, "Family Planning Annual Report: 2018 National Summary."

demic.[11] Now more than ever, the Title X provider network, already struggling in the wake of years of attacks and chronic underfunding, needs the robust support of Congress to continue to provide high-quality family planning and sexual health services.

Furthermore, family planning staffing has been impacted at health centers due in some instances to employees being redeployed to COVID response and because of the individual toll the pandemic has taken on staff, including short-term and long-term absences as employees deal with health and family issues. Staffing issues coupled with decreased patient visits and the likelihood that states will need to cut family planning funding in future budgets due to fiscal crisis means that current Federal funding for safety-net health centers is simply not enough. Access to essential services depends on health centers receiving sufficient funds to remain open and programmatic rules that allow expert providers to offer the best possible care.

Thousands of providers and millions of patients are counting on Congress to stand strong against attacks on family planning and support the Title X program. NFPRHA looks forward to working with committee members in those efforts.

Sincerely.

[This statement was submitted by Clare M. Coleman, President & CEO, National Family Planning & Reproductive Health Association.]

PREPARED STATEMENT OF THE NATIONAL HISPANIC MEDICAL ASSOCIATION

Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee, I appreciate the opportunity to submit a written testimony for the record for the fiscal year 2021 Appropriations for Labor, Health and Human Services, Education and Related Agencies. My name is Elena Rios, MD, MSPH, FACP and I have served as the President and CEO of the National Hispanic Medical Association (NHMA) since 1994. NHMA requests assistance, resources, and relations that promote improved health outcomes for Hispanics.

As of July 2016, there are about 57.5 million (17.8 percent) of Hispanics in the United States and it is projected to reach 119 million by 2060.[1] However, Hispanics continue to remain underrepresented in all disciplines of healthcare professionals. According to the AAMC, Hispanic physicians only account to 5.8 percent of the population as compared to their White counterpart (56.2 percent).[2]

In a 2016 report published by the Office of Personnel Management (OPM), Hispanic representation in the Senior Executive Service (SES) rose from 4.4 percent to 4.6 percent between 2015 and 2016.[3] This modest increase falls short when compared to Hispanic representation in the civilian workforce, which is 15 percent. In addition to the OPM findings, the Equal Employment Opportunity Commission (EEOC) found that Hispanics are underrepresented in senior positions across the Federal Government employment and leave at a faster rate than they are being recruited. EEOC also concluded that intentional efforts with national stakeholder groups are needed to increase the leadership pipeline in areas of critical need such as STEM and healthcare rather than internships, which have not resulted in much Federal employment.[4]

NHMA recommends providing at least $1 million for the Office of Minority Health (OMH) or the Health Resources & Services Administration (HRSA) to create a Hispanic Health Leadership Fellowship Program and at least $1.5 million for the National Institute on Minority Health and Health Disparities (NIMHD) to create a Hispanic Junior Faculty Research Accelerator. These two special initiatives will (1) allow the U.S. to produce an increased number of qualified health professionals from underrepresented communities; (2) increase the sustainable engagement of Hispanic health professionals in Federal-funded research programs; and (3) provide greater access to healthcare and improve health outcomes for members of the Hispanic community. NHMA has submitted these special initiative funding requests to Members of the Senate Appropriations Committee Subcommittee on Labor, Health and Human Services, Education, and Related Agencies and Members of Congress.

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[11] Morning Consult, on behalf of the National Family Planning & Reproductive Health Association (NFPRHA), conducted a poll using a national sample of 2,200 U.S. adults, between April 30—May 2, 2020. The interviews were conducted online, and the data were weighted to approximate a target sample of U.S. adults based on age, educational attainment, gender, race, and region. Results from the full survey have a margin of error of +/−2 percent.

[1] https://www.census.gov/newsroom/facts-for-features/2017/hispanic-heritage.html.

[2] https://www.aamc.org/data-reports/workforce/interactive-data/figure-18-percentage-all-active-physicians-race/ethnicity-2018.

[3] https://www.opm.gov/policy-data-oversight/diversity-and-inclusion/reports/feorp-2016.pdf.

[4] https://www.eeoc.gov/Federal/reports/hwg.html#—Toc471524086c.

The Hispanic Leadership Fellowship Program's goal is to create a 1 year training program to engage mid-career Hispanic physicians across the nation who are interested in decisionmaking positions the Federal Government. The curriculum will include didactic lectures, panels, case studies, leadership-skill building, healthcare policy, cultural competence, and exchanges with national leaders who direct Federal health policy and programs that directly and indirectly affect the health and wellness of the Hispanic population. The requested funding and report language for this program will address national findings related to the underrepresentation and shortage of Hispanic leaders within the Federal and state healthcare sectors.

The Hispanic Junior Faculty Research Accelerator Initiative will support NIH and its national efforts to improve health outcomes for Hispanics in areas marked by persistent health disparities by supporting the training of junior Hispanic researchers and researchers who are interested in the Hispanic population. Funding will allow top junior faculty candidates from across the United States to participate more robustly in NIH-sponsored programs and receive instruction, mentoring, and other assistance to develop research competencies. Junior researchers will be recruited from medicine and public health from across the nation and be matched with senior researchers who have experiences with Hispanic health research. This request aligns with the work of the Office of the Secretary, NIMHD. Additionally, the leadership of the Chief Officer of Scientific Workforce Diversity (OSWD) is leading NIH's effort to diversity the national scientific workforce and expand recruitment and retention of diverse professionals in fields relevant to NIH's mission. OSWD is purposeful in its efforts to capture and include diverse talent into biomedical research through research innovations and data-driven interventions in diversity including policies, processes, and programs. This funding request aligns with the work and mission of OSWD and is consisted with the recommendations include in the NIH-Wide Strategic Plan for fiscal years 2016–2020.[5]

Below are proposed report language for both initiatives:

Requested Report Language for Hispanic Leadership Fellowship Program:

Of the funds appropriated, $1 million is provided to support a Hispanic Leadership Fellowship Program initiative to support increasing the number and advancement of underrepresented persons to senior positions at the Federal level and other areas. The Committee encourages collaboration with a reputable national nonprofit stakeholder organization with a demonstrable history in developing Hispanic healthcare leaders.

Requested Report Language for Hispanic Junior Faculty Research Accelerator:

Of the funds appropriated, $1.5 million is provided to support a Hispanic Junior Faculty Research Accelerator initiative to support NIH efforts related to scientific workforce diversity and help ensure better health outcomes and reduce health disparities affecting the Hispanic community, as well as the various subgroups classified as Hispanic. NIH is encouraged to work with national Hispanic stakeholder groups.

NHMA believes that these modest requests will help increase diversity across Federal and state governments to help address the low number of Hispanics in the Federal healthcare workforce and ensure better health outcomes and reduce healthcare disparities affecting the Hispanic community. The growing number of Hispanics in the country shows the further need of more Hispanics in more senior positions who are familiar with the Hispanic population and can be culturally-sensitive when putting together policies who will affects millions. Strong Federal investments in a Hispanic Leadership Fellowship Program and a Hispanic Junior Faculty Research Accelerator Program are crucial to increase the representative of Hispanic physicians, caregivers, clinicians and researchers in health services research. These programs will provide to our nation's healthcare workforce the foundation necessary to tackle the challenges we are currently facing.

We look forward to working with you to improve the health of all Hispanics in the country.

[This statement was submitted by Elena Rios, MD, MSPH, FACP, President & CEO, National Hispanic Medical Association.]

PREPARED STATEMENT OF THE NATIONAL INDIAN CHILD WELFARE ASSOCIATION

The National Indian Child Welfare Association (NICWA), located in Portland, Oregon, has over 35 years of policy experience advocating on behalf of American In-

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[5] https://www.nih.gov/about-nih/nih-wide-strategic-plan.

dian and Alaska Native (AI/AN) children in child welfare and children's mental health systems. Thank you for the opportunity to provide fiscal year 2021 budget recommendations for child welfare and children's mental health programs administered by the Department of Health and Human Services (DHHS). Our full recommendations appear in the charts below with our priority recommendations described in more detail underneath the charts.

Child Welfare

Agency	Program	FY 2020 Enacted	FY 2021 Recommended
DHHS ACF/CB	Promoting Safe and Stable Families (mandatory/discretionary) (3% tribal set-aside from mandatory and discretionary)	$324.6/$92.5 million	**$450/$120 million**
	Tribal Court Improvement Program (designated amount per statute)	$1.0 million	**$5.0 million**
DHHS ACF/CB	Title IV-E Prevention Services Program	N/A	**Extend use of cultural evidence-based guidance to tribes in Title IV-E agreements with states (President's proposal – no cost)**
DHHS ACF/CB	Community-Based Child Abuse Prevention (tribal 1% set-aside shared with migrant populations)	$55.6 million	**$100 million**
DHHS ACF/CB	Child Welfare Services (tribal funding determined by regulatory formula)	$268.7 million	**$400 million**
DHHS HRSA	Maternal Infant & Early Childhood Home Visiting Program (3% tribal set-aside)	$400 million	**$450 million**

PRIORITY RECOMMENDATIONS

Promoting Safe and Stable Families recommendation (Title IV–B, Subpart 2–Discretionary Portion): Increase mandatory funding to $450 million and $120 million for discretionary funding under this program to provide additional access to tribes who are currently not eligible to apply for these funds based upon the current eligibility criteria that are tied to the funding formula, and increase tribal court improvement funding to $5 million.

The Promoting Safe and Stable Families Program provides funds to tribes for coordinated child welfare services that include family preservation, family support, family reunification, and adoption support services. This program has a mandatory capped entitlement appropriation as well as a discretionary appropriation. There is a 3 percent set-aside for tribes under each program. All tribes with approved plans are eligible for a portion of the set-aside that is equal to the proportion of their member children compared to the total number of member children for all tribes with approved plans. Based on this formula, tribes who would qualify for less than $10,000 are not eligible to receive any funding. This means that many tribes, typically those tribes that are most in need, cannot access it because the overall appropriation is currently too low. Out of the 573 federally recognized tribes, over 100 tribes have no access to these funds.

Tribal systems endeavor to reduce out-of-home placements whenever possible, saving children and their families additional trauma and helping states with services to Native families under their jurisdiction. Native children in state child welfare systems are three times more likely to be removed from their homes-as opposed to receiving family preservation services-than their non-Native counterparts.[1] Tribes are providing intensive family preservation and family reunification services in spite of inadequate funding and insufficient staffing, which is putting incredible strain on

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[1] Hill, R. B. (2008). An analysis of racial/ethnic disproportionality and disparity at the national, state, and county levels (p. 9). Seattle, WA: Casey Family Programs, Casey-CSSP Alliance for Racial Equity in Child Welfare, Race Matters Consortium Westat.

individual workers and programs.[2] New prevention services funding under Title IV–E will help a small portion of tribes, typically those that already receive Promoting Safe and Stable Funding, but many smaller tribes do not have access to Title IV–E and rely on these kinds of funds to reduce out of home placements and stabilize families.

The Promoting Safe and Stable Families Program offers support for culturally based services that tribes already have experience with, such as parenting classes, home visiting services, and respite care for caregivers of children. This program is vital to the tribes that depend on it to support efforts to prevent the unnecessary removal of AI/AN children from their homes.

Tribes are also eligible to apply for the Tribal Court Improvement Program, a competitive grant program authorized under Promoting Safe and Stable Families for states and tribes. A $1 million tribal set-aside was created in the 2011 Child and Family Services Improvement and Innovation Act, Public Law No. 112–34 (2011). Seven tribal court improvement project grantees are currently funded under this program. They are using these funds to strengthen their family courts and better integrate the work of their courts with their child welfare systems and with their state court partners who serve Native children and families under their jurisdiction.

Title IV–E Prevention Services Program: Extend DHHS cultural evidence-based guidance related to directly funded tribes under Title IV–E Prevention Services Program to tribes operating the Title IV–E Prevention Services Program through an agreement with a state.

The President's fiscal year 2021 budget proposal (DHHS fiscal year 2021, Administration for Children and Families, Justification of Estimates for Appropriation Committees, page 311) proposes to extend earlier issued guidance that provided tribes in Title IV–E agreements with states the same level of flexibility to utilize culturally-based services under the Title IV–E Prevention Services Program. This proposal does not require additional expenditure of Federal funds and is a reasonable extension of the previously issued guidance for tribes (see ACYF–CB–PI–18–10). Currently only 10 tribes are operating the Title IV–E program directly from the Federal Government while over 130 tribes are operating the Title IV–E program in an agreement with a state. The current guidance only provides authority to the small number of tribes operating the Title IV–E program directly through the Federal Government to establish and utilized cultural services. Not only have many tribes asked for this application to tribes in agreements with states, but also several states that have Title IV–E agreements with tribes. Extending the guidance to a larger number of Title IV–E tribes will have the benefit of supporting more effective services and assist states that are working to improve outcomes for Native children and families in partnership with tribes.

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[2] National Child Welfare Resource Center for Tribes. (2011). Findings from the national needs assessment of American Indian/Alaska Native child welfare programs (p. 23). Retrieved from nrc4tribes.org/files/NRCT%20Needs%20Assessment%20Findings__APPROVED.pdf.

Children's Mental Health

Agency	Program	FY 2020 Enacted	FY 2021 Recommended
DHHS SAMHSA	Programs of Regional and National Significance—Children and Family Programs (includes Circles of Care)	$7.2 million (funds reserved for Circles of Care)	**$8 million (Reserve for Circles of Care)**
DHHS SAMHSA	Children's Mental Health Services Program— Systems of Care	$125 million (no funding reserved for tribal System of Care grants)	**$135 million**
DHHS SAMHSA	GLS State/Tribal Youth Suicide Prevention (tribes receive portion of grant funds)	$35.4 million	**$50 million**
DHHS SAMHSA	GLS Campus Suicide Prevention Program	$6.4 million	**$10 million**
DHHS SAMHSA	AI/AN Suicide Prevention	$2.9 million	**$20 million**
DHHS SAMHSA	Tribal Behavioral Health Grant (divided equally between substance abuse prevention and mental health services)	$40 million	**$60 million**

PRIORITY RECOMMENDATIONS

Programs of Regional and National Significance, Children and Family Programs (includes Circles of Care): Ensure that $8 million under this line item continues to be reserved specifically for the tribal and urban Indian community Circles of Care program in fiscal year 2021.

The Children and Family Programs under Programs of Regional and National represents funds allocated to support the tribal Circles of Care program. Circles of Care is a competitive grant program exclusively for tribal communities. It is the cornerstone of tribal children's mental health programming.

Circles of Care is a three-year planning grant that helps communities design programs to specifically serve AI/AN children with serious behavioral health issues. Specifically, Circles of Care funds the development of the tribal capacity and infrastructure necessary to support a coordinated network of holistic, community-based, mental and behavioral health interventions in tribal communities.

Circles of Care is one of only two SAMHSA programs that allow tribes and tribal organizations to apply for funding without competing with other governmental entities (states, counties, or cities). There are currently 14 communities receiving Circles of Care funding.

AI/AN children and youth face a "disproportionate burden" of mental health issues while simultaneously facing more barriers to quality mental healthcare.[3] Since its inception in 1998, the Circles of Care program has affected 49 different tribal and urban Indian communities. These programs have been incredibly successful. The majority of tribes who have received these grants have created long-term, sustainable systems of care for their children.

Children's Mental Health Initiative (Systems of Care): Increase funding to $135 million to allow for continued support of the current four-year grantees and funding of new grantees in fiscal year 2021.

The children's mental health initiative supports the development of comprehensive, community-based "systems of care" for children and youth with serious emotional disorders. This includes funding for 1 year System of Care Expansion Planning Grants, four-year System of Care Expansion Implementation Grants, and six-year Children's Mental Health Initiative System of Care Grants. AI/AN communities are eligible for, and recipients of, each of these grants, but must compete with non-tribal applicants to receive these funds.

Children's Mental Health Initiative System of Care Grants support a community's efforts to further plan and implement strategic approaches to mental health serv-

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[3] American Psychiatric Association. (2010). Mental health disparities factsheet: American Indians and Alaska Natives (p. 4).

ices. These approaches are based on important principles: they must be family-driven; youth-guided; and meet the intellectual, emotional, cultural, and social needs of children and youth. Since 1993, 180 total projects have been funded, dozens of which have been in tribal communities. Currently, 12 tribal communities are funded.

Evaluation studies of System of Care have indicated return on investment from cost-savings in reduced use of in-patient psychiatric care, emergency room care, and residential treatment even when other community- or home-based care is provided. There are also cost savings from decreased involvement in juvenile justice systems, fewer school failures, and improved family stability.[4]

Programs of Regional and National Significance, Tribal Behavioral Health Program: Increase funding for the Tribal Behavioral Health program (mental health and substance abuse prevention programs) to $60 million in fiscal year 2021.

In the fiscal year 2020, the Tribal Behavioral Health Grants were funded at $40 million ($20 million in the Mental Health appropriation and $20 million in the Substance Abuse Prevention appropriation). NICWA recommends $60 million in fiscal year 2021 to continue to address the expansion of suicide prevention, mental health, and substance abuse activities for Native communities.

These are competitive grants designed to target tribal entities with the highest rates of suicide per capita over the last 10 years. These funds must be used for effective and promising strategies to address the problems of substance abuse and suicide and promote mental health among AI/AN young people.

AI/AN young people are more likely than other youth to have an alcohol use disorder. In 2007, 8.5 percent of all AI/AN youth struggled with alcohol use disorders compared to 5.8 percent of the general youth population.[5] Although these statistics are troubling, with adequate resources tribes are best able to serve these young people and help them heal before they reach adulthood.

There is growing evidence that Native youth who are culturally and spiritually engaged are more resilient than their peers. Research has revealed that 34 percent of Native adolescents preferred to seek mental or substance abuse services from a cultural- or religious-oriented service provider. In other research, American Indian caregivers preferred cultural treatments (e.g., sweat lodge, prayer) for their children and found the traditionally based ceremonies more effective than standard or typical behavioral health treatment.

PREPARED STATEMENT OF THE NATIONAL INDIAN HEALTH BOARD

Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee, thank you for the opportunity to offer this testimony. On behalf of the National Indian Health Board (NIHB) and the 574 Tribal Nations we serve, I submit this testimony for the record on the fiscal year 2021 budget for the Department of Health and Human Services (HHS). NIHB thanks the Committee for maintaining funding levels for Tribal programs within the fiscal year 2020 Labor-HHS Appropriations Act. These included a $50 million set aside for Tribal Opioid Response (TOR) grants; $21 million for Good Health and Wellness in Indian Country (GHWIC); and $40 million for Tribal Behavioral Health Grants. NIHB also greatly appreciates the Tribal set-aside in relief packages addressing COVID–19, including a baseline $125 million set aside in Centers for Disease Control and Prevention (CDC) funds through the CARES Act.

Since the earliest days of the Republic, all branches of the Federal Government have acknowledged the nation's constitutional obligations to Tribal Nations and the special trust obligation of the United States government to Tribal governments. Congress affirmed this special relationship with Tribes in the fiscal year 2019 Labor, Health and Human Services, Education, and Related Agencies (Labor-HHS) Committee report when it stated "...Indian Tribes are political, sovereign entities to which the Federal Government owes a trust responsibility. Congress has routinely codified this relationship, most notably in the provision of healthcare by establishing a health system for Tribal populations exclusively."[1]

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[4] Stroul, B. (2015). Return on investment on System of Care for children with behavioral health challenges: A look at wraparound. The TA Telescope, 1(2), pp. 1–2.

[5] U.S. Department of Justice, Office of Justice Programs, Office of Juvenile Justice and Delinquency Prevention. (2014). Attorney General's Advisory Committee on American Indian/Alaska Native Children Exposed to Violence: Ending violence so children can thrive (p. 81). Retrieved from www.justice.gov/sites/default/files/defendingchildhood/pages/attachments/2014/11/18/finalaianreport.pdf.

[6]

Unfortunately, the COVID–19 pandemic has exacerbated the existing structural challenges facing the Indian health system. Unlike state and local governments, Tribes do not have a local tax base to supplement public health funding. In addition, Tribes are routinely left out of larger public health funding streams, partly because it is erroneously assumed that Tribes will receive adequate state funding. Not only is this factually inaccurate, it runs afoul of the Federal obligation to fully fund health services in Indian Country, and the government to government relationship that exists in perpetuity between Tribal Nations and the United States.

Indeed, many Tribes lack critical public health infrastructure entirely—including for emergency preparedness and response, disease surveillance, preventive health services, and so forth. It is important to note that Tribes receive hardly any public health funding from the Indian Health Service (IHS), because IHS is primarily a healthcare delivery system. This means that the small pools of Federal public health funds Tribes receive represent the vast majority of available Tribal public health funds.

All Federal public health programs should not only include Tribes as eligible entities, but also include direct Tribal funding set-asides. Tribal set-asides further the fulfillment of the Federal trust obligation for health; but also, without a set-aside, Tribes will more than likely not receive meaningful public health funding. Many Tribal public health departments do not have the capacity to compete with state and local governments for competitive public health grants. The consequence is that Tribes are routinely left behind in development of public health infrastructure.

For instance, a 2019 U.S. Department of Health and Human Services report found that, from fiscal year 2014 to fiscal year 2018, Tribes received 0.06 percent of funds under the Preventive Health and Health Services Block Grant ($0.5 million out of $729.2 million). During that same time period, Tribes received only 0.03 percent of all Substance Abuse Prevention and Treatment Block Grant dollars ($3 million out of $8.8 billion). These are just two examples of how Tribes are largely left behind when direct Tribal set-asides do not exist in statute. Thus, we strongly urge that the Committee work to increase the number of direct Tribal set asides for public and behavioral health programs.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

Preventive Health and Health Services Block Grant (PHHSBG): Tribal public health infrastructure and capacity is significantly lower than that of states and counties, because Tribes were left behind during the nation's development of its public health infrastructure. As a result, Tribal health systems generally lack the capacity to conduct robust disease surveillance and tracking, engage in preparedness and disaster relief efforts, and provide comprehensive preventive health services. While only two Tribes receive a small portion of these funds, it is vital that this program be maintained and its reach in Indian Country expanded. NIHB requests that, in fiscal year 2021, Congress maintain PHHSBG funding at its currently enacted level and provide a direct, annual set aside of 5 percent for Tribes and Tribal organizations.

Good Health and Wellness in Indian Country (GHWIC): The GHWIC program is CDC's single largest investment in Indian Country. The program funds a total of 35 Tribes and Tribal organizations to improve chronic disease prevention efforts, expand physical activity, and reduce commercial tobacco use. NIHB is thankful to the Committee for including a $5 million increase to GHWIC for fiscal year 2019. However, the fiscal year 2021 President's Budget proposes elimination of this program for the third year in a row. NIHB requests that the Committee reject elimination of GHWIC and increase funding to $32 million for fiscal year 2021.

Funding for HIV, Viral Hepatitis, and Sexually Transmitted Infections: Tribal communities are disproportionately impacted by HIV, viral hepatitis, and sexually transmitted infections (STIs). According to the CDC, rates of new HIV infections increased by 81 percent among gay and bisexual AI/AN men from 2010 to 2016,[2] while AI/ANs continue to have the highest Hepatitis C mortality rates nationwide at 10.8 deaths per 100,000 in 2016.[3] Furthermore, gonorrhea rates among AI/ANs are 4.5 times higher than for Whites, while rates of chlamydia and syphilis are 2.7 and 2.1 times higher respectively.[4] Nevertheless, in fiscal year 2018, no Tribe or Tribal organization received STI or viral hepatitis prevention grants from CDC, and only two

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[2] CDC. (2019). HIV and American Indians and Alaska Natives. Retrieved from https://www.cdc.gov/hiv/pdf/group/racialethnic/aian/cdc-hiv-aian-fact-sheet.pdf.

[3] CDC. Surveillance for Viral Hepatitis: United States, 2016. Retrieved from https://www.cdc.gov/hepatitis/statistics/2016surveillance/commentary.htm.

[4] CDC. Sexually Transmitted Disease Surveillance, 2017. Retrieved from https://www.cdc.gov/std/stats17/natoverview.htm.

community-based organizations serving AI/ANs received HIV dollars. The fiscal year 2021 Budget Request includes a new $1.5 billion investment in CDC to further the President's announcement of ending the HIV epidemic by 2030. NIHB requests that the Committee provide direct 5 percent set asides in HIV, viral hepatitis, and STI funding for Tribes and Tribal organizations.

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION (SAMHSA)

Substance Abuse Prevention and Treatment Block Grant (SABG): The SABG is one of two major block grants administered by SAMHSA, the other being the Community Mental Health Services Block Grant (MHBG). Tribes are not eligible to receive MHBG grants, which contributes to the dearth of mental health services available within Tribal communities. While all 50 states, the District of Columbia, and eight U.S. territories receive SABG funding, only 1 Tribe is included. Increasing Tribal access to SABG is critical towards building Tribal behavioral health capacity and reducing Tribal behavioral and mental health disparities. NIHB requests that the Committee set aside SABG funding for Tribes and Tribal organizations and work with authorizing committees to extend eligibility for MHBG funding to Tribes.

Tribal Behavioral Health Grants: NIHB was pleased to see both the mental health and substance abuse TBHGs increased to $20 million each for fiscal year 2019 ($40 million total). These two Tribally-focused programs have created over 140 unique projects in Indian Country addressing a wide variety of mental and behavioral health needs, and have helped many Tribes address chronic shortages in mental and behavioral health services. NIHB requests that the Committee double funding for the TBHG program to $80 million total, and that SAMHSA engage in Tribal consultation on restructuring the program to be formula-based with the option for Tribes to apply for funding under 638 self-governance authority.

Opioid Funding: NIHB was pleased to see that the $50 million set aside for TOR grants and a $10 million set aside for medication-assisted treatment was maintained in fiscal year 2020. With the COVID–19 pandemic triggering increases to substance use and overdose death rates, and with AI/ANs experiencing the second highest overall opioid overdose death rates, dedicated funding to Tribes for prevention and treatment is essential. NIHB requests that the Committee double the Tribal opioid funding set aside to 10 percent for fiscal year 2021 so that more Tribes can participate and existing grantees can expand the scope and delivery of services.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

Health Workforce: As reported by IHS in its fiscal year 2021 Congressional Justification, the Indian health system currently has 1,330 vacancies for healthcare professionals including physicians, nurse practitioners, dentists, pharmacists, and physician assistants.[5] In fact, in a 2018 report released by the Government Accountability Office (GAO), provider vacancy rates across eight IHS Areas with substantial direct care responsibilities reached as high as 31 percent (GAO–18–580).[6] Without sufficient access to providers, the quality and accessibility of care in the Indian health system will not improve, and the health status of AI/ANs will remain lower than the general population. NIHB urges that the Committee maintain its $15 million set aside in NHSC funding for placements within the Indian health system and reject language in the fiscal year 2021 President's Budget declaring the set-aside unnecessary.

Health Centers: In addition to chronic provider shortages, the average age of I/T/U facilities is roughly 40 years, compared to an average age of roughly 10 years for health facilities nationwide.[7] In fact, research shows that an IHS facility built today would not be replaced for 400 years in the current budget environment.[8] IHS and Tribal health systems generally lack access to specialty care facilities, preventive health centers, behavioral and mental health clinics, and so forth. Despite the need, only 1.1 percent of patients served by HRSA's health center program were AI/AN in 2017. Out of 1,375 health center nationwide, only about 22 are Tribally operated. Direct access to health center funding can help improve Tribal health infrastructure by expanding funding for health services. As such, NIHB requests that the

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[5] Fiscal Year 2021 Justification of Estimates for Appropriations Committees: Indian Health Service.

[6] Government Accountability Office. (2018). Indian Health Service: Agency Faces Ongoing Challenges Filling Provider Vacancies.

[7] The 2016 Indian Health Service and Tribal Health Facilities' Needs Assessment Report to Congress. Retrieved from https://www.ihs.gov/newsroom/includes/themes/responsive2017/display__objects/documents/RepCong__2016/IHSRTC__on__FacilitiesNeedsAssessmentReport.pdf.

[8] Ibid.

Committee enact a 3–4 percent set aside in Health Center funding for the I/T/U system.

Action for Dental Health Program: Nationwide, Tribal communities struggle with dental afflictions and disparities, as well as a severe oral health provider shortage. On average, Indian Country has just 1 dentist for every 2,800 people, which is half the number of dentists per capita nationwide. This shortage contributes to poorer oral health outcomes across all age groups in Tribal communities. In fact, 41 percent of AI/AN 2–5 year olds and 46 percent of AI/AN adults over the age of 65 have untreated tooth decay, compared to 10 percent and 19 percent of non-Natives in the same age groups.[9] As one of the many policy solutions to restore Indian Country's oral health, NIHB supports funding for the Action for Dental Health Program (42 U.S.C. 280k(c)), which includes direct funding to Tribes. NIHB recommends the Committee appropriate such sums as may be necessary—including a designated funding set aside for Tribes—for the implementation of the Action for Dental Health Program in fiscal year 2021.

Centers for Medicare and Medicaid Services: The Medicaid system is a critical lifeline in Tribal communities, accounting for roughly 13 percent of the overall IHS budget. Moving Medicaid to a block grant system, as proposed in the fiscal year 2021 President's Budget, would have major fiscal impacts on Tribal health reimbursements. We also urge Congress to ensure that AI/ANs are exempt from any mandatory work requirements under Medicaid, as they would impose additional and unmanageable burdens on an IHS budget that heavily relies on Medicaid resources to make up for funding shortfalls. NIHB urges the Committee to maintain the Medicaid program as is, and expand its reach and availability for AI/ANs.

Expansion of Self-Governance at HHS: For over a decade, Tribes have been advocating for expansion of self-governance authority to HHS programs outside of IHS. Self-governance represents efficiency, accountability and best practices in managing and operating Tribal programs and administering Federal funds at the local level. This proposal was deemed feasible by a Tribal/Federal HHS workgroup in 2011. Therefore, NIHB requests the Committee direct HHS to enter into pilot projects for self-governance in fiscal year 2021.

Thank you for the opportunity to submit testimony on the fiscal year 2021 HHS budget. We thank the Committee for its efforts towards prioritizing funding to Indian Country. Please do not hesitate to contact our offices directly if you have any questions or if you require additional information.

[This statement was submitted by Victoria Kitcheyan, National Indian Health Board.]

PREPARED STATEMENT OF THE NATIONAL INSTITUTE OF MENTAL HEALTH

I appreciate the opportunity to provide written testimony on the National Institute of Health fiscal year 2021 budget appropriations.

The National Institute of Mental Health (NIMH) is the main Federal Government agency for research into mental illness. The NIMH was authorized through the passage of the National Mental Health Act in 1946 to better help individuals with mental health disorders through better diagnosis and treatments. With a budget of almost $2 billion in 2020, the NIMH conducts research and funds outside investigators to better understand mental illness and develop new treatments to reduce the burden these disorders have on individuals.

Unfortunately, the NIMH has a recent history of ignoring those with the most severe mental illnesses. As Treatment Advocacy Center Founder Dr. E. Fuller Torrey wrote in Psychiatric Times earlier this month:

> "Congress awarded the National Institute of Mental Health an additional $98 million as part of the National Institutes of Health budget resolution in December 2019, which brings the NIMH budget to just under $2 billion and represents a 35 percent increase since 2015, one of the largest increases in the history of the NIMH. Yet, during the 5 years from 2015 through 2019, NIMH funded a total of 2 new drug treatment trials for schizophrenia and bipolar disorder, according to clinicaltrials.gov. This contrasts with the 5-year period from 2006 through 2010 when NIMH funded 48 such trials. NIMH has thus almost entirely given up its role of evaluating drugs for the treatment of 2 disorders (emphasis added)."

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[9] Phipps and Ricks, April 2015; Bruce A. Dye, Gina Thornton-Evans, Xianfen Li, and Timothy J. Iafolla, NCHS Data Brief No. 191, "Dental Caries Sealant Prevalence in Children and Adolescents in the United States, 2011–2012," March 2015, http://www.cdc. gov/nchs/data/databriefs/db191.pdf.

In December 2019, the NIMH released a draft of their five-year strategic plan for public comment. They reported receiving more than 6,000 responses over the winter holidays, including from our organization identifying concrete examples of research initiatives the NIMH could be pursuing today to help people with serious mental illness recover and live better lives. Despite this robust response, NIMH made no substantive changes to the research goals or objectives in the final version released to the public earlier this week.

The NIMH research goals for 2020–2025 heighten the existing imbalance in NIMH research. In doing so, they offer little hope for new or better treatments for individuals who are currently afflicted with a mental illness during their lifetime, especially a serious mental illness. This failure is inexcusable given the large increase in research funding given to NIMH in recent years.

Future NIMH funding must be used to correct the existing imbalance, not worsen it, especially now that the COVID–19 pandemic has upended the mental health treatment system and will likely result in an exacerbation of symptoms in people currently affected and an increase in serious mental illnesses among Americans. Those with the most severe forms of mental illness deserve to be prioritized.

There is such a great need for new medications that have reduced side effects that deter mental health patients from sustaining treatment adherence. We have no medications that improve cognition for patients with schizophrenia; a resource that would help my own son a great deal. His life has been severely compromised by his serious mental illness and we want our government to lead the way in researching new medications to help some of our most challenged citizens. This is not the time to reduce research, but rather to expand the size and scope of the effort.

Thank you for your consideration of this request.

Sincerely.

PREPARED STATEMENT OF THE NATIONAL KIDNEY FOUNDATION

SUMMARY

The National Kidney Foundation (NKF) is pleased to submit testimony regarding the significant burden that Chronic Kidney Disease (CKD) places on our nation's healthcare system and urges the subcommittee to increase Federal funding for activities that support the Administration's July 2019 Advancing American Kidney Health (AAKH) initiative to improve kidney care and outcomes.

While there has always been a compelling need to increase funding for kidney disease, the need is more urgent than ever given the COVID–19 crisis, which has taken a disproportionate toll on patients with chronic kidney disease (CKD), end-stage renal disease (ESRD), and transplant recipients. Early analysis indicates that patients with CKD and ESRD are at enhanced risk of developing severe complications as a result of COVID–19 infection and a recent study from the New England Journal of Medicine found that kidney transplant recipients diagnosed with COVID–19 had a 30 percent mortality rate.

Not only is COVID–19 taking its toll on existing kidney patients, it is actively growing their ranks. In New York City, early estimates indicate that 20 to 40 percent of COVID–19 ICU patients develop Acute Kidney Injury (AKI), a condition that damages the kidneys and can require immediate dialysis. A whole group of people with no previous history of kidney disease now face acute kidney injury, which brings with it an increased risk for developing chronic kidney disease and kidney failure.

Given kidney patients' unique vulnerability to COVID–19, the long-term costs associated with kidney disease, and the significant burden this condition places on more than 37 million American adults, we urge Congress to provide $10 million for CDC to create a Kidney Disease Public Awareness Initiative; $5 million to expand the CDC CKD Initiative; $2.25 billion for the National Institute of Diabetes, Digestive and Kidney Diseases; $10 million for the National Living Donor Assistance Center; and $25 million to the KidneyX public-private partnership. We also request the subcommittee to consider the needs of kidney patients, particularly those with irreversible kidney failure, as you address the COVID–19 crisis for fiscal year 2021.

ABOUT CKD

CKD impacts 37 million American adults and is the nation's 9th leading cause of death. Kidney disease can be detected through simple blood and urine tests, yet 90 percent of CKD patients are undiagnosed, many until advanced stages when it is too late for interventions to slow disease progression. Nearly 750,000 Americans have irreversible kidney failure, also known as end-stage renal disease (ESRD), requiring either kidney dialysis at least 3 times per week or requiring a kidney transplant. African Americans develop ESRD at a rate of 3:1 compared to Whites and Hispanic Americans develop it at a rate of 1.3:1 compared to Whites. Medicare spends nearly $120 billion annually on the care of people with CKD, including $71 billion for individuals with CKD who have not progressed to kidney failure.

CKD is a disease multiplier, with many patients also experiencing cardiovascular disease, bone disease and other chronic conditions. CKD also is an independent risk predictor for heart attack and stroke. Early stage intervention can improve outcomes and lower healthcare costs, yet only 6 percent of patients with high blood pressure and 40 percent with diabetes (which are responsible for two-thirds of all cases of ESRD) receive testing for CKD. To improve awareness, early identification, and early stage intervention, NKF calls on Congress to invest in kidney health programs throughout HHS.

KIDNEY PUBLIC AWARENESS INITIATIVE

A key aspect of the Advancing American Kidney Health (AAKH) initiative is increased awareness of CKD among the public and healthcare practitioners to improve early detection, provide early intervention and improve outcomes. Early intervention can slow the progression of CKD and in some instances prevent kidney failure, reduce the impact of comorbidities and reduce hospitalizations and readmissions. Unfortunately, there is very little funding dedicated to increasing consumers' awareness of their risk for kidney disease. A sustained Kidney Public Awareness Initiative will educate at-risk individuals to enhance awareness of the causes and consequences of kidney disease and educate clinical professionals on the importance of early detection and opportunities for intervention. We urge the subcommittee to provide $10 million for this important effort.

A Kidney Public Awareness Initiative also can help reduce severe outcomes associated with COVID–19. Hospitalized COVID–19 patients, many of whom who had no history with kidney disease, are experiencing acute kidney injury (AKI). These patients as well as those with chronic kidney disease who are not on dialysis are at increased risk of severe outcomes from the virus, including the possibility of permanent kidney failure. Increased public awareness might reduce the incidence of kidney failure.

CDC CHRONIC KIDNEY DISEASE INITIATIVE

The CDC Chronic Kidney Disease Initiative is a comprehensive public health strategy to address CKD. Primarily, current activities in this program are devoted to a surveillance, epidemiology, and assistance to the National Center for Health Statistics for CKD data collection. To enhance the fight against CKD, the National Kidney Foundation requests $5 million for the CKD program to establish and implement activities between national, state, and local public health networks and national partners to (1) develop strategies to identify and address gaps in CKD early detection and monitor progress; (2) support strategies to improve CKD early detection and treatment by primary care providers and; (3) facilitate the dissemination of information through state and local public health networks.

NATIONAL LIVING DONOR ASSISTANCE CENTER (NLDAC)

With 95,000 Americans on a wait list for a kidney transplant and fewer than 24,000 kidney transplants in 2019, removing barriers to living donation is widely viewed as a key opportunity to expand the number of transplants to improve patients' quality of life. The National Living Donor Assistance Program helps offset living donors' expenses that are not reimbursed by insurance or other programs, out of pocket expenses that often are a barrier to donation. For many people, living organ donation would not have been possible without this financial assistance.

We are increasingly concerned that our nation's economic downturn, severe job loss and job insecurity will prevent many individuals to consider being a living donor. Further, many kidney patients will be reluctant to seek a living donor for these same reasons. NKF requests the Committee to provide $10 million in fiscal year 2021. Addressing financial barriers so that individuals are not burdened with out of pocket expenses related to their donation is the right thing to do for organ donors and kidney patients.

NIH NIDDK

Despite the high prevalence of CKD and its impact on patients and on Medicare (the ESRD program represents 7 percent of Medicare spending but is only 1 percent of Medicare beneficiaries), NIH funding for kidney disease research is only about

$700 million annually. A key goal of the AAKH is providing new opportunities for research. America's scientists are at the cusp of many potential breakthroughs in improving our understanding of CKD, including genetic kidney disease. Further advances can lead to new therapies to delay and treat kidney diseases, which has the potential to provide cost savings to the government like that of no other chronic disease.

COVID–19 presents additional needs and opportunities for research on the short and long-term impacts of the pandemic on individuals with acute kidney injury, chronic kidney disease, dialysis patients and kidney transplant recipients. Funding is needed for epidemiological studies and clinical trials to better understand and treat their kidney challenges and other complications that result from the virus. We request $2.25 billion for NIDDK.

KIDNEYX

The National Kidney Foundation is an enthusiastic partner in the Kidney Innovation Accelerator (KidneyX), an HHS and American Society of Nephrology initiative to support and drive innovation in the prevention, diagnosis and treatment of CKD. KidneyX consists of prize competitions to attract entrepreneurs, including those who are trying to develop an artificial kidney. KidneyX has attracted interest from a large and talented sphere of innovators. We urge the subcommittee to provide $25 million in fiscal year 20201 to enable this promising research and innovation to move forward.

Thank you for your past support and consideration of the National Kidney Foundation's requests for fiscal year 2021.

PREPARED STATEMENT OF THE NATIONAL MARROW DONOR PROGRAM/BE THE MATCH

Chairman Blunt, Ranking Member Murray and members of the Subcommittee, my name is Kristin Akin from Chesterfield, Missouri. On behalf of the patients, family members, donors, couriers, volunteers, and staff of the National Marrow Donor Program (NMDP)/Be The Match, I want to express my most sincere gratitude to the members of the Committee for your work last year, to fully fund for the first time the C.W. Bill Young Cell Transplantation Program (Program) within the Health Resources and Services Administration (HRSA), Health Care Systems account. In fiscal year 2021, we respectfully request that the subcommittee maintain full funding for the program at the President's requested and authorized amount of $30,009,000.

By establishing a national bone marrow donor registry in the mid-1980s, Congress promised patients with blood cancers, like leukemia and lymphoma, that they would have a way to find a life-saving donor match. While bone marrow transplant started as a cure for a single disease, we now provide cures for over 70 diseases, everything from cancers, blood disorders, immune deficiencies and Sickle Cell. Just last December, the Program completed its milestone 100,000th transplant between a matched, unrelated donor and a patient. This has been a true public/private partnership for more than 30 years and it is obvious that the funding is saving lives.

My son, Andrew Preston Akin, was born on June 5, 2007. At ten weeks old, what initially started as severe jaundice quickly landed us in the Pediatric Intensive Care Unit (PICU) at our local hospital. After months of tests, on September 7, 2007, our world was officially turned upside down when we were informed that Andrew actually had a rare immune deficiency called Hemophagocytic Lymphohistiocytosis (HLH), and the only cure was a bone marrow transplant.

Our then six-month-old son underwent his first bone marrow transplant in an effort to save his life. He was started on the standard protocol for HLH (HLH 2004) and initially responded very positively. But, suddenly, his HLH came roaring back and not only did we have to move up his transplant, we used umbilical cord cells, as there was not a suitable bone marrow match on the registry at the time. Grateful and optimistic that this was the end of HLH and the beginning of a new and healthy Andrew, we were devastated to learn that 2 months after his transplant, it did not work, and he would need another one.

In the meantime, we continued with steroids, chemotherapy and a host of other drugs, all the while keeping him in a bubble away from any and all germs. The search began again to find Andrew the best possible unrelated, matched bone marrow donor. Excited that marrow was going to be the answer to our prayers, Andrew underwent his second bone marrow transplant right before his first birthday. Sadly, almost a year to the day of his diagnosis, we learned that again, for various reasons, his transplant was not a success.

Through this process we learned several things about Andrew's disease: the cause of his HLH was among the newest genetic mutations—X-Linked Lymphoproliferative Disorder #2 (XLP–2). Because it is X-linked, the doctors immediately tested me and our other son Matthew. On my 34th birthday, I received among the worst news in my life: not only was I the carrier, but my healthy 4-year old son also carried the mutation, meaning it was only a matter of time before he, too, would get HLH.

After countless discussions with the team of experts, we weighed the pros and cons of taking Matthew into transplant while he was healthy or waiting until the disease struck.

We did another preliminary search on the bone marrow registry and found one perfect match. Not knowing if that match would be there down the road, we made the extremely difficult decision to transplant Matthew prophylactically.

At the same time, we prepared Andrew for his third bone marrow transplant in less than 2 years.

We were fighting for the lives of our two sons.

Andrew, only 27 months old, developed severe pulmonary complications that ultimately took his life on September 5, 2009 in the PICU.

Matthew was just two weeks post-transplant, we thought life could not get any worse, but somehow, eight short months later, it did. Our first-born son, Matthew Austin Akin passed away in the same PICU on May 1, 2010. He was only 5 and a half years old.

My husband and I have experienced every parent's worst nightmare, twice, but we both agreed we would not allow our son's deaths to be the last thing people remembered about them. Its why my husband and I started the Matthew and Andrew Akin Foundation in their memory: to raise awareness and critical funds for HLH, NMDP, and the American Red Cross, and also to advocate for other parents and children. However, I would be remiss if I did not share that a very large part of what drives us to continue to help others is the fact that we were blessed with the opportunity to be parents again, twice, through adoption. William and Christopher are the reason we have love in our hearts and can fight for the memory of their brothers Matthew and Andrew.

While Matthew and Andrew ultimately lost their lives due to disease complications, NMDP was our line of hope that we held onto from day one when learned that a successful bone marrow transplant was the only cure. With each transplant my boys received, we were reminded of the kindness of strangers, the feeling of indebtedness to NMDP and Congress for establishing the registry and the power of a worldwide network. It has been and will continue to be my honor to volunteer my time with NMDP.

The C.W. Bill Young Cell Transplantation Program, authorized by Congress, has been funded by the Committee and fulfills three important missions. The first is the nation's registry, which includes more than 22 million selfless volunteers, like my sons' donors, who stand ready to be a life-saving bone marrow donor. It also includes more than 300,000 cord blood units, 106,000 of which are in the National Cord Blood Inventory, which is also funded by your Committee. When we couldn't find a matching donor for Andrew right away, a cord blood transplant was our only hope for his first transplant. Through international relationships, NMDP has access to more than 35 million potential donors and 783,000 cord blood units worldwide.

While Matthew and Andrew were able to proceed to transplant thanks to their selfless matching donors, there are still many patients who cannot find a match on the registry. This is why the full funding you provided in fiscal year 2020, and which we are asking for in fiscal year 2021, is so critically important. From the moment doctors search the registry for a donor, to the safe delivery of the life-saving cells to the bedsides of patients for transplant—NMDP is there every step of the way. NMDP ensures that the global network, technology, and logistical support are in place to facilitate a transplant.

The Program's second mission is to support patients and families through its Office of Patient Advocacy. NMDP works tirelessly to improve the lives of patients and provide one-on-one support to these individuals and their families. They offer the resources and guidance patients need throughout the transplant process—from deciding if transplant is right for them to adjusting to life after transplant.

Finally, the Stem Cell Therapeutic Outcomes Database is a third program component that helps doctors significantly impact/improve survival for blood cancer and other diseases while also improving the quality of life for thousands of transplant patients. NMDP is relentless in its search to find answers that will lead to better donor matching, more timely transplants, and treatment of even more blood diseases through transplant.

Thank you for the opportunity to share my story and most importantly thank you for learning a little bit about my beautiful sons Matthew and Andrew. Your longstanding support for this Program is the hope that people hold onto after receiving their life-threatening diagnosis. On behalf of those who are alive today, those who are currently searching the national registry for their potential life-saving donor and for those who will need to look to the Program for help in the future, I urge you to once again provide full funding for the C.W. Bill Young Cell Transplantation Program at the authorized amount of $30,009,000 as you did for the current year and as is recommended in the President's budget. In this unprecedented time that is full of uncertainty, full funding for NMDP will certainly help save lives and there is no better work than that.

[This statement was submitted by Kristin Akin, Staff, National Marrow Donor Program/Be The Match.]

PREPARED STATEMENT OF THE NATIONAL MULTICULTURAL ALLIANCE

The National Multicultural Alliance (NMCA), formerly National Minority Consortia (NMC), submits this statement regarding the fiscal year 2021 request for fiscal year 2023 advance appropriation for the Corporation for Public Broadcasting (CPB). We are an alliance of five separate and distinct national organizations, who, with modest support from CPB, bring authentic voices and unique stories of diversity to all of America's communities via public broadcasting and its digital platforms. Our requests are the following: (1) To provide a much needed increase in funding to $515 million in fiscal year 2023 advance appropriation for CPB; and (2) that Congress direct CPB to meaningfully increase its commitment to diverse programming and serving underserved communities.

Provide fiscal year 2023 advance appropriation for CPB of $515 million. Public broadcasting enhances the lives of millions of Americans, including those in rural areas with free, unique local and national education resources that would otherwise not be available. Public television stations provide the only preschool education for more than half of America's children.

Public broadcasting upholds strong ethics of responsible journalism and thoughtful examination of American history, life and culture. In America, where more than half of all children born today are racial and ethnic minorities, it is essential that our public media system can continue to deliver well-researched and authentic stories that reflect our nation's unique and rapidly diversifying populace.

From children's educational content to public safety awareness, America's public broadcasting system is a necessary tool to ensure a well-educated, well-informed, and cultured civil society capable of meeting the responsibilities of self-government in the world's most important democracy. The Federal investment in public media is essential to making these services available to everyone, everywhere, every day for free.

Direct CPB to increase its efforts for diversity to meet the demands of a growing and diverse public. We applaud the leadership of Representative Lucille Roybal-Allard and the House Appropriations Committee which last year included in its House Report 116–62, page 227, the following statement:

> "According to the Public Broadcasting Act, one of the greatest priorities of public broadcasting is to address the 'needs of unserved and underserved audiences, particularly children and minorities.' Programming that reflects the histories and perspectives of diverse racial and ethnic communities is a core value and responsibility of public broadcasting, therefore the Committee supports continued investment in the National Minority Consortia to help accomplish this goal."

We urge Congress in bill and/or report language to continue to include language that recognizes the importance of the work of the five members of the National Multicultural Alliance (NMCA) and the need to rapidly increase and expand efforts across programming, content creation, and training, to meet the demands of an increasingly diverse public.

The National Multicultural Alliance develops, funds, acquires and distributes diverse content to public media entities to serve underrepresented communities. These stories reflect the current social issues and the rich culture and history and of our rapidly changing multicultural landscape, transcending statistics and bringing universal American stories to all U.S. citizens.

The five members of the National Multicultural Alliance each receive an appropriation of $1.3 million per year from CPB. Combined, this amount totals to just under $6.8 million in discretionary funds from CPB per year which is only 1.5 percent of the current CPB budget. A modest 10 percent increase by CPB to the NMCA appropriation for a combined total of $7.5 million would go a long way in supporting the continued development of diverse content for public media and the support of filmmakers of color. Through its work, the NMCA helps to ensure the future strength and relevance of public media with content from and about diverse communities.

ABOUT THE NATIONAL MULTICULTURAL ALLIANCE (NMCA) ORGANIZATIONS

Black Public Media (BPM), formerly known as National Black Programming Consortium, develops produces, funds, and distributes media content about the African American and global Black experience. BPM supports diverse voices through training, education, and investment in visionary content makers. Some award-winning programs include The Black Press: Soldiers without Swords (Stanley Nelson), I Am Not Your Negro (Raoul Peck), Maya Angelou: Still I Rise (Rita Coburn-Whack), and Shirley Chisholm: Unbought & Unbossed (Shola Lynch).

The Center for Asian American Media (CAAM) presents stories that convey the richness and diversity of Asian American experiences to the broadest audience possible. CAAM funds, produces, and exhibits works in film, television and digital media. Recent films include The Chinese Exclusion Act, by Ric Burns and Li-Shin Yu; Norman Mineta and His Legacy: An American Story, by Dianne Fukami; and the upcoming May 2020 PBS broadcast of Asian Americans, a co-production of CAAM and WETA. CAAM also presents CAAMFest, the world's largest film festival for Asian and Asian American film.

Latino Public Broadcasting (LPB) is public media's largest Latino-focused content developer and funder providing programming to public television's nearly 360 stations and media platforms. Supporting the work of Latino filmmakers, LPB has awarded more than 13 million dollars in production funding and provided approximately 248 hours of national programming and digital content to PBS. LPB's VOCES on PBS reached 3.7 million viewers with content on the rich diversity of the Latino experience. Some productions include Latino Americans, DOLORES, Raúl Juliá The World's a Stage, The Longoria Affair, among others.

Pacific Islanders in Communications (PIC) develops media content that results in a deeper understanding of Pacific Island history, culture, and contemporary challenges. PIC provides funding support for productions, talent development, broadcast services, and community engagement. PIC's Emmy award winning series Family Ingredients is gearing up for its third season on PBS and its signature series Pacific Heartbeat, which reached over 24 million households last year, will begin its ninth season in April. Eating Up Easter will air on Independent Lens later this year.

Vision Maker Media (VMM) serves Native producers and Indian country by developing, producing and distributing educational content for broadcast and digital media. This year, VMM will deliver 20 documentaries to Public Broadcasting stations. Also, Vision Maker Media supports production training for American Indians and Alaska Native communities. A key strategy of VMM's work is the development of strong partnerships with tribal nations, Indian organizations and Native communities. Recent productions include American Masters Words from a Bear, Dawnland, Blackfeet Flood, Attla and a second season of Skindigenous. Vision Maker Media strives to share Native perspectives by Native independent filmmakers nationally.

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Stephen Gong, Center for Asian American Media, 145 9th St., Suite 350, San Francisco, CA 94103 sgong@caamedia.org; www.caamedia.org 415-863-0814.

Sandie Viquez Pedlow, Latino Public Broadcasting, 2550 N. Hollywood Way, Suite 301, Burbank, CA 91505 sandie.pedlow@lpbp.org; www.lpbp.org 202-499-0840.

Leanne Ka'iulani Ferrer, Pacific Islanders in Communications, 615 Pi'ikoi St., Suite 1504, Honolulu, HI 96814 lferrer@piccom.org; www.piccom.org 808-591-0059.

Rebekka Schlichting, Vision Maker Media, 1800 N. 33rd St., Lincoln, NE 68503 rschlichting@netas.unl.edu; www.visionmakermedia.org 402-472-3522.

PREPARED STATEMENT OF THE NATIONAL MULTIPLE SCLEROSIS SOCIETY

Mr. Chairman and Members of the Subcommittee, the National Multiple Sclerosis Society (Society) thanks you for this opportunity to provide testimony regarding funding of critically important Federal programs that impact over one million Americans who live with or are affected by multiple sclerosis (MS). We would be remiss not to acknowledge the COVID–19 pandemic that is impacting the entire world. The Federal agencies and programs under the jurisdiction of this Committee are critically important to all Americans but will be even more so now and as the country recovers from the pandemic's impact on the nation's health and its economy.

Therefore, the Society urges the Subcommittee to provide the following in fiscal year 2021:

- —$471 million for the Agency for Healthcare Research and Quality (AHRQ)
- —$8.45 billion for the Centers for Disease Control and Prevention (CDC) inclusive of $5 million for the National Neurological Conditions Surveillance Program authorized in the 21st Century Cures Act;
- —$10 million for the Lifespan Respite Care Program;
- —Robust support for Medicare and Medicaid and protection of Medicaid's current financing structure; and
- —At least $44.7 billion for the National Institute of Health (NIH), including funds provided to the agency through the 21st Century Cures Act (Public Law 114–255) for targeted initiative;
- —At least $150 million for the Patient Centered Outcomes Research Institute (PCORI); and
- —At least $13.5 billion for the Social Security Administration's administrative budget.

MS is an unpredictable, often disabling disease of the central nervous system that interrupts the flow of information within the brain, and between the brain and body. Symptoms range from numbness and tingling to blindness and paralysis. The progress, severity, and specific symptoms of MS in any one person cannot yet be predicted. A 2019 study confirmed that nearly one million Americans live with MS, more than double previous estimates and Federal Agencies and programs underneath the LHHS jurisdiction ensure that these people have what they need to live their bets lives.

The Society is a fundamental partner with the Federal Government to address the challenges of each person affected by MS. We believe that the President's fiscal year 2021 proposed budget request would hinder MS research and hamper the ability of people with MS from receiving the coverage and services they need and rely on. The Society urges the Committee to reject these proposed cuts and instead, adequately fund research and programs and health coverage and services important to people with MS.

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY (AHRQ)

AHRQ is a small agency that is revolutionizing the healthcare system based on healthcare costs and quality. It provides evidence for healthcare providers to use to make healthcare safer, higher quality, more accessible, equitable, and affordable. Reports like these are vital in ensuring that the healthcare community has science and evidence-based information to aid in consultations on treatment decisions. Now more than ever, the healthcare community needs high quality, evidence-based guidelines on which they can rely. The Society recommends Congress provide $471 million for AHRQ in fiscal year 2021.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

As the nation is currently in the middle of the COVID–19 pandemic, the importance of the CDC cannot be overstated. The CDC is tasked with protecting public health and safety through the control and prevention of disease, injury, and disability. Unfortunately, consistent underfunding has limited the Agency's ability to collect data and fulfill its mission, including tracing the incidence and prevalence of neurological diseases like MS. The 21st Century Cures Act authorized the creation of the National Neurological Conditions Surveillance System (NNCSS) within the Agency, and Congress has provided funding for it since 2018. CDC has set up pilot projects in MS and Parkinson's disease in order to determine what information to collect and the best methods that can be expanded to use in other neurologic areas. Having strong and reliable prevalence data is critical to protecting the public health and funding new and novel research to treat neurologic conditions. The Society urges Congress to increase funding for the CDC in fiscal year 2021 by providing $8.45 billion to the Agency, inclusive of the $5 million for the NNCSS.

CENTERS FOR MEDICARE & MEDICAID SERVICES

Medicare.—It is estimated that between 25–30 percent of the MS population relies on Medicare as its primary insurer. Many of these individuals are under the age of 65 and receive the Medicare benefit because of their disability. The Society urges Congress to ensure appropriate reimbursement levels for Medicare providers; maintaining access to diagnostics and durable medical equipment including power and manual complex rehabilitation technology and related accessories; protecting access to needed speech, physical and occupational therapy services; updating local coverage determinations to keep pace with advances in care; and affordable access to prescription drugs.

Medicaid.—Medicaid provides comprehensive health coverage to over 10 million persons living with disabilities, plus six million persons with disabilities who rely on Medicaid to fill Medicare's gaps. Between 5–10 percent of people with MS have Medicaid coverage and people with MS also rely on Medicaid for access to long-term services and supports. The Society urges Congress to maintain robust funding for Medicaid and reject proposals to cap or block grant the program. Especially in the midst of the COVID–19 pandemic, ensuing that individuals have health coverage is vital and we oppose any policy shift that would limit or cut services for people with MS.

LIFESPAN RESPITE CARE PROGRAM

The Lifespan Respite Care Program provides competitive grants to states to establish or enhance statewide lifespan respite programs that better coordinate and increase access to quality respite care. Approximately one quarter of individuals living with MS require long-term care services at some point during their lifetime. Often, a family member steps into the role of primary caregiver. Family caregivers allow the person living with MS to remain home for as long as possible and avoid premature admission to costlier institutional facilities. Family caregiving, while essential, can be draining and stressful. Respite offers professional short-term help to give caregivers a break from the stress of providing care and has been shown to provide family caregivers with the relief necessary to maintain their own health and bolster family stability. Much existing respite care has age eligibility requirements and importantly, the Lifespan Respite Care Program serves families regardless of special need or age. MS is typically diagnosed between the ages of 20 and 50, and Lifespan Respite programs are often the only open door to needed respite services. For these reasons, the Society asks that Congress provide $10 million for the Lifespan Respite Care Program in fiscal year 2021.

NATIONAL INSTITUTES OF HEALTH

The NIH is the nation's premiere biomedical research institution and directly supports jobs in all 50 states. The NIH is a fundamental partner in the Society's mission to stop MS in its tracks, restore what has been lost, and end MS forever. To date, the Society has invested over $1 billion to MS research to date; but we rely on Congress to provide consistent and sustained investments to the agency to cultivate an environment that is optimal for scientific discovery. NIH continues to provide the basic research necessary to facilitate the development of novel therapies. In fact, the NIH has provided the basic research that has led to every MS treatment that is available today. Though much progress has been made in MS, there is still a great deal of unmet need, particularly those who live with progressive forms of the disease- now is not the time to decrease much needed Federal investment in NIH. The Society urges Congress to provide at least $44.7 billion for the NIH, including funds provided to the agency through the 21st Century Cures Act for targeted initiatives.

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

PCORI serves a vital role in ensuring that the public and private healthcare sectors have valid and trustworthy data on health outcomes, clinical effectiveness, and appropriateness of different medical treatments by both conducting research and evaluating existing studies. Its research addresses the need for real-world evidence and patient-focused outcomes data that will improve healthcare quality and help shift healthcare payment models toward value-based care. To date, PCORI has invested over $69 million in comparative effectiveness studies in MS. These studies will provide important evidence for the best ways to address questions surrounding what care approaches work best for whom, in what care settings. We recommend that Congress reauthorize PCORI to continue its important mission and fully fund PCORI in fiscal year 2021.

SOCIAL SECURITY ADMINISTRATION (SSA)

Due to the unpredictable nature and sometimes serious impairment caused by the disease, SSA recognizes MS as a chronic illness or "impairment" that can cause disability severe enough to prevent an individual from working. During such periods, people living with MS are entitled to and rely on Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) benefits to survive. The National MS Society urges Congress to provide robust funding of at least $13.5 billion for the Social Security Administration's administrative budget.

We thank the Committee for the opportunity to provide written testimony on our recommendations for the base funding for Agencies and programs under the jurisdiction of the fiscal year 2021 LHHS appropriations bill. The agencies and programs we have outlined above are of vital importance to people living with MS and all Americans. Please do not hesitate to contact the Society with any questions that you may have, and we look forward to continuing to work with the Committee to help move us closer to a world free of MS.

[This statement was submitted by Leslie Ritter, Associate Vice President, Federal Government Relations, National Multiple Sclerosis Society.]

PREPARED STATEMENT OF THE NATIONAL PANCREAS FOUNDATION

SUMMARY OF FISCAL YEAR 2021 APPROPRIATIONS RECOMMENDATIONS

- —The Foundation joins the broader research community in requesting that the National Institutes of Health (NIH) receive a funding increase of at least $3 billion for fiscal year 2021 to bring total agency funding up to a minimum of $44.7 billion annually.
  - —Please provide proportional increases for the various NIH Institutes and Centers, including the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Cancer Institute (NCI).
- —The Foundation joins the broader public health community in requesting that the Centers for Disease Control and Prevention (CDC) receive a funding increase of at least $600 million in discretionary resources to bring total agency funding up to a minimum of $8.3 billion annually.
  - —Please provide $5 million in dedicated, line-item funding for a "Chronic Disease Education and Awareness Program" within the National Center for Chronic Disease Prevention and Health Promotion to facilitate support for meritorious and timely public health campaigns (as outlined in the fiscal year 2020 House L–HHS Appropriations Bill).

Chairman Blunt, Ranking Member Murray, and distinguished members of the subcommittee, thank you for the opportunity to submit testimony on behalf of the National Pancreas Foundation (NPF) and the patient community that we serve. We deeply appreciate the investments in the National Institutes of Health (NIH) that have occurred over the past five fiscal years and the research advancements that additional resources have facilitated, most notably in treatment progress for pancreatitis. For fiscal year 2021, we urge you to maintain this commitment to medical research and to similarly increase support for emerging public health programs, most notably at the Centers for Disease Control and Prevention (CDC). Thank you again.

ABOUT THE FOUNDATION

The National Pancreas Foundation is a patient-driven, non-profit organization that provides hope for those suffering from pancreatitis and pancreatic cancer by funding cutting edge research, advocating for new and better therapies, and providing support and education for patients, caregivers, and healthcare professionals.

CONDITIONS OF THE PANCREAS

Pancreatitis can be acute of chronic. It is characterized by inflammation of the pancreas, and chronic pancreatitis does not heal or improve-it gets worse over time and leads to permanent damage. Chronic pancreatitis eventually impairs a patient's ability to digest food and make pancreatic hormones. Chronic pancreatitis can strike at any age, but often develops in patients between the ages of 30 and 40, and is more common in men than women. The annual incidence rate is 5 -12 per 100,000 and the prevalence is 50 per 100,000. Pancreatitis can be managed with proper information and healthy practices.

Pancreatic cancer is currently the third leading cause of cancer deaths in the United States. One of the major challenges associated with pancreatic cancer is that the condition often goes undetected for a long period of time because signs and symptoms seldom occur until advanced stages. By the time symptoms occur, cancer cells are likely to have spread (metastasized) to other parts of the body, often preventing surgical removal of tumors. Research indicates an emerging link between pancreatitis and the onset of pancreatic cancer.

NIH RESEARCH: PROGRESS AND OPPORTUNITIES

NIDDK has been a leader on pancreatitis research while NCI has facilitated key breakthroughs for pancreatic cancer. More work needs to be done though as translation and clinical research are necessary to ensure innovative treatment options and diagnostic tools can be deployed to the benefit of affected patients.

In this regard, NIDDK recently hosted an effort with the community to capitalize on progress for pancreatitis and ensure promising ideas move into the FDA pipeline for review. The need remains great as pancreatitis patients currently have extremely limited treatment options despite the severity of the illness.

Moreover, the Cancer Moonshot has been extremely meaningful for scientific efforts focused on pancreatic cancer. Similar to pancreatitis though, treatment options remain extremely limited despite the severity of the disease. In fact, due to improvements in other areas and an overall lack of progress in outcomes, pancreatic cancer is now the third leading cause of cancer deaths in America.

Over recent years, key Committee Recommendations have been included that have moved key pancreas research projects forward and it is our hope that the Subcommittee will continue to demonstrate an interest in this area during the fiscal year 2021 process as treatment development activities reach a critical phase.

CDC PUBLIC HEALTH OPPORTUNITIES

The National Center for Chronic Disease Prevention and Health Promotion coordinates line-item public health programs on a variety of conditions. Recently, CDC has limited their public health activities almost exclusively to these named efforts. While these programs have been highly successful for the conditions they represent, there is a tremendous public health need to launch a similar program for pancreatitis.

A lack of adequate professional and public information about pancreatitis leads to a suboptimal situation where patients are not effectively managing the condition and as it progresses inappropriate interventions occur, most notably unnecessary surgery to remove the pancreas. The CDC can fill key knowledge gap with a pancreatitis program to disseminate best practices to the professional community and make sure public health messages reach at-risk individuals. Pancreatitis can often be managed if the proper information is available, which can prevent the progression of disease, including the onset of pancreatic cancer.

A modest $5 million program will provide CDC with the resources and flexibility it needs to fund collaborative public health efforts that can have tremendous impact.

Diane Tonelli's Story

I am a resident of Massachusetts and I have chronic pancreatitis. I was first diagnosed in 2002 w acute pancreatitis-idiopathic just shy of 2 years after my dad had died from pancreatic cancer. I was hospitalized 2 times, managed for pain and treated with TPN.

I struggled intensely the first few years. I lost 28 pounds, down to 92 pounds by mid-summer of 2002.

During the first few years I had genetic testing which was positive for genetic mutation CFTR R117H- cystic fibrosis and negative for BRCA1 and 2, SPINK1 and PRSS1.

Over the years since initial diagnosis I have had yearly screening. The disease had progressed to chronic pancreatitis with imaging revealing moderate to severe disease. I've had a sweat test which revealed probable Cystic fibrosis and bone density testing has revealed osteoporosis (density of an 80 year old) due to decrease nutrition related to pancreas insufficiency.

Currently I take pancreatic enzymes and continue to follow with GI for pancreas severity and have screening for pancreatic cancer.

[This statment was submitted by David Bakelman, Chief Executive Officer, National Pancreas Foundation.]

PREPARED STATEMENT OF THE NATIONAL RESPITE COALITION

Mr. Chairman, I am Jill Kagan, Chair, National Respite Coalition (NRC), a network of state respite coalitions, providers, caregivers, and national, state and local organizations. We are requesting $10 million for the Lifespan Respite Care Program administered by the Administration on Aging, Administration for Community Living, Department of Health and Human Services, in the fiscal year 2021 Labor, HHS, and Education Appropriations bill. The increase will enable: (1) State replication of Lifespan Respite best practices to allow family caregivers, regardless of the care recipient's age or disability, to access affordable respite; (2) improved respite quality and expanded respite provider capacity; and (3) person and family-centered respite services and information for family caregivers on how to find, use and pay for respite services.

Respite Care Saves Money and Benefits Families. Delaying a nursing home placement for individuals with Alzheimer's or avoiding hospitalization for children with autism can save Medicaid billions of dollars. Researchers at the University of Pennsylvania studied the records of 28,000 children with autism enrolled in Medicaid in 2004 and concluded that for every $1,000 states spent on respite, there was an 8 percent drop in the odds of hospitalization (Mandell, et al., 2012). Respite may help delay or avoid facility-based placements (Gresham, 2018; Avison, et al., 2018), improve maternal employment (Caldwell, 2007), strengthen marriages (Harper, 2013), and significantly reduce caregiver depression, stress and burden levels linked to caregiver health (Broady and Aggar, 2017; Lopez-Hartmann, et al., 2012; Zarit, et al., 2014).

With at least two-thirds (66 percent) of family caregivers in the workforce (Mantos, 2015), U.S. businesses lose from $17.1 to $33.6 billion per year in lost productivity of employed caregivers (MetLife Mature Market Institute, 2006). Higher absenteeism among working caregivers costs the U.S. economy an estimated $25.2 billion annually (Witters, 2011). The University of NE Medical Center conducted a survey of caregivers receiving respite through the NE Lifespan Respite Program and found that 36 percent of family caregivers reported not having enough money at the end of the month to make ends meet, but families overall reported a better financial situation when receiving respite (Johnson, J., et al., 2018).

Who Needs Respite? About 41 million unpaid family caregivers of adults provided an estimated 34 billion hours of care—worth $470 billion—to loved ones and friends in 2017 (Reinhard, SC, et al. 2019). Eighty percent of those needing long-term services and supports (LTSS) are living at home. Two-thirds of older people with disabilities receiving LTSS at home receive care exclusively from family caregivers (Congressional Budget Office, 2013).

Concerns about providing care for a growing aging population are paramount. However, caregiving is a lifespan issue. The majority (54 percent) of family caregivers care for someone between the ages of 18 and 75 (NAC and AARP, 2020). The National Children's Health Survey found the number of children with special healthcare needs to be close to 14 million (Child and Adolescent Health Measurement Initiative, 2020). Families caring for children with special healthcare needs provide nearly $36 billion worth of care annually (Romley, et al., 2016).

National, State and local surveys have shown respite to be among the most frequently requested services by family caregivers (Anderson, L, et al., 2018; Maryland Caregivers Support Coordinating Council, 2015). Yet, 86 percent of family caregivers of adults did not receive respite services at all in 2019 (NAC and AARP, 2020). Nearly half of family caregivers of adults (44 percent) identified in the National Study of Caregiving were providing substantial help with healthcare tasks, yet, fewer than 17 percent used respite (Wolff, 2016). The Elizabeth Dole Foundation has recommended that respite should be more widely available to military caregivers (Ramchand, et al., 2014).

Respite Barriers and the Effect on Family Caregivers. While most families want to care for family members at home, research shows that family caregivers are at risk for emotional, mental, and physical health problems (Family Caregiver Alliance, 2006; American Psychological Association, 2012; Spillman, J., et al., 2014). When caregivers lack effective coping styles or are depressed, care recipients may be at risk for falling, developing preventable secondary health conditions or limitations in functional abilities. The risk of care recipient abuse increases when caregivers are depressed or in poor health (American Psychological Association, nd). Parents of children with special healthcare needs report poorer general health, more physical health problems, worse sleep, and increased depressive symptoms compared to parents of typically developing children (McBean, A, et al., 2013).

Respite, that has been shown to ease family caregiver stress, is too often out of reach or completely unavailable. In a survey of more than 3000 caregivers of individuals with intellectual and developmental disabilities (ID/DD), nine in ten reported that they were stressed. Nearly half (49 percent) reported that finding time to meet their personal needs was a major problem. Yet, more than half of the caregivers of individuals with ID (52 percent), Autism Spectrum Disorder (ASD) (56 percent) or ID and ASD (60 percent) reported that it was difficult or very difficult to find respite care (Anderson, L., et al., 2018). Respite may not exist at all for those with Alzheimer's, ALS, MS, spinal cord or traumatic brain injuries, or children with serious emotional conditions.

Barriers to accessing respite include fragmented and narrowly targeted services, cost, and the lack of information about respite or how to find or choose a provider. Moreover, a critically short supply of well-trained respite providers may prohibit a family from making use of a service they so desperately need.

Lifespan Respite Care Program Helps. The Lifespan Respite Care Program, designed to address these barriers to respite quality, affordability and accessibility, is a competitive grant program to states administered by ACL in the Administration on Aging. The premise behind the program is both care relief and cost effectiveness. Lifespan Respite provides funding to states to expand and enhance local respite services across the country, coordinate community-based respite services to reduce duplication and fragmentation, improve coordination with other community resources, and improve respite access and quality.

Since 2009, 37 states and DC have received Lifespan Respite grants. Congress appropriated $2.5 million each year from fiscal year 2009–fiscal year 2012 and slightly less in fiscal year 2013–fiscal year 2015 due to sequestration. In fiscal year 2016 and fiscal year 2017, the program received $3.3 million, and $4.1 million in fiscal year 2018 and fiscal year 2019. We are grateful for the increase to $6.1 million in fiscal year 2020. With these funds, States are required to establish statewide coordinated Lifespan Respite care systems to serve families regardless of age or special need, provide planned and emergency respite care, train and recruit respite workers and volunteers and assist caregivers in accessing respite. Lifespan Respite helps states maximize use of limited resources and deliver services more efficiently to those most in need. Increasing funding could allow funding of several new states and help current grantees complete their ground-breaking work, serve the unserved, and integrate services and grant activities into statewide long-term services and support systems.

During the current pandemic, when family caregiver social isolation is escalating, grantees and their primary partners continue to provide respite safely in states where they are permitted to do so. They are the frontline workers who may be the only outside contact and support these families are receiving. If they cannot provide in-person respite, the network has expanded support services to include regular phone call and email check ins, delivery of care packages, online support groups, and virtual training and other educational services via Facebook and other social media outlets.

Last year, the House passed the Lifespan Respite Care Reauthorization Act of 2019, introduced by Reps. Jim Langevin (D–RI) and Rep. Cathy McMorris Rodgers (R–WA) With continued bipartisan support, the bill authorizes $200 million over 5 years. The Senate bill, introduced by Senators Susan Collins (R–ME) and Tammy Baldwin (D–WI), passed the Senate in February. The Senate bill authorizes $10 annually ($50 million over 5 years).

How is Lifespan Respite Program Making a Difference? In describing the Lifespan Respite Care Program, a distinguished National Academies of Sciences, Engineering, and Medicine panel concluded in the report Families Caring for an Aging America, "Although the program is relatively small, respite is one of the most important caregiver supports." State Lifespan Respite programs are engaged in innovative activities:

- —AL, AR, AZ, CO, DE, MD, MT, ND, NE, NV, NC, OK, RI, SC, TN, VA, WA, and WI, administer successful self-directed respite vouchers for underserved populations, such as individuals with Alzheimer's disease, traumatic brain injury, MS or ALS, adults with intellectual or developmental disabilities (I/DD), rural caregivers, or those on waiting lists for services. When families are willing and states permit it, these programs continue to operate during the pandemic.
- —AL's respite voucher program found a substantial decrease in the percentage of caregivers reporting how often they felt overwhelmed with daily routines after receiving respite. Caregivers in NE's Lifespan Respite program reported significant decreases in stress levels, fewer physical and emotional health issues, and reductions in anger and anxiety.
- —Innovative and sustainable respite services, funded in AL, CO, MA, NC, and NY through mini-grants to community-based agencies, also have documented benefits to family caregivers.
- —AL, IA, MD and NE offer emergency respite and AL, AR, CO, NE, NY, PA, RI, SC and TN implemented new volunteer or faith-based respite services.
- —Respite provider recruitment and training are priorities in AR, NE, NY, SC, VA, and WI.

State agency partnerships are changing the landscape. Lifespan Respite WA, housed in Aging & Long-Term Support Administration, partnered with WA's Children with Special Health Care Needs Program, Tribal entities and the state's Traumatic Brain Injury program to provide respite vouchers to families across ages and disabilities. The OK Lifespan Respite program partnered with the state's Transit Administration to develop mobile respite in isolated rural areas. States, including NY and NV, are building "no wrong door systems" in partnership with Aging and Disability Resource Centers to improve respite access. States are developing long-term sustainability plans, but without continued Federal support, many grantees will be cut off before these initiatives achieve their full impact.

No other Federal program has respite as its sole focus, helps ensure respite quality or choice, and supports respite start-up, training or coordination. We urge you to include $10 million in the fiscal year 2021 Labor, HHS, and Education appropriations bill. Families will be able to keep loved ones at home, saving Medicaid and other Federal programs billions of dollars.

For more information, please contact Jill Kagan, National Respite Coalition at jkagan@archrespite.org. Complete references available on request.

[This statement was submitted by Jill Kagan, Chair, National Respite Coalition.]

PREPARED STATEMENT OF THE NATIONAL RURAL HEALTH ASSOCIATION

On behalf of the National Rural Health Association (NRHA), we ask that you continue to support critically important rural health programs as you move forward with fiscal year 2021 funding measures. We thank you for your leadership and support for rural health programs and hope you will continue these important efforts.

NRHA is a national nonprofit membership organization with more than 21,000 members whose mission is to improve the health and healthcare of rural Americans and to provide leadership on rural issues through advocacy, communications, education, and research. NRHA's membership is a diverse collection of individuals and organizations that share a common interest in ensuring all rural communities have access to quality, affordable healthcare.

We appreciate the efforts of the Subcommittee on Labor, Health and Human Services, Education, and Related Agencies immensely and applaud your leadership in supporting rural health programs. This letter outlines recommendations that will strengthen the rural healthcare safety net and ensure that rural Americans maintain access to critical healthcare services.

Now, more than ever before, it is crucial that the Committee support programs that seek to address the severe healthcare crises that are escalating in rural America. Rural healthcare providers, who were struggling to keep their doors open prior to the COVID–19 virus pandemic, are having to decrease operations, furlough and lay off staff, and even close their doors during this pandemic. Relief is needed for rural healthcare providers before it is too late.

The rural hospital closure crisis continues to intensify. In 2019, the United States experienced the greatest number of rural hospital closures in a single year since the beginning of the century, and 2020 is on pace to surpass that record. So far, four rural hospital, have closed during the COVID–19 virus pandemic, and at least 130 rural hospitals have closed since 2010. The pandemic has also exacerbated healthcare workforce shortages that have plagued rural communities for decades; over 75 percent of rural counties are classified as Health Professional Shortage Areas (HPSAs).

COVID–19 is now rapidly spreading to areas in rural America. According to a recent Kaiser Family Foundation report, "In the two-week period between April 13 and April 27, non-metro counties saw a 125 percent increase in coronavirus cases (from 51 cases per 100,000 people to 115), on average, and a 169 percent increase in deaths (from 1.6 deaths per 100,000 people to 4.4)." All of this is happening at a time when nearly half of rural hospitals are operating a financial loss.

Compared to their urban counterparts, rural Americans are older, more likely to have underlying health conditions, and less likely to have health insurance or financial resources to weather this storm. Additionally, the latest research indicates that COVID–19 cases are disproportionately more common among low wage workers, people without health insurance, people with underlying health conditions, people of color, and Indigenous people: rural Americans. We must ensure that the health disparities that have plagued rural communities for decades are not exacerbated by this pandemic."

To keep rural providers doors' open as the fight against this pandemic continues, NRHA asks for robust funding of the fragile rural healthcare safety net. We encourage the Committee to recognize that rural America is facing crises now and desperately needs immediate solutions

Several indispensable discretionary programs help ensure the efficient and equitable delivery of healthcare services in rural areas. To better meet these needs, while simultaneously understanding the fiscal constraints demanded by Congress, the NRHA requests a modest, across-the-board funding increase of 20 percent (unless another amount has specifically been authorized by law). These programs include:

—The Rural Health Care Services Outreach, Network and Quality Improvement Grants (Outreach programs) improve rural community health by focusing on quality improvement, increasing healthcare access, coordination of care, and integration of services. The Outreach Grant Program funds critical community-based projects for the purpose of increasing access to care in rural communities, and Network Development Grants address the financial challenges of working with underserved rural communities. These grants can be targeted for specific pandemic needs, such as tracking rural PPE and testing availability. Additionally, these programs have the flexibility to focus on community-specific outreach and have an excellent track record of improving population health. Great successes have been achieved through these grants in establishing community-based diabetes control, heart disease and stroke prevention programs. Utilization of these grants for pandemic preparedness and control is the most cost-effect and rapid way to implement community-based rural programs.

—Rural Hospital Flexibility Grants are used by each state to implement specific rural strategies to ensure access to primary care in rural communities. Utilization of these grants is the most effective way to provide relief and resources to rural areas that have been severely impacted by COVID–19. These grants allow flexibility, targeted funding, and rapid distribution. This extraordinarily successful grant program can be used by hospitals to procure needed equipment, expand telehealth, and establish rural-specific pandemic plans. Critical Access Hospitals (CAHs) provide essential services to their communities, and their continued viability supports access to care and the health of the rural economy. Additionally, funding for these grants support partnerships between states and CAHs to work on quality and performance improvement activities, as well as help eligible rural hospitals convert to CAH status and enhance CAH-related emergency medical services, which is desperately needed during this crisis. Additionally, it provides support to rural hospitals with fewer than 50 beds through awards to 46 states with eligible hospitals and increases the delivery of mental health services or other healthcare services to meet the needs of veterans living in rural areas.

—Funding for the Rural Health Policy Development program is used to support the Federal Office of Rural Health Policy (FORHP) as they advise the Secretary on rural health issues, conduct and oversee research on rural health, and provide support for grants that enhance healthcare delivery in rural communities.

—State Offices of Rural Health, located in all 50 states, help their individual rural communities build healthcare delivery systems. They accomplish this mission by collecting and disseminating information, providing technical assistance, helping to coordinate rural health interests state-wide, and by supporting efforts to improve recruitment and retention of health professionals.

—Telehealth funding is for the Office for the Advancement of Telehealth, including the Telehealth Network Grant Program, which promotes the effective use of technologies to improve access to health services and to provide distance education for health professionals.

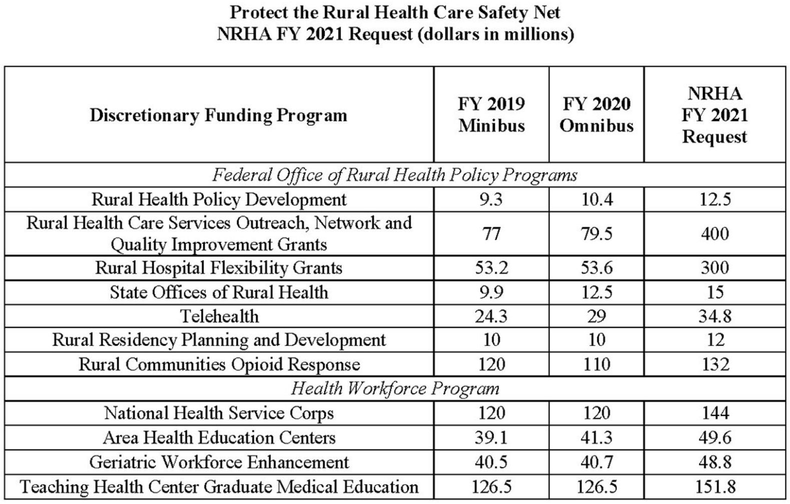
—The Rural Residency Planning and Development Program seeks to expand the number of rural residency training programs and subsequently increase the number of physicians choosing to practice in rural areas. For the purpose of this program, rural residencies are allopathic and osteopathic physician residency training programs that primarily train in rural communities.

—The Rural Communities Opioid Response Program (RCORP) initiative aims to reduce the morbidity and mortality associated with substance use disorder (SUD), including opioid use disorder (OUD), in high risk rural communities by providing funding and technical assistance to multi-sector consortia to enable them to identify and address OUD prevention, treatment, and recovery needs at the community, county, state, and/or regional levels.

—National Health Service Corps supports qualified healthcare providers that are dedicated to working in underserved areas by providing scholarship and loan-repayment programs for those serving medically underserved communities and populations with health professional shortages and/or high unmet needs for health services.

- —The Area Health Education Centers (AHEC) Program develops and enhances education and training networks within communities, academic institutions, and community-based organizations. AHECs develop and maintain a diverse healthcare workforce and broaden the distribution of the health workforce. The redesigned AHEC Program invests in interprofessional networks that address social determinants of health and incorporate field placement programs for rural and medically underserved populations.
- —The Geriatrics Workforce Enhancement Program (GWEP) improves healthcare for older adults by developing a healthcare workforce to provide value-based care that improves health outcomes for older adults by integrating geriatrics and primary care delivery sites/systems.
- —The Teaching Health Center Graduate Medical Education (THCGME) Program increases the number of primary care physician and dental residents, increasing the overall number of these primary care providers. Teaching Health Centers (THCs) specifically have been shown to attract residents from rural and/or disadvantaged backgrounds who are more inclined to practice in underserved areas than those from urban and economically advantaged backgrounds.

NRHA is grateful for your support in recognizing the need for providing a sound future for the delivery of rural healthcare. We hope you will continue to support the millions of Americans in rural and underserved areas by acknowledging and considering these funding priorities.



Protect the Rural Health Care Safety Net
NRHA FY 2021 Request (dollars in millions)

Discretionary Funding Program	FY 2019 Minibus	FY 2020 Omnibus	NRHA FY 2021 Request
Federal Office of Rural Health Policy Programs			
Rural Health Policy Development	9.3	10.4	12.5
Rural Health Care Services Outreach, Network and Quality Improvement Grants	77	79.5	400
Rural Hospital Flexibility Grants	53.2	53.6	300
State Offices of Rural Health	9.9	12.5	15
Telehealth	24.3	29	34.8
Rural Residency Planning and Development	10	10	12
Rural Communities Opioid Response	120	110	132
Health Workforce Program			
National Health Service Corps	120	120	144
Area Health Education Centers	39.1	41.3	49.6
Geriatric Workforce Enhancement	40.5	40.7	48.8
Teaching Health Center Graduate Medical Education	126.5	126.5	151.8

[Contact: Maggie Elehwany, Vice President, Government Affairs and Policy, National Rural Health Association melehwany@nrharural.org.]

PREPARED STATEMENT OF THE NATIONAL TECHNICAL INSTITUTE FOR THE DEAF AND ROCHESTER INSTITUTE OF TECHNOLOGY

Mr. Chairman and Members of the Committee:

I respectfully submit the fiscal year 2021 budget request for NTID (National Technical Institute for the Deaf), one of nine colleges of RIT (Rochester Institute of Technology), in Rochester, New York. Created by Congress by Public Law 89–36 in 1965, NTID provides a university-level technical and professional education for students who are deaf and hard of hearing, leading to successful careers in high-demand fields for a sub-population of individuals historically facing high rates of unemployment and under-employment. NTID students study at the associate, baccalaureate, master's and doctoral levels as part of a university (RIT) that includes more than 17,000 hearing students. NTID also provides baccalaureate and graduate-level education for hearing students in professions serving deaf and hard-of-hearing individuals.

BUDGET REQUEST

On behalf of NTID, for fiscal year 2021 I would like to request $84,932,000 for Operations. NTID has worked hard to manage its resources carefully and responsibly. NTID actively seeks alternative sources of public and private support, with approximately 26 percent of NTID's Operations budget coming from non-Federal funds, up from 9 percent in 1970. Since fiscal year 2006, NTID raised almost $24 million in support from individuals and organizations.

NTID's fiscal year 2021 request of $84,932,000 includes almost $3,500,000 for establishing a national hub of innovation for deaf scientists in Rochester, New York. The "Hub" will be a collaborative partnership with the University of Rochester and other area organizations that will enhance the access of deaf and hard-of-hearing persons to career opportunities as scientists, biomedical researchers and health professionals. Hub programs will include a summer research institute, a pre-career training pipeline for deaf and hard-of-hearing scientists, mentoring programs, a postdoc-to-faculty program, and guidance for biomedical research institutions and medical schools on best practices for training deaf and hard-of-hearing scientists and health professionals.

NTID's fiscal year 2021 request also includes an additional $1,000,000 to expand the NTID Regional STEM Center (NRSC) partnership, which serves deaf and hard-of-hearing students in 12 southeastern states by promoting training and postsecondary participation in STEM fields, providing professional development for teachers, and developing partnerships with business and industry to promote employment opportunities. Via the NRSC, deaf and hard-of-hearing middle school students are introduced to STEM programs and careers that will help inform their academic and career decisions. Deaf and hard-of-hearing high school students can take NTID STEM dual-credit courses and participate in career exploration and college preparation programs that will help them transition from high school to college. In fiscal year 2019, up to 3,404 students, 2,850 educators, 644 parents, 290 employers, 323 interpreters and 174 vocational rehabilitation staff enrolled in NRSC programs (some may have enrolled in multiple programs).

Though the total impact and costs of the coronavirus are not yet known, many NTID students rely on Pell Grants and have limited financial resources, many NTID students do not have computer/WiFi access at home and cannot readily adapt to online learning, the demand for making online resources ASL-accessible has already generated unanticipated expense, and co-op opportunities for students have been diminished as industry grapples with the virus. NTID will rally to support the persistence and graduation of students whose college careers have been disrupted by this virus, but it will take extra resources. The coronavirus has also demonstrated the national need for timely, accurate and official information in ASL about pandemics and healthcare concerns—a service the Hub could provide.

Currently, NTID is focused on creating a safe environment for students to return to campus in the fall. Strategies under consideration are size limits on lectures, online and face-to-face instruction, virus and antibody testing, contact tracing, social distancing measures, daily monitoring, quarantine housing, enhanced disinfection, new food service models, touchless technologies, sanitized air handling, and upgrading of all residence halls and academic facilities to support new safety guidelines.

ENROLLMENT

Truly a national program, NTID has enrolled students from all 50 states. In Fall 2019 (fiscal year 2020), NTID's enrollment was 1,129 students. NTID also serves students nationwide through Project Fast Forward, a project that builds a pathway for deaf and hard-of-hearing students to transition from high school to college in selected STEM disciplines by allowing deaf and hard-of-hearing high school students to take dual-credit courses, earning RIT/NTID college credit while they are still in high school. In fiscal year 2020, 363 deaf and hard-of-hearing high school students enrolled in dual-credit courses at partner high schools.

NTID ACADEMIC PROGRAMS

NTID offers high quality, career-focused associate degree programs preparing students for specific well-paying technical careers. NTID also provides transfer associate degree programs to better serve our student population seeking bachelor's, master's, and doctoral degrees. These transfer programs provide seamless transition to baccalaureate and graduate studies in the other colleges of RIT.

A cooperative education (co-op) component is an integral part of academic programming at NTID and prepares students for success in the job market. A co-op assignment gives students the opportunity to experience a real-life job situation and focus their career choice. Students develop technical skills and enhance vital personal skills such as teamwork and communication, which will make them better candidates for full-time employment after graduation. Last year, 232 students participated in 10-week co-op experiences that augment their academic studies, refine their social skills, and prepare them for the competitive working world.

STUDENT ACCOMPLISHMENTS

NTID deaf and hard-of-hearing students persist and graduate at rates higher than or on par with national persistence and graduation rates for all students at two-year and four-year colleges. For NTID deaf and hard-of-hearing graduates, over the past 5 years, an average of 95 percent have found jobs commensurate with their education level. Of our

Fiscal year 2018 graduates (the most recent class for which numbers are available), 95 percent were employed 1 year later, with 65 percent employed in business and industry, 15 percent in education and non-profits, and 20 percent in government.

Graduation from NTID has a demonstrably positive effect on students' earnings over a lifetime, and results in a notable reduction in dependence on Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). In fiscal year 2012, NTID, the Social Security Administration (SSA), and Cornell University examined earnings and Federal program participation data for more than 16,000 deaf and hard-of-hearing individuals who applied to NTID over our entire history. The study showed that NTID graduates, over their lifetimes, are employed at a higher rate and earn more (therefore paying more in taxes) than students who withdraw from NTID or attend other universities. NTID graduates also participate at a lower rate in SSI programs than students who withdrew from NTID.

Using SSA data, at age 50, 78 percent of NTID deaf and hard-of-hearing graduates with bachelor degrees and 73 percent with associate degrees report earnings, compared to 58 percent of NTID deaf and hard-of-hearing students who withdrew from NTID and 69 percent of deaf and hard-of-hearing graduates from other universities. Equally important is the demonstrated impact of an NTID education on graduates' earnings. At age 50, $58,000 is the median salary for NTID deaf and hard-of-hearing graduates with bachelor degrees and $41,000 for those with associate degrees, compared to $34,000 for deaf and hard-of-hearing students who withdrew from NTID and $21,000 for deaf and hard-of-hearing graduates from other universities.

An NTID education also translates into reduced dependency on Federal transfer programs, such as SSI and SSDI. At age 40, less than 2 percent of NTID deaf and hard-of-hearing associate and bachelor degree graduates participated in the SSI program compared to 8 percent of deaf and hard-of-hearing students who withdrew from NTID. Similarly, at age 50, only 18 percent of NTID deaf and hard-of-hearing bachelor degree graduates and 28 percent of associate degree graduates participated in the SSDI program, compared to 35 percent of deaf and hard-of-hearing students who withdrew from NTID.

ACCESS SERVICES

Access services include sign language interpreting, real-time captioning, classroom notetaking services, captioned classroom video materials, and assistive listening services. NTID provides an access services system to meet the needs of a large number of deaf and hard-of-hearing students enrolled in baccalaureate and graduate degree programs in RIT's other colleges as well as students enrolled in NTID programs who take courses in the other colleges of RIT. Access services also are provided for events and activities throughout the RIT community. Historically, NTID has followed a direct instruction model for its associate-level classes, with limited need for sign language interpreters, captionists, or other access services. However, the demand for access services has grown recently as associate-level students request communication based on their preferences.

During fiscal year 2019, 145,284 hours of interpreting were provided—an increase of 24 percent compared to fiscal year 2010. During fiscal year 2019, 25,978 hours of real-time captioning were provided to students—a 33 percent increase over fiscal year 2010.

SUMMARY

NTID's fiscal year 2021 funding request ensures that we continue our mission to prepare deaf and hard-of-hearing people to excel in the workplace and expand our outreach to better prepare deaf and hard-of-hearing students to excel in college. NTID students persist and graduate at rates higher than or on par with national rates for all students. NTID graduates have higher salaries, pay more taxes, and are less reliant on Federal SSI programs. NTID's employment rate is 95 percent over the past 5 years. Therefore, I ask that you please consider funding our fiscal year 2021 request of $84,932,000 for Operations.

We are hopeful that the members of the Committee will agree that NTID, with its long history of successful stewardship of Federal funds and an outstanding educational record of service to people who are deaf and hard of hearing, remains deserving of your support and confidence. Likewise, we will continue to demonstrate to Congress and the American people that NTID is a proven economic investment in the future of young deaf and hard-of-hearing citizens. Quite simply, NTID is a Federal program that works.

[This statement was submitted by Dr. Gerard J. Buckley, President, National Technical Institute, Vice President and Dean, Rochester Institute of Technology.]

PREPARED STATEMENT OF THE NATIONAL VIOLENT DEATH REPORTING SYSTEM

Thank you for this opportunity to submit testimony in support of funding for the National Violent Death Reporting System (NVDRS), which is administered by the National Center for Injury Prevention and Control at the Centers for Disease Control and Prevention (CDC). The National Violence Prevention Network (NVPN), a broad and diverse alliance of health and welfare, suicide and violence prevention, and law enforcement supports a funding level for fiscal year 2021 of $25.5 million to allow for the continuation nationwide expansion of the NVDRS program, which now includes all 50 states, the District of Columbia and Puerto Rico. NVPN also advocate for increased funding to the Centers for Disease Control and Prevention to support gun violence research at a level of $50 million for fiscal year 2020.

BACKGROUND

In 2016 alone, more than 64,000 Americans were victims of violent deaths. These deaths include homicide, suicide, domestic violence, abuse and neglect, gang violence, and other causes.[1] In addition, an average of 123 people[2] (20 of which are military veterans[3]) take their own lives each day. Violence-related death and injuries cost the United States $107 billion in medical care and loss in productivity.[4,5] Nearly 1.5 million years of potential life before age 65 were lost just in 2017 in homicides and suicides.

The NVDRS program makes better use of data that are already being collected by health, law enforcement, and social service agencies. The NVDRS program, in fact, does not require collection of any new data. Instead it links together information that, when kept in separate compartments, is much less valuable as a tool to characterize and monitor violent deaths. With a clearer picture of why violent deaths occurs, law enforcement, public health officials, and others can work together to identify those at risk and target effective preventive services.

In 2018, NVDRS was finally able to expand to all 50 states, Washington DC, and Puerto Rico thanks to the $23.5 million appropriation level. As states begin to enter data into the system, the U.S. will finally have a truly nationwide program with which to study circumstances surrounding violent deaths.

NVDRS IN ACTION

Opioid deaths are a serious public health issue. Drug overdose deaths are the leading cause of injury deaths in America.[6] It is important to invest in surveillance

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[1] Centers for Disease Control and Prevention . (2015). Injury Prevention & Control : Division of Violence Prevention. Retrieved April 26, 2018, from http://www.cdc.gov/violenceprevention/nvdrs/.

[2] Americans for Suicide Prevention. (n.d.). Suicide Statistics. Retrieved April 26, 2018, from Americans for Suicide Prevention: http://afsp.org/about-suicide/suicide-statistics/.

[3] Office of Suicide Prevention, Department of Veterans Affairs (2016, August). Suicide Among Veterans and Other Americans, 2001–2014. Retrieved April 26, 2018, from Department of Veterans Affairs : https://www.mentalhealth.va.gov/docs/2016suicidedatareport.pdf.

[4] Centers for Disease Control and Prevention . (2016, June 18). National Violent Death Reporting System—An Overview . Retrieved 26 April, 2018, from National Violent Death Reporting System: http://www.cdc.gov/violenceprevention/pdf/nvdrs__overview-a.pdf.

[5] Centers for Disease Control and Prevention. (2015, December 15). National Violent Death Reporting System—State Profiles. Retrieved March 7, 2017, from A CDC website: https://www.cdc.gov/violenceprevention/nvdrs/stateprofiles.html.

[6] U.S. Department of Health and Human Services . (2016, April 8). The U.S. Opioid Epidemic. Retrieved April 14, 2016, from U.S. Department of Health and Human Services: http://www.hhs.gov/opioids/about-the-epidemic/.

of opioid addiction to determine the extent of the problem and implement treatment options and community-based prevention strategies. NVDRS has already proven to be an invaluable tool in many states like Alaska, Indiana and Utah that collect information, through toxicology reports, about prescription-opioid overdose associated with violent deaths. Combined 2010 NVDRS data showed that 24 percent of violent deaths tested were positive for opiates.[7,8]

Children are often the most vulnerable as they are dependent on their caregivers during infancy and early childhood. Sadly, NVDRS data has shown that young children are at the greatest risk of homicide in their own homes. Combined NVDRS data from 18 of the states that currently participate in NVDRS, showed that African American children aged 4 years and under are more than three times as likely to be victims of homicide than Caucasian children,[9] and that homicides of children aged four and under are most often committed by a parent or caregiver in the home. The data further notes that household items, or "weapons of opportunity," were most commonly used, suggesting that poor stress responses may be factors in these deaths. Knowing the demographics and methods of child homicides can lead to more effective, targeted prevention programs.

Intimate partner violence (IPV) is another issue where NVDRS is proving its value. While IPV has declined along with other trends in crime over the past decade, thousands of Americans still fall victim to it every year. An analysis of intimate partner homicide based on NVDRS data from 18 states shows that intimate partners represented 87 percent of intimate partner violence-related homicides victims and corollary victims (family members, police officers, friends etc.) represented the remaining 13 percent of victims.[10]

Despite being in its early stages in several states, NVDRS is already providing critical information that is helping law enforcement and public health officials target their resources to those most at risk of intimate partner violence. For example, NVDRS data shows that while occurrences are rare, most murder-suicide victims are current or former intimate partners of the suspect or members of the suspect's family. In addition, NVDRS data indicate that women are about seven times more likely than men to be killed by a spouse, ex-spouse, lover, or former lover, and most of these incidents occurred in the women's homes.[7]

NVDRS & VA SUICIDES

Although it is preventable, every year more than 44,193 Americans die by suicide and another one million Americans attempt it, costing more than $44 billion in lost wages and work productivity.[2] Because NVDRS includes information on all violent deaths—including deaths by suicide—the program can be used to develop effective suicide prevention plans at the community, state, and national levels.

A 2015 study showed that 19.9 percent of all veteran deaths between 2001 and 2007 were suicide, with male veterans three times as likely as female veterans to commit suicide.[11] The central collection of such data can be of tremendous value for organizations such as the Department of Veterans Affairs that are working to improve their surveillance of suicides. The types of data collected by NVDRS including gender, blood alcohol content, mental health issues and physical health issues can help prevention programs better identify and treat at-risk individuals.

In addition to veteran suicides, NVDRS data has been crucial in many states like Oregon, Utah, New Jersey and North Carolina in understanding the circumstances surrounding elder suicide. This has allowed the states to collaborate locally and implement programs that target those populations at greatest risk.

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[7] Centers for Disease Control and Prevention. (2014, January 17). Surveillance for Violent Deaths—National Violent Death Reporting System, 16 States, 2010. Retrieved April 14, 2016, from Morbidity and Mortality Weekly Report—Surveillance Summaries/Volume 63/No.1: http://www.cdc.gov/mmwr/pdf/ss/ss6301.pdf.

[8] Alexander GC, F. S. (2015). The Prescription Opioid Epidemic: An Evidence-Based Approach. Baltimore: Johns Hopkins Bloomberg School of Public Health. http://www.jhsph.edu/research/centers-and-institutes/center-for-drug-safety-and-effectiveness/opioid-epidemic-town-hall-2015/2015-prescription-opioid-epidemic-report.pdf.

[9] Center for Disease Control and Prevention. (2013). National Violent Death Reporting System . Retrieved April 14, 2014, from A Web-based Injury Statistics Query and Reporting System (WISQARS) Database: https://wisqars.cdc.gov:8443/nvdrs/nvdrsDisplay.jsp.

[10] Smith, S. G., Fowler, K. A., & and Niolon, P. H. (March 2014). Intimate Partner Homicide and Corollary Victims in 16 States—NVDRS 2003–2009. American Journal of Public Health, 461–466.

[11] Kang, H., Bullman, T. A., & Smolenski, D. J. (2015). Suicide risk among 1.3 million veterans who were on active duty during the Iraq and Afghanistan wars. Annals of Epidemiology, 96–100.

FEDERAL ROLE NEEDED

NVDRS is a relatively low-cost program that yields high-quality results. While state-specific information provides enormous value to local public health and law enforcement officials, data from all 50 states, the U.S. territories and the District of Columbia must be obtained to complete the national picture. Aggregating this additional data will allow us to analyze national trends and also more quickly and accurately determine what factors can lead to violent death so that we can devise and disseminate strategies to address those factors.

STRENGTHENING AND EXPANDING NVDRS IN FISCAL YEAR 2019

We cannot reduce funding for a program that just reached its capacity to start operations in all 50 states. Congress needs to fund NVDRS at the level of $25.5 million.

We thank you for the opportunity to submit this statement for the record. The investment in NVDRS has already begun to pay off, as NVDRS-funded states are adopting effective violence prevention programs. We believe that national implementation of NVDRS is a wise public health investment that will assist state and national efforts to prevent deaths from domestic violence, veteran suicide, teen suicide, gang violence and other violence that affect communities around the country. We look forward to working with you to complete the nationwide expansion of NVDRS by securing an fiscal year 2021 appropriation of $25.5 million. In addition, we hope that the subcommittee delegates $50 million to the CDC for gun violence research to make use of the data collected by this important program.

[This statement was submitted Kate McFadyen, Chair, National Violence Prevention Network.]

PREPARED STATEMENT OF THE NEC SOCIETY

Chairman Blunt, Ranking Member Murray, and distinguished members of the Subcommittee, as you work to develop the fiscal year 2021 Labor-Health and Human Services Appropriations bill, thank you for considering the views of the community of physicians, researchers, patients, and caregivers affected by necrotizing enterocolitis (NEC).

ABOUT THE NEC SOCIETY

The NEC Society is 501(c)(3) non-profit, patient-led organization that collaborates with the world's leading scientists and clinicians in the NEC community. Necrotizing enterocolitis (NEC) is a devastating intestinal disease that affects vulnerable infants in their first weeks and months of life. NEC causes an inflammatory process that can lead to intestinal tissue damage and death. Despite significant advances in neonatal care, the morbidity and mortality rates associated with this disease have not significantly improved in decades. In the U.S. alone, thousands of babies develop NEC each year and hundreds of babies die from this complex intestinal condition. Once diagnosed, many babies only live for a few hours or days, and survivors can have lifelong neurological and nutritional complications. In addition to the stagnant morbidity and mortality rates, the prevention and treatment options for NEC are inadequate. The NEC Society is dedicated to building a world without necrotizing enterocolitis by accelerating research, raising awareness, and uniting diverse stakeholders. The NEC Society intentionally elevates the voices of women, underrepresented communities, and individuals with unique experiences, as they bring critical insight and exponentially advance the NEC Society's vision of a world without NEC.

FISCAL YEAR 2021 APPROPRIATIONS RECOMMENDATIONS

The NEC Society joins the broader medical research community in thanking Congress for continuing to support the National Institutes of Health with sustainable growth. Please continue to advance scientific progress through proportional funding increases by providing at least a $3 billion funding increase for fiscal year 2021 to bring NIH's budget up to $44.7 billion.

In this regard, please provide proportional funding increases for all NIH Institutes and Centers, including, but not limited to the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

The NEC Society also joins the public health community in asking Congress to provide the Centers for Disease Control and Prevention (CDC) with $8.3 billion through fiscal year 2021 and to establish funding to increase awareness, education of chronic diseases such as necrotizing enterocolitis. The CDC's National Center for Chronic Disease Prevention and Public Health Promotion has programs dedicated to improving surveillance, physician education, and public awareness for several chronic diseases. We encourage the Subcommittee to establish a $5,000,000 merit-based programmatic activity in this area that will allow CDC to work with stakeholder organizations to expand important initiatives on chronic diseases such as necrotizing enterocolitis. This program seeks to provide collaborative opportunities for chronic disease communities that lack dedicated funding from ongoing CDC activities. Such a mechanism allows public health experts at the CDC to review project proposals on an annual basis and direct resources to high impact efforts in a flexible fashion.

PATIENT PERSPECTIVE

Thank you for the opportunity to submit this testimony before you today. The NEC Society looks forward to working with you all to advance medical research and public health activities that will improve patient outcomes for the members of our community suffering from necrotizing enterocolitis.

I founded the NEC Society a year after my 11-month-old son, Micah, died from complications of NEC. Over the last 5 years, the NEC Society has become the world's leading organization working on this devastating neonatal disease. Through this work, I have met remarkable families, clinicians, and scientists from around the globe who share my belief that we can prevent necrotizing enterocolitis. NEC is not an inevitable complication of premature birth; we can and must do more for our most vulnerable infants. There is an urgent need for prioritized research funding so we can identify the most effective path forward as we work to save babies just like my son Micah.

[This statement was submitted by Jennifer Canvasser, MSW, Founder & Director, NEC Society.]

PREPARED STATEMENT OF THE NEPHCURE KIDNEY INTERNATIONAL

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2021

—Provide $44.7 billion for the National Institutes of Health (NIH)

—Provide a proportional increase for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Institute on Minority Health and Health Disparities (NIMHD) and support the expansion of the FSGS/NS research portfolio at NIDDK and NIMHD by funding more research into primary glomerular disease.

Chairman Blunt and Ranking Member Murray, thank you for the opportunity to present the views of NephCure Kidney International regarding research on idiopathic focal segmental glomerulosclerosis (FSGS) and primary nephrotic syndrome (NS). NephCure is the only non-profit organization exclusively devoted to fighting FSGS and the NS disease group. Driven by a panel of respected medical experts and a dedicated band of patients and families, NephCure works tirelessly to support kidney disease research and awareness.

NS is a collection of signs and symptoms caused by diseases that attack the kidney's filtering system. These diseases include FSGS, Minimal Change Disease and Membranous Nephropathy. When affected, the kidney filters leak protein from the blood into the urine and often cause kidney failure, which requires dialysis or kidney transplantation. According to a Harvard University report, 73,000 people in the United States have lost their kidneys as a result of FSGS. Unfortunately, the causes of FSGS and other filter diseases are poorly understood.

FSGS is the second leading cause of NS and is especially difficult to treat. There is no known cure for FSGS and current treatments are difficult for patients to endure. These treatments include the use of steroids and other dangerous substances which lower the immune system and contribute to severe bacterial infections, high blood pressure and other problems in patients, particularly child patients. In addition, children with NS often experience growth retardation and heart disease. Finally, NS that is caused by FSGS, MCD or MN is idiopathic and can often reoccur, even after a kidney transplant.

FSGS disproportionately affects minority populations and is five times more prevalent in the African American community. In a groundbreaking study funded by

NIH, researchers found that FSGS is associated with two APOL1 gene variants. These variants developed as an evolutionary response to African sleeping sickness and are common in the African American patient population with FSGS/NS. Researchers continue to study the pathogenesis of these variants.

FSGS has a large social impact in the United States. FSGS leads to end-stage renal disease (ESRD) which is one of the most costly chronic diseases to manage. In 2008, the Medicare program alone spent $26.8 billion, 7.9 percent of its entire budget, on ESRD. In 2005, FSGS accounted for 12 percent of ESRD cases in the U.S., at an annual cost of $3 billion. It is estimated that there are currently approximately 20,000 Americans living with ESRD due to FSGS.

Research on FSGS could achieve tremendous savings in Federal healthcare costs and reduce health status disparities.

ENCOURAGE FSGS/NS RESEARCH AT NIH

There is no known cause or cure for FSGS and scientists tell us that much more research needs to be done on the basic science behind FSGS/NS. More research could lead to fewer patients undergoing ESRD and tremendous savings in healthcare costs in the United States. NephCure works closely with NIH and has partnered with NIH on two large studies that will advance the pace of clinical research and support precision medicine. These studies are the Nephrotic Syndrome Study Network and the Cure Glomerulonephropathy Network.

With collaboration from other Institutes and Centers, ORDR established the Rare Disease Clinical Research Network. This network provided an opportunity for NephCure Kidney International, the University of Michigan, and other university research health centers to come together to form the Nephrotic Syndrome Study Network (NEPTUNE). Now in its second 5-year funding cycle, NEPTUNE has recruited over 450 NS research participants, and has supported pilot and ancillary studies utilizing the NEPTUNE data resources. NephCure urges the subcommittee to continue its support for RDCRN and NEPTUNE, which has tremendous potential to facilitate advancements in NS and FSGS research.

NIDDK houses the Cure Glomerulonephropathy Network (Cure GN), a multicenter 5-year cohort study of glomerular disease patients. Participants will be followed longitudinally to better understand the causes of disease, response to therapy, and disease progression, with the ultimate objective to cure glomerulonephropathy. NephCure recommends that the subcommittee continues to support the work that the Cure Glomeruloneuropathy [CureGN] initiative has accomplished towards further understanding rare forms of kidney diseases. It is estimated that annually there are 20 new cases of ESRD per million African Americans due to FSGS, and 5 new cases per million Caucasians. This disparity is largely due to variants of the APOL1 gene. Unfortunately, the incidence of FSGS is rising and there are no known strategies to prevent or treat kidney disease in individuals with the APOL1 genotype. NIMHD began supporting research on the APOL1 gene in fiscal year 2013. Due to the disproportionate burden of FSGS on minority populations, it remains appropriate for NIMHD to continue to advance this research. NephCure asks the subcommittee to recognize the work that NIMHD and NIDDK are doing to address the connection between the APOL1 gene and the onset of FSGS and encourage NIMHD to work with community stakeholders to identify areas of collaboration.

As a result of the important research done through NIH we have been able to work with FDA to establish new endpoints for clinical trial leading to more trials than ever before. This has led to the creation of the Kidney Health Gateway Clinical that will connect patients with breakthrough clinical trials and access top Nephrotic Syndrome doctors all in one place. These crucial trials will hopefully lead to more treatment options for our patients.

Patient Perspective

Meet 13-year-old Macy! She was diagnosed with Nephrotic Syndrome and later FSGS when she was three. Her 10-year journey with kidney disease has been long and hard. Macy did not respond to treatments for her kidney disease and within 2 years of diagnosis, her native kidneys were damaged beyond repair and she was in kidney failure and on dialysis. At the age of five, she received a living donor kidney transplant, but her disease, FSGS came back and attacked her new to her kidney. It took a full year of aggressive treatments to get Macy's FSGS into remission post-transplant. For the past 10 years, Macy has taken 18 to 26 medications a day. Those medications and her kidney disease have led to multiple co-morbidities. She is currently followed by 7 specialties, has endured 30+ surgeries & been hospitalized over 100 times. Macy participates in the Beads of Courage program in which she earns different beads for each procedure, appointment etc. The strand of beads you see in this photo are just the beads she earned in 2018! Those black beads are for pokes (lab draws, IV's, Shots) and Macy earned over 400 last year. As you can see kidney disease is tough! Although Macy continues to struggle with kidney disease and will need another transplant sooner than later, she doesn't let that stop her from living life! Macy loves dancing and musical theater, art, and hanging out with her dog Bentley!

[This statement was submitted by Irving Smokler, PH.D., President and Founder, NephCure Kidney International.]

PREPARED STATEMENT OF THE NEUROFIBROMATOSIS NETWORK

Thank you for the opportunity to submit testimony to the Subcommittee on the importance of funding for the National Institutes of Health (NIH), and specifically for continued research on Neurofibromatosis (NF), a genetic disorder closely linked to many common diseases widespread among the American population. My name is Kim Bischoff and I am the Executive Director of the Neurofibromatosis (NF) Network, a national organization of NF advocacy groups. We respectfully request that you include the following report language on NF research at the National Institutes of Health within the Office of the Director account in the fiscal year 2021 Labor, Health and Human Services, Education Appropriations bill.

Neurofibromatosis [NF].—The Committee supports efforts to increase funding and resources for NF research and treatment at multiple Institutes, including NCI, NINDS, NIDCD, NHLBI, NICHD, NIMH, NCATS, and NEI. Children and adults with NF are at elevated risk for the development of many forms of cancer, as well as deafness, blindness, developmental delays and autism; the Committee encourages NCI to increase its NF research portfolio in fundamental laboratory science, patient-directed research, and clinical trials focused on NF-associated benign and malignant cancers. The Committee also encourages NCI to support clinical and preclinical trials consortia. Because NF can cause blindness, pain, and hearing loss, the Committee urges NINDS to continue to aggressively fund fundamental basic science research on NF relevant to restoring normal nerve function. Based on emerging findings from numerous researchers worldwide demonstrating that children with NF are at significant risk for autism, learning disabilities, motor delays, and attention deficits, the Committee encourages NINDS, NIMH, and NICHD to increase their investments in laboratory-based and patient-directed research investigations in these areas. Since NF2 accounts for approximately 5 percent of genetic forms of deafness, the Committee encourages NIDCD to expand its investment in NF2-related research. NFl can cause vision loss due to optic gliomas. The Committee encourages NEI to expand its investment in NF1-focused research on optic gliomas and vision restoration.

On behalf of the Neurofibromatosis (NF) Network, I speak on behalf of the over 100,000 Americans who suffer from NF as well as the millions of Americans who suffer from diseases and conditions linked to NF such as cancer, brain tumors, heart disease, memory loss, and learning disabilities. Thanks in large part to this Subcommittee's strong support, scientists have made enormous progress since the discovery of the NF1 gene in 1990 resulting in clinical trials now being undertaken at NIH with broad implications for the general population.

NF is a genetic disorder involving the uncontrolled growth of tumors along the nervous system which can result in terrible disfigurement, deformity, deafness, pain, blindness, brain tumors, cancer, and even death. In addition, approximately one-half of children with NF suffer from learning disabilities. NF is the most common neurological disorder caused by a single gene and is more common than Cystic Fibrosis, hereditary Muscular Dystrophy, Huntington's disease and Tay Sachs combined. There are three types of NF: NF1, which is more common, NF2, which initially involves tumors causing deafness and balance problems, and Schwannomatosis, the hallmark of which is severe pain. While not all NF patients suffer from the most severe symptoms, all NF patients and their families live with the uncertainty of not knowing whether they will be seriously affected because NF is a highly variable and progressive disease.

Researchers have determined that NF is closely linked to heart disease, learning disabilities, memory loss, cancer, brain tumors, and other disorders including deafness, blindness and orthopedic disorders, primarily because NF regulates important pathways common to these disorders such as the RAS, cAMP and PAK pathways. Research on NF therefore stands to benefit millions of Americans.

Learning Disabilities/Behavioral and Brain Function

Learning disabilities affect one-half of people with NF1. They range from mild to severe and can impact the quality of life for those with NF1. In recent years, research has revealed common threads between NF1 learning disabilities, autism, and other related disabilities. New drug interventions for learning disabilities are being developed and will be beneficial to the general population. Research being done in this area includes working to identify drugs that target Cyclic AMP, so they can be paired with existing drugs targeting RAS. Identification of new drug combinations may benefit people with multiple types of learning disabilities.

Bone Repair

At least a quarter of children with NF1 have abnormal bone growth in any part of the skeleton. In the legs, the long bones are weak, prone to fracture and unable to heal properly; this can require amputation at a young age. Adults with NF1 also have low bone mineral density, placing them at risk of skeletal weakness and injury. Research currently being done to understand bone biology and repair will pave the way for new strategies to enhancing bone health and facilitating repair.

Pain Management

Severe pain is a central feature of Schwannomatosis, and significantly impacts quality of life. Understanding what causes pain, and how it could be treated, has been a fast-moving area of NF research over the past few years. Pain management is a challenging area of research and new approaches are highly sought after.

Nerve Regeneration

NF often requires surgical removal of nerve tumors, which can lead to nerve paralysis and loss of function. Understanding the changes that occur in a nerve after surgery, and how it might be regenerated and functionally restored, will have significant quality of life value for affected individuals. Light-based therapy is being tested to dissect nerves in surgery of tumor removal. If successful it could have applications for treating nerve damage and scarring after injury, thereby aiding repair and functional restoration.

Cancer

NF can cause a variety of tumors to grow, which includes tumors in the brain, spinal cord and nerves. NF affects the RAS pathway which is implicated in 70 percent of all human cancers. Some of these tumor types are benign and some are malignant, hard to treat and often fatal. Previous studies have found a high incidence of intracranial glioblastomas and malignant peripheral nerve sheath tumors (MPNSTs), as well as a six-fold incidents of breast cancer compared to the general population. One of these tumor types, malignant peripheral nerve sheath tumor (MPNST), is a very aggressive, hard to treat and often fatal cancer. MPNSTs are fast growing, and because the cells change as the tumor grows, they often become resistant to individual drugs. Clinical trials are underway to identify a drug treatment that can be widely used in MPNSTs and other hard-to-treat tumors.

The enormous promise of NF research, and its potential to benefit over 175 million Americans who suffer from diseases and conditions linked to NF, has gained increased recognition from Congress and the NIH. This is evidenced by the fact that numerous institutes are currently supporting NF research, and NIH's total NF research portfolio has increased from $3 million in fiscal year 1990 to an estimated $32 million in fiscal year 2019. Given the potential offered by NF research for progress against a range of diseases, we are hopeful that the NIH will continue to build on the successes of this program by funding this promising research and thereby continuing the enormous return on the taxpayers' investment.

We appreciate the Subcommittee's strong support for the National Institutes of Health and will continue to work with you to ensure that opportunities for major advances in NF research at the NIH are aggressively pursued. Thank you.

[This statement was submitted by Kim Bischoff, Executive Director, Neurofibromatosis Network.]

PREPARED STATEMENT OF THE NEW MEXICO SOUTHERN COLORADO COMMUNITY HEALTH REPRESENTATIVE ASSOCIATION

I write this testimony for the third year in a row on behalf of the New Mexico Southern Colorado Community Health Representatives Association (NMSCCHRA). The CHRs have been the original tribally contracted and administered local tribal health program for 50 years. The CHRs are the 'Boots on the Ground' tribal health providers when no other health services are available in Native American communities. The funding for this valuable community-based health program is funded from the Indian Health Service under the budget cited above. The Association had been advocating and informing the U.S. Congressional committees on the need to maintain and continue the CHR program as well as the Health Education line items for the past 3 years. It is a service staffed by local tribal community members providing tribal specific and customized services. The elimination of such a service will leave some tribes with No health providers in rural areas. We encourage your support of the overall IHS budget and 2–3 percent yearly increases since 2008, however, we realize there is still a huge need for public health infrastructure in Native lands.

The President's budget request proposes to combine funding for CHR ($ 62.8 million in fiscal year 2020), Health Education ($20.56 million in fiscal year 2020) and nationalization of the Community Health Aide Program ($5 million in 2020) into a new 'Community Health' line item funded at $44.1 million. By combining all three-line items to one would reduce the yearly funding by $44 million for all three combined. All three-line items should remain as stated in the Indian Health Care Improvement Act which authorizes the IHS budget and has been institutionalized as line items. All 3-line items should be increased as has been recommended by the Tribal Leaders IHS budget formulation workgroup for the past few years. The workgroup put the CHR program as priority in Native lands and the IHS budget should be funded based on need to $9.1 billion. The Association has gone on record stating the three-line items are Public Health in concept and service administration, have historical clinical significance in purpose and evidence practice in their respective communities. Education and CHRs are the first steps in public health practice and protocol in Indian Country. You are now seeing the confusion and poor public health practice occurring if such programs are not funded adequately in the coronavirus pandemic.

Congress has a constitutional obligation to mandatory fund the Indian Health Service budget and for IHS not remain as a discretionary budget. There is nothing discretionary about healthcare when lives are at stake. The CHR Association is aware of the many Federal service providers supporting the CHR program. As Federal employees they took an oath to abide by the orders of the President and fear of consequences is evident by this Administration of any contraposing professional opinions. We have testified on CHR patient information not being accepted by in the RPMS system and denying pertinent patient information not being put in the patients EHR. We continue to support the $25 million EHR line item request in the hopes of mandating CHR workload inclusion in the $8 million in the 2020 spending package. The IT systems should not compromise patient care and billing requirements.

The Association supports an indefinite appropriation and separate line item for the section 105(l) facility leases. This has forced IHS to take from services program accounts to pay for these leases. This also forces the budget to take from CHR, Health Ed and other line items from direct service tribes to pay other contracting/ compacting tribes on leases at the expense of locally controlled public health services.

The CHRs have been the translators, advocates, educators in the Coronavirus public health efforts especially at the local community levels. We have CHRs who can translate in our native languages, understand the cultural impacts of health practices and maintain trust and understanding by community members. The CHRs will represent tribes and serve as liaisons with other Federal and state partners especially in rural and reservation areas with Coronavirus as well as other health service systems administered in our communities.

We appreciate your continued support for Advance Appropriations to keep our healthcare facilities and programs open during government shutdowns. The IHS funded programs are direct service providers like the VA and should be funded with no regard to political grandstanding. Thank you very much for recognizing the CHR program and your efforts in protecting and promoting Native American healthcare.

Respectfully,

New Mexico and Southern Colorado Community Health Representative Association Executive Board.

Prepared Statement of the Nez Perce Tribe

Honorable Chairman and members of the Committee, the Nez Perce Tribe (Tribe) would like to thank you for the opportunity to provide recommendations to the Committee as it evaluates and prioritizes fiscal year 2021 appropriations for programs within the Department of Labor, Department of Health and Human Services, and the Department of Education.

As with any government, the Tribe performs a wide array of work and provides a multitude of services to its tribal membership as well as the community at large. The Tribe has been a leader in education, workforce development, and social services in this area and places a high priority on these programs and the services they provide to residents on the Nez Perce Reservation (Reservation). The Tribe relies on specific Federal programs and grants to fund this important work and, therefore, provides the following fiscal year 2021 appropriations recommendations for these agencies.

The Tribe recommends $20 billion be provided for Title I, Part A of the Every Student Succeeds Act Local Education Agency Grants. Rural public schools on the Reservation use this funding to address the obstacles low-income students face meeting academic standards.

The Tribe recommends $6.9 million be allocated for the State-Tribal Education Partnership Program (STEP) authorized in Title VI, Part A, Subpart 3 of the Every Student Succeeds Act. The Tribe is one of the participants in the STEP which provides an avenue for states and tribes to work together to improve and enhance education delivery and parent involvement in areas with high populations of tribal students. The STEP has been a success for the Tribe and continued funding is needed to keep the program active. The Tribe supports the Administration's proposed new bill language that would allow the Secretary of Education to make State-Tribal Education Partnership and Native language immersion grants for up to 5 years, instead of the current 3 years.

The Tribe recommends that at least the same amount be appropriated in fiscal year 2021 as was allocated in fiscal year 2020 for Impact Aid, $1.486 billion. Impact Aid compensates school districts for Federal ownership of lands within a district's tax base. Over 14,000 students and 12 school districts rely heavily on Impact Aid dollars to provide education services. For example, Impact Aid accounts for 31 percent of the budget for the Lapwai School District, an Idaho public school here on the Reservation. Without Impact Aid dollars, the school will be forced to make significant reductions in staffing and resources for students.

The Tribe recommends that Congress appropriate $10 million in fiscal year 2021 for Tribal Education Departments in the Department of Education, which would complement the $2.5 million appropriated in fiscal year 2020 to the Bureau of Indian Affairs for these programs. This funding provides for the development and implementation of education programs operated by tribes to assist in the delivery of education services within a reservation.

The Tribe recommends the $11.36 billion be provided for Head Start in fiscal year 2021. Indian Head Start needs to be fully funded as these programs play a vital role in school readiness, child development, and early education for over 24,000 Native children. The Nez Perce Tribe Early Childhood Program provides services to 190 children. The majority of our funding goes to salaries and benefits while infrastructure needs are not addressed. We need our facility in Lapwai and our facility in Kamiah to be renovated or we need new construction so an increase in this funding is essential. The Indian Head Start programs address the whole child from a health, cultural, and education perspective. These programs operate on slim budgets but provide extraordinary returns in ensuring children are as prepared as possible to begin their education journey.

The Tribe recommends the fiscal year 2020 funding levels be maintained in fiscal year 2021 for all Tribal Behavioral Health Grants under the Substance Abuse and Mental Health Services Administration. The grants address a wide range of mental health and substance abuse issues such as youth suicide, opioid addiction, and methamphetamine addiction that are prevalent on the Reservation and threaten to overwhelm the Tribe's Social Services Department and health clinic. In addition, the competitive grants and tribal set-asides provided for promoting safe and stable families, child welfare services, and child abuse prevention should be maintained at fiscal year 2020 levels for fiscal year 2021 as well.

The Tribe appreciates the fiscal year 2020 funding of $50 million to address the opioid crisis in Indian Country. However, this funding pales in comparison to the funding that has been provided to states on this issue. The Tribe recommends funding to address opioid use and its effects on communities be increased and also made available in forms other than grants. Indian Country suffers from opioid addiction at a higher rate than most communities and all communities need access to monies to help address this problem. Funding in the form of grants places a high administrative burden on tribes and forces tribes to compete against each other unnecessarily. Congresswoman McCollum has also voiced concern over such methodologies for tribal funding.

The Tribe opposes the Administration's proposed elimination of fiscal year 2021 funding for the Department of Labor's Division of Indian and Native American Programs, and recommends $60.5 million be appropriated, an increase of $5.5 million over fiscal year 2020 enacted level funding. The Workforce Innovation and Opportunity Act, Section 166 Indian and Native American Programs serve the training and employment needs of tribes through programs such as the Indian Employment, Training, and Related Services Demonstration Act of 1992. The Tribe has used this funding to provide important programs that have helped develop the workforce and economy on the Reservation. This program has been very successful but will not continue without funding.

Within the Temporary Assistance for Needy Families program, administered by the Administration for Children and Families, the Tribe supports the Administration's fiscal year 2021 budget request that would increase funding for the Healthy Marriage Promotion and Responsible Fatherhood Grants program from $148.8 million to $150 million. The Tribe strongly supports the Administration's proposed 5-year reauthorization of the Healthy Marriage and Responsible Fatherhood program. Over the last several years, the Tribe has been able to use program funding to strengthen parenting, work and relationship skills amongst the youth on the Reservation which is vital to for the growth and preservation of Nez Perce culture.

Thank you for your consideration of the Tribe's requests with respect to these fiscal year 2021 appropriations.

PREPARED STATEMENT OF THE NORTHWEST PORTLAND AREA INDIAN HEALTH BOARD

Chairman Blunt and Ranking Member Murray, and Members of the Subcommittee: My name is Nickolaus Lewis, and I serve as a council member of the Lummi Indian Business Council, Chair of the Northwest Portland Area Indian Health Board (NPAIHB or Board), Representative on the Substance Abuse Mental Health Services Administration (SAMHSA) Technical Tribal Advisory Committee, and Portland Area Representative on the Centers for Medicare and Medicaid Services (CMS) Tribal Technical Advisory Group. I thank the Subcommittee for the opportunity to provide testimony on behalf of NPAIHB on the fiscal year 2021 Department of Health and Human Services (HHS) budget.

NPAIHB is a tribal organization, established in 1972, under the Indian Self-Determination and Education Assistance Act (ISDEAA), Public Law 93–638 that advocates on behalf of the 43 federally-recognized Indian Tribes in Idaho, Oregon, and Washington on specific healthcare issues. The Board's mission is to eliminate health disparities and improve the quality of life of American Indians and Alaska Natives (AI/AN) by supporting Northwest Tribes (also known as Portland Area Tribes) in the delivery of culturally appropriate, high quality healthcare.

For fiscal year 2021, NPAIHB makes these specific requests to the Subcommittee for the HHS budget:

HHS AND ITS AGENCIES

COVID–19.—Although coronavirus (COVID–19) is not the same as the influenza virus, it is transmitted in a very similar way. The last pandemic of influenza lasted around 2 years and we can expect a similar course of disease for COVID–19 unless we are able to deliver an effective vaccine and or antiviral treatment sooner. This Subcommittee must consider the importance of fiscal year 2021 funding for tribes to mitigate the effects of and eradicate COVID–19 in their communities for at least a 2-year period. Without this support, tribes will be forced to make impossible decisions. The economic crisis in tribal communities, due to the closure of tribal businesses for 2 months, has resulted in some tribes carefully opening their businesses at limited capacity with much of the nation doing the same. The difference between tribal businesses and other for profit businesses is that tribal business revenues are reallocated to fund critical health and social service programs. We anticipate that the reopening of economies nationwide will result in another wave of COVID–19 infections, with more AI/AN people being impacted. The AI/AN population faces increased risk for COVID–19 infections, and the infection is impacting a younger subset of the AI/AN population, which is different than the general population. For fiscal year 2021, we respectfully request that this Subcommittee honor treaty and trust obligations to tribes by providing comprehensive funding to address COVID–19 medical and behavioral health needs of AI/AN people in addition to annual core funding needs. NPAIHB specifically recommends COVID–19 tribal set-asides across all HHS agencies that are equitable to funding distributions to states. In addition, funding should be made available directly to IHS, tribes or tribal organizations (not through states) or transferred entirely to IHS through interagency transfer agreements for distribution to tribes through IHS funding distribution methodologies. Any grants should be streamlined as to application and reporting processes.

In addition, NPAIHB recommends that this Subcommittee fund a Tribal Public Health Clearinghouse with public health emergency supplies. Tribes as sovereign nations should not have to go through states to access the Strategic National Stockpile. The Clearinghouse should be accessible to tribes and tribal organizations/entities and be stocked with medical supplies, testing kits and supplies, including a full range of personal protective equipment (PPE) (N95 masks, surgical masks, gowns, gloves, etc.). In a NPAIHB survey conducted over the past 6 weeks with Portland Area Tribes, at least one tribe still does not have testing kits and 17 percent report low supplies of PPE- this is unacceptable. NPAIHB also recommends that any treatment or vaccinations that may become available in fiscal year 2021 be provided directly to all IHS and tribal facilities directly for administration at their clinics and also be made available through the Tribal Public Health Clearinghouse.

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

COVID–19 Funding.—The impact of COVID–19 on our people as to their mental health is of great concern and the long-term impacts are still unknown. As a result of COVID–19, in just 2 months, there have been increased impacts on mental health, suicidal ideation, depression, and substance use. We anticipate there will be many unexpected losses within our tribal communities from COVID–19 so NPAIHB generally requests increases to all SAMHSA tribal-specific programs and the development of new funding sources to address the aftermath of COVID–19.

Tribal-Specific Programs.—For fiscal year 2021, we request increases to SAMHSA tribal programs as follows: fund Tribal Behavioral Health Grant program at $50 million for fiscal year 2021 with $25 million for mental health and $25 million for substance abuse (funded in fiscal year 2020 at $40 million—$20 for mental health and $20 million for substance abuse); fund Garrett Lee Smith Suicide Prevention Tribal Set Aside at $3.5 million (funded in fiscal year 2020 at $2.9 million); fund Zero Prevention Initiative at $3 million (funded in fiscal year 2020 at $2.2 million); and fund Tribes under the National Child Traumatic Stress Initiative (NCTSI) at $1.5 million ($1 million set aside in fiscal year 2020).

Youth Behavioral Health Programs.—There are not enough youth-specific funding opportunities to prevent or comprehensively address youth services needed for mental health and substance use issues. Specifically, our tribes have prioritized the need for Youth Residential Treatment Centers that provide aftercare and transitional living for both substance use and mental health. While there are two facilities in the Portland Area, the Healing Lodge of the Seven Nations in Spokane and NARA Northwest in Portland, more are needed with expanded services. For fiscal year 2022, we request that SAMHSA consult with tribes on developing youth specific programs and constructing new facilities and funding sources that comprehensively address the needs of our youth.

Opioid Crisis and Funding..—While NPAIHB appreciates the $50 million set-aside for tribes and tribal organizations for Tribal Opioid Response (TOR) funding, it is not enough funding. Tribes are innovative and have developed opioid treatment models that could be replicated with flexible funding. For example, in our area, the Swinomish Tribal Community has established Didgwalic Wellness Center (http://www.didgwalic.com/). The clinic includes wrap around services and a full continuum of care for patients- MAT, counseling, primary care and oral health services. Other tribes in the Northwest are interested in establishing similar programs but are in need of funding to replicate this model.

We recommend that TOR funding be increased to $100 million in fiscal year 2021 (funded at $50 million in fiscal year 2020), and that funding continue to be non-competitive, provided directly to tribes, and that the funding term be increased from 2 years to 5 years. We further recommend an increased tribal set-aside for MAT funding at $15 million (funded at $10 million in fiscal year 2020).

Tribal Epidemiology Centers. The NPAIHB Northwest Tribal Epidemiology Center (NWTEC) has played a critical role in ensuring that Portland Area Tribes receive their share of the TOR funding. For the funding cycle of fiscal year 2018–fiscal year 2019, the NWTEC applied for and received funding for 28 tribes in our area for fiscal year 2018 and fiscal year 2019 and just applied for another 2-year cycle of funding. TECs are not allowed to directly apply for TOR funding for staffing, trainings or to provide technical assistance to subgrantees. In fiscal year 2021, NPAIHB requests a $2.5 million set-aside for Tribal Epidemiology Centers to administer TOR consortium grants and to conduct trainings (e.g., data waiver trainings and skills building sessions for SUD-providers) and to provide technical assistance to subgrantees.

Behavioral Health Workforce Development. The Community Health Aide Program (CHAP) has been a successful program in Alaska and includes training and certification for behavioral health aides (BHAs). BHAs are selected by and for the community they serve which ensures culturally appropriate services. Lack of behavioral health providers is a significant issue and need in the Portland Area. Our area has been at the forefront of CHAP expansion in the lower 48. In partnership with Northwest Indian College and area tribes, NPAIHB has begun the process of creating and implementing education programs for Behavioral Health Aides (BHAs) in the Portland Area. We recommend that SAMHSA partner with IHS and tribes to develop the BHA work force and allocate $15 million for the development of BHA programs in fiscal year 2022.

OFFICE OF THE SECRETARY

National HIV Elimination Strategy and Minority AIDS Initiative (MAI). On February 5, 2019, President Trump in his State of the Union announced his initiative on Ending the HIV Epidemic in the United States within 10 years. However, no funding was provided to IHS or tribes under the Consolidated Appropriations Act of 2020 for Ending the HIV Epidemic—despite the fact that other programs were funded. Since IHS is under the Interior, Environment and Related Agencies Subcommittee, not LHE, IHS was left out of funding. This must change in fiscal year 2021. We recommend $27 million in Ending the HIV Epidemic funding be transferred to IHS via the Office of Infectious Disease and HIV/AIDS Policy, who has worked with IHS for over 10 years to award Minority HIV/AIDS Funds via interdepartmental delegations of authority (IDDA). Similarly, the MAI allocates resources to CDC, HRSA, NIH, SAMHSA, and OMH. IHS does not receive direct MAI dollars. Excluding IHS from MAI dollars has far reaching and harmful impacts on IHS's ability to provide HIV/AIDS and HCV prevention, treatment, and outreach efforts. NPAIHB recommends that this Subcommittee create a fund mechanism for IHS to receive MAI dollars in the amount of $10 million for distribution via the Office of Infectious Disease and HIV/AIDS Policy.

Minority HIV/AIDS Fund. The Minority HIV/AIDS Fund is the only HHS funding source that includes funding to IHS for HIV and hepatitis C (HCV) prevention, treatment, outreach and education. For fiscal year 2021, we recommend at least $60 million for Minority HIV/AIDS Fund with at least $10 million to IHS.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

COVID–19 Funding.—Surveillance, contact tracing and public health nurses, will be key to preventing the spread of COVID–19 in tribal communities. For fiscal year 2021, we recommend that $250 million be allocated to tribes for these important activities/roles during the pandemic.

Fund Good Health and Wellness in Indian Country. The Good Health and Wellness in Indian Country (GHWIC) initiative supports efforts by American Indian and Alaska Native communities to implement holistic and culturally adapted approaches to reduce tobacco use, improve physical activity and nutrition, and increase health literacy. With COVID–19, tribal communities are more focused than ever on the importance of traditional foods and the nutritional and healing qualities of these food in a time of crisis. Additional funding is needed for GHWIC to address food access issues, food insecurity, and support traditional food and local food system initiatives during COVID–19. NPAIHB recommends that Good Health and Wellness in Indian Country program be funded at $32 million in fiscal year 2021.

Public Health Infrastructure & Environmental Impacts. While many tribal health programs have some public health infrastructure, it is often underfunded and may lack the capacity to respond effectively to health, natural, and manmade disasters. The COVID–19 pandemic provides an example of how many tribes across Indian country were lacking the basic public health infrastructure to respond to this unexpected event and public health emergency. In fiscal year 2021, we request that CDC provide direct funding for tribal public health infrastructure in the amount of $1 billion by authorizing a Tribal Public Health Emergency Fund established through the Secretary of HHS that tribes can access directly for tribally-declared public health emergencies (analogous to tribal disaster declarations to access FEMA).

Include Tribes in HIV/HCV Funding Opportunities. CDC HIV/HCV prevention and education generally flows to states via block grants. This system leaves many tribes with limited or no resources, and forces tribes to compete with states for funding. As an example, in fiscal year 2020, the CDC received $341 million in fiscal year 2020 for HCV grants but tribes were ineligible to apply (CDC–RFA–PS20–2009). For fiscal year 2021, we recommend a tribal set-aside of $25 million for HIV and HCV prevention.

CENTERS FOR MEDICARE AND MEDICAID SERVICES (CMS)

Medicaid and Medicare Telehealth Services.—Telehealth is a key component to ensuring AI/AN Medicaid and Medicare beneficiaries, have access to healthcare when they do not have transportation to get to a provider or, as with COVID–19, someone is in a high-risk group for serious illness and should not visit a medical facility. IHS and tribal facilities have demonstrated that telehealth visits are a safe and effective way to provide services to AI/AN Medicaid and Medicare beneficiaries during COVID–19. CMS' expansion of telehealth services on a temporary and emergency basis related to COVID–19 has benefited AI/AN Medicaid and Medicare beneficiaries and these telehealth policies should be made permanent under legislation. In addition, because of the lack of broadband in some rural tribal communities, it is important that all telehealth services be reimbursable with a phone visit, when no video is available. Finally, we recommend an increased tribal Medicare encounter rate for telehealth, including phone only visits, for Indian Health Care Providers equal to an in-person visit.

For more information, please contact Laura Platero, NPAIHB, at lplatero@npaihb.org.

[This statement was submitted by Nickolaus Lewis, Chairman, Northwest Portland Area Indian Health Board.]

PREPARED STATEMENT OF THE NURSING COMMUNITY COALITION

During these unique times, we recognize how crucial Federal investments for the nursing workforce and the nursing pipeline are to our patients and the health of our nation. Given these realities, and as we combat the COVID–19 pandemic, the Nursing Community Coalition respectfully requests that Congress continues robust investment in nursing workforce, education, and research in fiscal year 2021 by supporting at least $278 million for the Nursing Workforce Development programs (authorized under Title VIII of the Public Health Service Act [42 U.S.C. 296 et seq.] and administered by HRSA), and at least $182 million for the National Institute of Nursing Research (NINR), one of the 27 Institutes and Centers within NIH.

The Nursing Community Coalition is comprised of 63 national nursing organizations who work together to advance healthcare issues that impact education, research, practice, and regulation. Collectively, the Nursing Community Coalition represents Registered Nurses (RNs), Advanced Practice Registered Nurses (APRNs, including Certified Nurse-Midwives, Nurse Practitioners, Clinical Nurse Specialists, and Certified Registered Nurse Anesthetists), nurse leaders, nursing students, faculty, and researchers, as well as other nurses with advanced degrees. Together, we reiterate the request for increased funding for Title VIII Nursing Workforce Development programs and NINR, especially as we address the current, and future, health challenges.

PROVIDING CARE TO ALL AMERICANS THROUGH THE NURSING LENS

Nurses make up the largest group of health professionals in the United States and are indispensable to the health and well-being of all Americans. With more than four million licensed practitioners across the country, nurses are responding to healthcare challenges, including COVID–19, in all communities, especially in rural and underserved areas, and consistently provide high-quality patient-centered care.[1]

The main source of Federal funding for the nursing workforce are the Title VIII Nursing Workforce Development programs, which bolster nursing education at all levels, strengthen the nursing workforce, and are essential to ensuring the demand for nursing care is met throughout this nation. Funding for Title VIII is essential, but especially crucial during public health emergencies as these programs connect patients with high-quality nursing care in community health centers, hospitals, long-term care facilities, local and state health departments, schools, workplaces, and patients' homes.

A prime example of this is the Title VIII Advanced Nursing Education (ANE) programs. ANE programs support APRN students and nurses to practice on the front lines and in rural and underserved areas throughout the country. In Academic Year 2018–2019, ANE programs supported more than 9,100 students.[2] Of these students,

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[1] National Council of State Boards of Nursing. (2020). Active RN Licenses: A profile of nursing licensure in the U.S. as of March 21, 2020. Retrieved from: https://www.ncsbn.org/6161.htm.

[2] Department of Health and Human Services fiscal year 2021 Health Resources and Services Administration Justification of Estimates for Appropriations Committees. Pages 141–145.

73 percent of Advanced Nursing Education Workforce (ANEW) and 62 percent of Advance Nursing Education program had clinical training sites in primary care settings, while 78 percent of Nurse Anesthetist Trainee (NAT) recipients were trained in medically-underserved areas.[3]

Together, Title VIII Nursing Workforce Development programs serve a vital need and help to ensure that we have a robust nursing workforce that is prepared to respond to public health threats and ensure the health and safety of all Americans. The Nursing Community Coalition respectfully requests at least $278 million for the Title VIII Nursing Workforce Development programs in fiscal year 2021.

IMPROVING PATIENT CARE THROUGH SCIENTIFIC RESEARCH AND INNOVATION

For more than thirty years, scientific endeavors funded at the National Institute of Nursing Research (NINR) have been essential to advancing the health of individuals, families, and communities. Rigorous inquiry and research are indispensable when responding to the ever-changing healthcare landscape and healthcare emergencies such as COVID–19. From precision genomics to palliative care and wellness research to patient self-management, NINR has been at the forefront of evidence driven research to improve care.[4]

It is imperative that we continue to support this necessary scientific research, which is why the Nursing Community Coalition respectfully requests at least $182 million for the NINR in fiscal year 2021.

Now, more than ever, it is vital that we have the resources to meet today's public health challenges, such as COVID–19. Investing in Title VIII Nursing Workforce Development programs and NINR are essential to meeting that need. By funding Title VIII and NINR, Congress can continue to reinforce and strengthen the foundational care nurses provide daily in communities across the country. Thank you for your support of these crucial programs.

60 Members of the Nursing Community Coalition Submitting this Testimony

Academy of Medical-Surgical Nurses
American Academy of Ambulatory Care Nursing
American Academy of Emergency Nurse Practitioners
Academy of Neonatal Nursing
American Academy of Nursing
American Association of Colleges of Nursing
American Association of Critical-Care Nurses
American Association of Neuroscience Nurses
American Association of Nurse Anesthetists
American Association of Nurse Practitioners
American Association of Post-Acute Care Nursing
American College of Nurse-Midwives
American Nephrology Nurses Association
American Nurses Association
American Organization for Nursing Leadership
American Pediatric Surgical Nurses Association, Inc.
American Public Health Association, Public Health Nursing Section
American Psychiatric Nurses Association
American Society for Pain Management Nursing
American Society of PeriAnesthesia Nurses
Association for Radiologic and Imaging Nursing
Association of Community Health Nursing Educators
Association of Nurses in AIDS Care
Association of Pediatric Hematology/Oncology Nurses
Association of periOperative Registered Nurses
Association of Public Health Nurses
Association of Rehabilitation Nurses
Association of Veterans Affairs Nurse Anesthetists
Association of Women's Health, Obstetric and Neonatal Nurses
Chi Eta Phi Sorority, Incorporated
Commissioned Officers Association of the U.S. Public Health Service
Dermatology Nurses' Association
Emergency Nurses Association
Friends of the National Institute of Nursing Research

Retrieved from: https://www.hrsa.gov/sites/default/files/hrsa/about/budget/budget-justification-fy2021.pdf.

[3] Department of Health and Human Services fiscal year 2021 Health Resources and Services Administration Justification of Estimates for Appropriations Committees. Pages 142–143. Retrieved from: https://www.hrsa.gov/sites/default/files/hrsa/about/budget/budget-justification-fy2021.pdf.

[4] National Institutes of Health, National Institute of Nursing Research. The NINR Strategic Plan: Advancing Science, Improving Lives. Pages 4, 10 Retrieved from https://www.ninr.nih.gov/sites/www.ninr.nih.gov/files/NINR__StratPlan2016__reduced.pdf.

Gerontological Advanced Practice Nurses Association
Hospice and Palliative Nurses Association
Infusion Nurses Society
International Association of Forensic Nurses
International Society of Psychiatric-Mental Health Nurses
National Association of Clinical Nurse Specialists
National Association of Hispanic Nurses
National Association of Neonatal Nurse Practitioners
National Association of Neonatal Nurses
National Association of Nurse Practitioners in Women's Health
National Association of Pediatric Nurse Practitioners
National Association of School Nurses
National Black Nurses Association
National Council of State Boards of Nursing
National Forum of State Nursing Workforce Centers
National League for Nursing
National Nurse-Led Care Consortium
National Organization of Nurse Practitioner Faculties
Nurses Organization of Veterans Affairs
Oncology Nursing Society
Organization for Associate Degree Nursing
Pediatric Endocrinology Nursing Society
Preventive Cardiovascular Nurses Association
Society of Pediatric Nurses
Society of Urologic Nurses and Associates
Wound, Ostomy and Continence Nurses Society

[This statement was submitted by Rachel Stevenson, Executive Director, Nursing Community Coalition.]

PREPARED STATEMENT OF ONE VOICE AGAINST CANCER

One Voice Against Cancer (OVAC) is a broad coalition of public interest groups representing millions of cancer patients, researchers, providers, survivors and their families, delivering a unified message to Congress and the White House on the need for increased funding for cancer research and prevention priorities. For fiscal year 2021, we are asking that Congress fund the National Institutes of Health at $44.684 including $6.928 billion for the National Cancer Institute (NCI). We are also asking that the Centers for Disease Control and Prevention's (CDC) Division of Cancer Prevention and Control (DCPC) receive $559 million including $70 million for the National Program of Cancer Registries (NPCR).

Cancer is a major public health problem worldwide and is the second leading cause of death in the United States. It is estimated that more than 1.8 million people in the U.S. will be diagnosed with cancer this year. Additionally, approximately 606,520 Americans will die from the disease in 2020, which translates to more than 1,660 people a day. Recent estimates show that cancer costs the U.S. economy more than $216 billion annually in direct treatment costs and lost productivity, a number that will increase dramatically as incidence rates climb.

For the last 50 years, every major medical breakthrough in cancer can be traced back to the National Institutes of Health (NIH) and the National Cancer Institute (NCI). We know that investment in research at the NIH and NCI leads to lives saved.

The cancer death rate rose during most of the 20th century but Federal investments in cancer research and prevention have resulted in a continuous decline in the cancer death rate since its peak in 1991. The U.S. cancer death rate declined by 29 percent from 1991 to 2017, including a 2.2 percent drop from 2016 to 2017, the largest single-year drop in cancer mortality ever reported. This translates into almost 3 million fewer cancer deaths. Today, there are more than 16.9 million American cancer survivors.

Additionally, more than 80 percent of Federal funding for the NIH and NCI is spent on biomedical research projects at research facilities across the country. In fiscal year 2019, the NIH provided over $30 billion in extramural research to scientists in all 50 states and the District of Columbia. NIH research funding also supported more than 475,000 jobs and more than $81 billion in economic activity last year.

Thanks to your bipartisan, bicameral leadership, Congress has increased funding for NIH by $11.6 billion over the past 5 years. We are especially grateful that Congress dedicated new funding in fiscal year 2020 to address a precipitous decline in the success rate for research project grant (RPG) applications at NCI.

The NCI is experiencing a demand for research funding that is far beyond that of any other Institute or Center (IC). Between fiscal year 2013 and fiscal year 2018, the number of R01 (investigator-initiated) grant applications to NCI rose by 45.9

percent. For all other ICs during that time, the number of R01 applications rose by just 4.9 percent.

As a result of this extraordinary demand from the scientific community, the RPG success rate at NCI dropped from 13.7 percent in fiscal year 2013 to 11.3 percent in fiscal year 2018. This is a situation unique to NCI, at a time when cancer researchers are making historic advances in new treatments and therapies. The success rate for NIH overall during that same period rose from 16.8 percent to 20.2 percent.

We thank Congress for addressing this issue in the fiscal year 2020 Labor, Health and Human Services, and Education (Labor-HHS) Appropriations bill, but sustained investments will be required to improve the success rate at NCI and maintain the current pace of progress in cancer research. Therefore, OVAC recommends at least $44.7 billion for NIH in fiscal year 2021, a $3 billion increase over the fiscal year 2020 level. For NCI, we recommend $6.9 billion, which is both the amount proposed by NCI in its fiscal year 2021 professional judgment budget and the level needed to provide an increase for NCI which is proportional to that of NIH overall.

Preventing cancer is also critically important. About half of the over 600,000 cancer deaths that will occur this year could be averted through the application of existing cancer control interventions. The Centers for Disease Control and Prevention's (CDC's) Division of Cancer Prevention and Control (DCPC) provides key resources to states and communities to prevent cancer. Although we have seen declines in the cancer death rate overall, progress is slowing for cancers that are amenable to early detection through screening (e.g., breast cancer, prostate cancer, and colorectal cancer), and substantial racial and geographic disparities persist for highly preventable cancers, such as those of the cervix and lung. Increased investment in the equitable application of existing cancer control interventions as spearheaded by CDC's DCPC will accelerate progress in the fight against cancer. For this reason, we request $559 million overall for DCPC, an increase of $178 million over the fiscal year 2020 level.

Within DCPC, cancer registries are vital in identifying emerging trends, investigating disparities, understanding patterns of care, and evaluating the impact of early detection and treatment advances on cancer incidence and outcomes. The National Program of Cancer Registries (NPCR) provides technical, operational, and financial support for states to manage their own cancer registries. We are grateful that Congress prioritized cancer registries in CDC's new data initiative, created in the fiscal year 2020 Labor-HHS appropriations bill. However, there is currently a data lag of 24 months within the system. With new resources, the CDC could create a cloud-based system that would record data in real time, greatly enhancing the ability of states to develop targeted approaches to preventing and treating cancer. We therefore request a dedicated increase in funding for NPCR of $19 million to ensure that DCPC can move forward with the necessary improvements.

Additionally, oncology nurses are on the front lines when it comes to providing quality cancer care and contribute significantly to cancer research. More funding for the Health Resources and Services Administration's nurse training programs is necessary to support more nursing scholarships and loan repayment applications and to address the current and future nursing workforce shortage.

Below please find an overview of OVAC's program level requests in the Labor-HHS bill:

National Institutes of Health (NIH)—$44.684 billion, including:

—National Cancer Institute (NCI): $6.928 billion
—National Institute on Minority Health and Health Disparities (NIMHD): $360 million
—National Institute on Nursing Research (NINR): $181 million

Centers for Disease Control and Prevention (CDC) Cancer Programs—$559 million, including:

—National Comprehensive Cancer Control Program: $50 million
—National Program of Cancer Registries: $70 million
—National Breast and Cervical Cancer Early Detection Program: $275 million
—Colorectal Cancer Control Program: $70 million
—National Skin Cancer Prevention Education Program: $5 million
—Prostate Cancer Awareness Campaign: $35 million
—Ovarian Cancer Control Initiative: $12 million
—Gynecologic Cancer and Education and Awareness (Johanna's Law): $15 million
—Cancer Survivorship Resource Center: $900,000

Health Resources and Services Administration (HRSA)

—Title VIII Nursing Programs: $270.5 million

Once again, thank you for your continued leadership on funding issues important in the fight against cancer. Obviously, the COVID–19 pandemic has upended our entire society including cancer research, treatment and prevention but cancer continues to impact millions of people and their families and it does not take a break because of the pandemic. Funding for cancer research, prevention, survivorship, and nursing must continue to be top budget priorities in order to increase the pace of progress in the fight against cancer. OVAC once again calls on Congress to sustain our nation's commitment to cancer research and prevention by increasing support for these efforts.

[This statement was submitted by Caroline Powers, Chair, One Voice Against Cancer, Director, Federal Relations, American Cancer Society Cancer Action Network.]

PREPARED STATEMENT OF TERESA PARKER

Chairman Blunt, Ranking Member Murray and Subcommittee Members,

Thank you for your public service and for the opportunity to submit testimony.

INTEREST AND BACKGROUND

I have recently retired after working over 40 years at MARVA Workshop where I served as the Executive Director for the last 21 years. MARVA is a 501(c)3 nonprofit organization with a mission to provide meaningful work and employment services for individuals with Intellectual and Developmental Disabilities (IDD).

MARVA Workshop, like many other Community Rehab Programs (CRP) across the nation, has a focus on assisting individuals to achieve goals that are important to them. Our job is to facilitate a successful outcome for each individual in the way that they define success. Sometimes this is accomplished in the workshop setting, other times through competitive integrated employment, but it is a choice made by the individual. Unfortunately, center based work has come under attack from multiple entities that bluntly and emphatically state workshops isolate, segregate and exploit. These offensive adjectives used by organizations like the National Disability Rights Network (NDRN) to express their disapproval of center based opportunities, do not match the sentiments conveyed by the individuals and families of the people we serve, and thousands and thousands of others across the United States. We understand and fully agree that center based work is not the appropriate option for everyone, but I humbly suggest that neither is competitive integrated employment.

For example "Ron" has worked at MARVA for over 20 years. Prior to MARVA, he experienced failure over and over, and had been fired at least 10 times from various jobs. He was broke, discouraged, homeless, and desperate. Turning to his mother, she directed him to MARVA. Today, Ron will quickly tell you, "Since working at MARVA my life has never been the same! MARVA...helped me be independent and encouraged me to feel a sense of worth. I plan to work at MARVA for many years to come. I don't ever want to get fired again!″

Ron found what worked for him. He lives in his own house, drives his own vehicle, pays his bills and taxes, and has a social life, but sadly many Subject Matter Experts (SME) would say this is not successful employment because it is at a "sheltered workshop." They would suggest that he is not experiencing the quality of life available to him through competitive integrated employment. They have a right to their opinion, but you will NOT convince Ron or his family that he should consider "other options." We believe the opinion of Ron and those in similar situations should carry more value than the opinions of SMEs.

The ideology that "workshops are inherently bad and all individuals with disabilities can work in competitive integrated employment" has unfortunately permeated into many Federal agencies to the point that providing services to those with the most significant disabilities has become a nightmare. I see us all on the same side, with differing views of how to accomplish a noble goal, but regrettably the current funding allocations gives the other side an unfair advantage.

EXAMPLES OF CONCERNS

Operating under the Department of Health and Human Services, the Administration on Intellectual and Developmental Disabilities and the Administration for Community Living include grantees that are outspoken in their dislike of center based work programs. The list includes:

—Protection and Advocacy Systems (P&A)
—Developmental Disabilities Councils (DD Councils)

—University Center for Excellence in Developmental Disabilities (UCEDD)
—President's Committee for People with Intellectual Disabilities (PCPID)

These groups adamantly oppose our existence, but offer no viable solutions to increase employment for individuals with severe IDD. Their goal to remove all workshop employment as an option would reduce the number of employed individuals with disabilities. It would also create a problematic void in the lives of some of our most vulnerable citizens and the lives of their families. Without work centers, a large percentage of this group would end up sitting at home wasting away.

Another area of concern is the significant number of dollars awarded to some nonprofit organizations who openly advocate for the removal of workshop settings. This list is not exhaustive, but includes:

—National Disability Rights Network (NDRN)—www.ndrn.org
—Association of University Centers on Disabilities (AUCD)—www.aucd.org
—National Disability Institute (NDI)—www.realeconomicimpact.org
—National Association of Councils on Developmental Disabilities (NACDD)—www.nacdd.org
—Disability Rights Education and Defense Fund (DREDF)—www.dredf.org
—Autistic Self-Advocacy Network (ASAN)—www.autisticadvocacy.org

These groups are quick to talk about capacity building, employer engagement, job carving, etc., but rarely, if ever, offer realistic tangible alternatives for the most vulnerable individuals with disabilities. The ones that are a challenge to create meaningful work for even in our controlled environments. The ones that cannot follow instructions, ones that need assistance in the restroom, the ones that do not understand the need to control their outbursts, the ones that wander and get lost, the ones that know no stranger, the ones that smile warmly, but do not have a clue what is being said, these, these are the ones that will sadly be impacted the most by the current mindset that workshops are outdated and completely ineffective.

EXAMPLES OF GRASSROOTS EFFORTS TO SUPPORT CHOICE

The following is a list of grassroots efforts that have sprung up across the nation to bring awareness the negative impact the current trends and philosophies are having on individuals with severe intellectual and developmental disabilities and their families. Please take the time to review their efforts.

A–TEAM USA—www.ateamusa.net
Dignity Has A Voice—www.dignityhasavoice.com
Together for Choice—www.togetherforchoice.org
National Council on Severe Autism—www.ncsautism.org

These groups represent themselves or their loved ones impacted by disability policy and programs. Please consider their heartfelt unbiased positions.

REQUEST

I respectfully request that language be incorporated into all funding allocations associated with DHHS that requires recognition of center based employment services (workshops) as viable options for those whom elect those services.

Respectfully submitted,

Teresa Parker

PREPARED STATEMENT OF PATH

This testimony is submitted by Heather Ignatius on behalf of PATH, an international nonprofit organization that drives transformative innovation to save lives and improve health in low- and middle-income countries. PATH is appreciative of the opportunity afforded by Chairman Blunt, Ranking Member Murray, and members of the Subcommittee on Labor, Health and Human Services, Education and Related Agencies to submit written testimony regarding fiscal year 2021 funding for global health programs within the U.S. Department of Health and Human Services (HHS). PATH acknowledges and appreciates the strong leadership the Committee has shown in supporting HHS' work in this area—especially given the current pandemic—and we recommend that support continue. Therefore, we respectfully request that this Subcommittee provide no less than the fiscal year 2020 enacted level of $570.8 million to the CDC's Center for Global Heath (CGH) to sustain programming for global immunization, malaria, global health security, and research and development. Within CGH, we specifically support increases for CDC's Division of

Global Health Protection, which should be increased from $183.2 million to $225 million to bolster capacity to prevent, detect, and rapidly respond to emerging diseases—such as COVID–19—in low- and middle-income countries. We also support an additional $50 million for the Infectious Disease Rapid Response Fund, $30 million for CGH's Division of Parasitic Diseases and Malaria, and $226 million for the Global Immunization Division. This funding allows CDC to save lives, reduce disease, and improve health around the world.

The Vital Role of HHS in Global Health and Security

We are grateful for the global health funding that has already been provided in supplementals over the last few months. In that time, COVID–19 has reached almost every country in the world—crippling economies, overwhelming healthcare systems, filling hospitals, dwindling supplies, and emptying public spaces. As the disease burden grows both within the U.S. and around the globe, so does the need for additional funding. As we learned from past outbreaks such as Ebola, investments that help countries contain diseases at the source are some of the most effective and important the U.S. can make. These investments have been used to train epidemiologists, engage affected communities, improve disease detection and tracking systems, build Emergency Operations Centers (EOCs), and upgrade labs. Such efforts have allowed partner countries to greatly shorten their response times to outbreaks and epidemics—for example, Cameroon was able to shorten their response timeline from 8 weeks to 24 hours.

As a result of U.S. investments in the wake of Ebola, many countries are starting from a much stronger place as they face the COVID–19 pandemic. Countries have also drawn key lessons from the Ebola outbreak; for instance, the Democratic Republic of the Congo (DRC) has established two new coordination mechanisms to unite the country's top epidemiologists and virologists. In addition, their Emergency Operations Center (EOC), funded by the U.S. Centers for Disease Control and Prevention (CDC) through the agency's global health security investments and launched during the Ebola outbreak, will help the DRC continue to build capacity and reputation as a leader in outbreak management in Africa. Because of this investment, the Democratic Republic of the Congo is better prepared today than it was 5 years ago. However, despite the progress made by past investments, some populations will face COVID-related interruptions to essential services and will suffer from poor nutrition, outbreaks of vaccine-preventable diseases, and other health issues like HIV/AIDS and malaria. We must sustain support for these critical programs.

Two other entities within HHS, the National Institutes of Health (NIH) and the Biomedical Advanced Research and Development Authority (BARDA), are also playing critical roles in protecting Americans from COVID–19 and other health security threats. NIH and BARDA are currently taking steps to speed the development and manufacturing of vaccines to prevent COVID–19, working with New Jersey-based Janssen Research & Development, part of Johnson & Johnson, as well as Moderna of Cambridge, Massachusetts. The NIH and BARDA also support the CDC's global work by building critical overseas capacity to stop the spread of deadly diseases and developing new tools and technologies to prevent, detect, and treat future outbreaks.

The ongoing threat that COVID–19 and other infectious diseases pose to the health, economic security, and national security of the United States demands dedicated and steady funding for global health security. Just as we invest in a strong military in preparation for other security risks, Congress must ensure a continued robust investment in global health security preparedness, research and development, and response capability.

Protecting the U.S. Through Leadership in Global Health Research and Development

The ongoing COVID–19 pandemic is a clear call for investment in America's capacity to rapidly develop and deploy new technologies that can prevent, detect, and treat emerging global health threats. The U.S. leads the world in research and development (R&D) for tools that solve some of humanity's most pressing health problems. The annual G-Finder report from Policy Cures Research estimates that in 2018, the U.S. contributed $1.598 billion through NIH and $27 million through CDC to the development of global health products. Incredible progress is possible when the U.S. puts the full power of its resources to work. For example, in response to the 2014 Ebola outbreak, U.S. funding for Ebola R&D increased from negligible levels in 2013, to $101 million in 2014, to $298 million in 2015—resulting in the registration of four new products for Ebola and select viral hemorrhagic fevers, as well as the advancement of 11 new U.S.-supported Ebola products. These efforts were supported by the CDC as well as NIH, BARDA, and agencies outside HHS, which all played unique and critical roles in the product development process.

However, as a nation we have failed to sustain investment in a suite of technologies that will help us respond to the disease threats most likely to impact Americans and populations around the globe. For example, development of a promising SARS vaccine was halted in 2016 due to lack of funding—only to be re-started after the spread of COVID–19. Congress must ensure that the U.S. is making smarter and sustained investments for just-in-case development and just-in-time delivery of the tools we will need for the most likely threats to human health.

The National Biodefense Strategy rightly recognizes the importance of investments in R&D to prepare for future outbreaks, calling for funding and leadership in emerging technologies as R&D is integrated into Federal planning. Today more than ever, the U.S. is at the forefront of global health innovation because of long-term investment in NIH, CDC, and BARDA. To accelerate progress toward life-saving tools for a range of health threats, we call for maintaining robust funding for NIH and particularly for the NIAID and the Fogarty International Center; providing funding to match CDC's increased responsibilities in global health and security for the Center for Global Health and the National Center for Emerging Zoonotic and Infectious Diseases; and supporting funding for BARDA's critical work in emerging infectious diseases. As a complement to continued investment in BARDA and NIH, the U.S. should invest in the Coalition for Epidemic Preparedness Innovations (CEPI) which is working to advance at least nine COVID–19 vaccine candidates. Investment in CEPI would allow the U.S. to leverage funding from other global donors and ensure the U.S. can influence the impact and outcome of CEPI's efforts.

Successful implementation of these components requires urgent coordination across agencies and strategic investments. Congress should monitor progress on investments in emerging technologies and medical countermeasures, as well as the integration of R&D into Federal planning, including facilitating policies and incentives across interagency response R&D efforts.

Immunization Programs During COVID–19 and Beyond

HHS is also achieving complementary global health and security goals through investment in immunization, with most vaccine delivery activities overseen by CDC's Global Immunization Division. Vaccines are among the most high-impact and cost-effective tools available today to combat infectious disease threats-many vaccine-preventable diseases were once global pandemics much like COVID–19. This pandemic is a stark reminder of how fast an outbreak can spread without a vaccine to protect us. Thanks to immunization, outbreaks of childhood diseases such as polio, measles, diphtheria, and pertussis are preventable, and communities are protected from some of the most infectious and lethal pathogens. Immunization programs prevent an estimated 2.5 million deaths each year among children under the age of five; these programs also bolster local health systems and enable better disease detection. Even before the COVID–19 pandemic, vaccines for measles, polio, and other diseases were out of reach for 20 million children under the age of one every year. In 2018, more than 13 million children below the age of one globally did not receive any vaccines at all, many of whom live in countries with weak health systems. Given these difficulties, the disruption to immunization programs caused by COVID–19 could create pathways to disastrous outbreaks in 2020 and well beyond. As healthcare is disrupted globally, maintaining global vaccination efforts is critical to preventing needless deaths.

Fighting to Eliminate Malaria

The CDC plays a critical role in the fight against malaria, as co-implementer of the President's Malaria Initiative (PMI)—alongside the U.S. Agency for International Development—as well as through its Parasitic Diseases and Malaria program. These programs provide crucial technical assistance, with a focus on monitoring, evaluation, and surveillance, as well as operational and implementation research. Malaria prevention and treatment programs have prevented more than seven million deaths globally since 2000; as the world responds to COVID–19, we must safeguard these incredible gains. This progress could not have been accomplished without sustained U.S. commitment. Into the future, eliminating malaria by 2040 could save 11 million additional lives and unlock an estimated $2 trillion in economic benefits from gains in productivity and health savings.

According to the World Health Organization's World Malaria Report, nearly half the world's population lives in areas at risk of malaria—there were an estimated 228 million cases and 405,000 deaths from the disease in 2018 alone. It is also important to note that malaria deaths increase during pandemics, when sick people are unable to access healthcare in overburdened health systems. The COVID–19 pandemic is having a catastrophic impact on the most vulnerable communities worldwide, threatening our progress against malaria. This year, the Global Fund celebrated the distribution of the 2 billionth bed net to prevent malaria infections—but if COVID–19 leads to severe disruption of malaria services such as insecticide-treated net campaigns and access to antimalarial medicines, malaria deaths in sub-Saharan Africa could double in coming years. To reduce the pressure that COVID–19 is exerting on health systems, it is critical that we continue to deliver malaria interventions at the community level. As PMI has expanded, CDC's mandate has grown, but its budget for malaria has remained stagnant. In fiscal year 2021, Congress should fully fund PMI and increase funding for the CDC Division of Parasitic Diseases and Malaria (DPDM) program from $26 million to $30 million, to better track, treat, and test for malaria, and to ensure these services continue in the midst of a global health crisis.

An investment in Health, at Home and Around the World

With strong funding for global health programs within HHS, the department will be able to improve access to proven health interventions in the communities where they are needed most, as well as respond to the emerging challenge of COVID–19. By fully funding global health and BARDA accounts, the U.S. can prevent the further spread of disease, protect the health of Americans, and minimize the impact on vulnerable populations worldwide.

[This statement was submitted by Heather Ignatius, Director, US and Global Advocacy, PATH.]

PREPARED STATEMENT OF THE PERSONALIZED MEDICINE COALITION

Chairman Blunt, Ranking Member Murray and distinguished members of the subcommittee, the Personalized Medicine Coalition (PMC) appreciates the opportunity to submit testimony on the National Institutes of Health (NIH) fiscal year 2021 appropriations. PMC is a nonprofit education and advocacy organization comprised of more than 230 institutions from across the healthcare spectrum. As the subcommittee begins work on the fiscal year 2021 Labor, Health and Human Services, Education and Related Agencies appropriations bill, we ask that the NIH receive an appropriation of at least $44.7 billion in fiscal year 2021, a $3 billion increase over the NIH's program level funding in fiscal year 2020.

At this historic moment for medicine and humanity, biomedical research has perhaps never been more important. We sincerely appreciate the additional funding provided for NIH to respond to COVID–19 across the recent supplemental appropriations bills. PMC commends the NIH's leadership during the current COVID–19 pandemic and recognizes that these emergency resources are playing an important role in identifying therapies and vaccines, as well as improving testing and diagnostic methods. We also believe NIH-funded basic research is critical to our understanding of how the virus expresses itself across populations and individuals to eventually develop personalized treatment plans for patients. Increasing funding for the agency's efforts to lead scientific discovery across other disease areas, however, is not any less important because of COVID–19. Therefore, we encourage the Committee to consider a $3 billion increase in program level funding in addition to any emergency appropriations related to COVID–19 research and relief and in addition to funding for the Innovation Account established in the 21st Century Cures Act. This funding level would allow for meaningful growth above inflation in the NIH's base budget and expand the agency's capacity to support promising science in all disciplines, including personalized medicine.

Personalized medicine, also called precision or individualized medicine, is an evolving field in which physicians use diagnostic tests to identify specific biological markers, often genetic, that help determine which medical treatments will work best for each patient. By combining this information with an individual's medical records, circumstances, and values, personalized medicine allows doctors and patients to develop targeted treatment and prevention plans. Personalized healthcare promises to detect the onset of disease and pre-empt its progression, as well as improve the quality, accessibility, and affordability of healthcare.[1]

I. THE ROLE OF NIH IN PERSONALIZED MEDICINE

For each of the past 5 years, personalized medicines have accounted for a quarter or more of the new drugs approved by the U.S. Food and Drug Administration

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[1] http://www.personalizedmedicinecoalition.org/Userfiles/PMC-Corporate/file/The-Personalized-Medicine-Report1.pdf.

(FDA), with a record of 42 percent in 2018.[2] In 2005, personalized medicines accounted for only 5 percent of new drug approvals.[3] The most recent approvals address the root causes of rare diseases in many patients for whom there were no options before; expand treatment options for cancer patients; and target therapies to responder populations.

As the primary Federal agency conducting and supporting basic and translational research investigating the causes, treatments and cures for both common and rare diseases, NIH is leading scientific discovery for personalized medicines. Many institutes and centers at the NIH are supporting research that is informing the development of personalized medicines, including the National Human Genome Research Institute (NHGRI), the National Cancer Institute (NCI), the National Institute on Aging (NIA), and the National Heart, Lung and Blood Institute (NHIBI). An increase for NIH in fiscal year 2021 would protect its foundational role in the identification and development of personalized medicines.

II. SUSTAINING BASIC AND TRANSLATIONAL RESEARCH

Increased investments in the work of the NIH in fiscal year 2021 are justified in part by emerging scientific insights that present new opportunities in personalized medicine. By increasing NIH's budget for fiscal year 2021, Congress can accelerate the pace at which these insights are translated into improved care for American patients.

Scientific discovery in personalized medicine begins with basic research that gathers fundamental knowledge about the molecular basis of a disease and with translational research aimed at applying that knowledge to develop a treatment or cure. Basic research has contributed to the development of more than 180 personalized medicines that are on the market and available for patients as of 2020.[4,5]

The future of cancer care, for example, is expected to be profoundly influenced by the use of biomarkers that will guide researchers and physicians at every stage from drug development to disease management. In 2018, 55 percent of all oncology trials involved the use of biomarkers, compared to 15 percent in 2000.[6] According to the NIH's latest Annual Report to the Nation on the Status of Cancer, cancer death rates continued to decline 1.5 percent on average per year from 2001 to 2017 across all ages, genders, and racial and ethnic groups.[7] This success can be attributed to significant progress in cancer prevention, early detection, and treatment as a result of investments in basic research.

Basic genomics research also offers opportunities beyond oncology, especially for rare diseases. Rare diseases affect an estimated 25 to 30 million Americans, and with advances in genomics, the molecular causes of 6,500 rare diseases have been identified—but only about 5 percent have an FDA-approved treatment. In 2019, NIH awarded approximately $38 million in grants to 20 teams and a data management center to study a wide range of rare diseases.[8] Research groups, which include scientists, clinicians, patients, families, and advocates, are collaborating on natural history studies, measuring treatment outcomes, and studying biomarkers that provide indicators of how a drug is working in patients. Pooling patients, data, experiences, and resources promises to lead to more successful clinical trials sooner for rare disease patients who presently have few or no treatment options.

There are other people living with highly prevalent diseases that are still in need of better treatments and a cure. The Alzheimer's Association estimates that 5.8 million Americans are living with Alzheimer's disease, for example.[9] Despite increasing numbers of Alzheimer's diagnoses, there are no treatments that can prevent or alter the course of the disease. Researchers are studying the genetic underpinnings of Alzheimer's disease to more fully understand its complexity. The Accelerating Medicines Partnership for Alzheimer's disease led by the NIH has identified over 500

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[2] http://www.personalizedmedicinecoalition.org/Userfiles/PMC-Corporate/file/PM__at__FDA__The__Scope__and__Significance__of__Progress__in__2019.pdf.

[3] http://www.personalizedmedicinecoalition.org/Userfiles/PMC-Corporate/file/PM__at__FDA__The__Scope __and__Significance__of__Progress__in__2019.pdf.

[4] http://www.personalizedmedicinecoalition.org/Userfiles/PMC-Corporate/file/The-Personalized-Medicine-Report1.pdf.

[5] http://www.personalizedmedicinecoalition.org/Resources/Personalized__Medicine__at__FDA__An__Annual__Research__Report.

[6] http://www.personalizedmedicinecoalition.org/Userfiles/PMC-Corporate/file/The__Evolution__of__Biomarker__Use__in__Clinical__Trials__for__Cancer__Treatments.pdf.

[7] https://www.nih.gov/news-events/news-releases/annual-report-nation-cancer-death-rates-continue-decline-2020?utm__source=sfmc&utm__medium=email&utm__campaign=adhoc&utm__content=newsletter.

[8] https://ncats.nih.gov/news/releases/2019/rdcrn-funding.

[9] https://www.alz.org/media/Documents/alzheimers-facts-and-figures__1.pdf.

drug targets. To build upon this progress, in 2019 the NIH launched two new research centers focused on accelerating the discovery and development of treatments and cures for people living with Alzheimer's.[10]

The NIH is also leading efforts to develop tools and resources in gene therapy and artificial intelligence that will facilitate the identification and development of new personalized medicines for common and rare diseases. Wait times to produce vectors—or the "delivery vehicles"—in gene therapy and gene editing studies currently run one to 2 years due to their resource intensity.[11] Funding in fiscal year 2021 would enable the NIH to create a consortium addressing this bottleneck to bringing new gene therapies to clinical trials for patients.

III. ACCELERATING PERSONALIZED MEDICINE RESEARCH

Increasing the NIH's base budget will also ensure that the agency has the resources necessary to advance the longstanding aspects of its mission without deprioritizing supplemental initiatives in personalized medicine recently supported by Congress.

The 21st Century Cures Act (Cures Act) provided support for important initiatives that will benefit personalized medicine. The first initiative, the All of Us™ Research Program, launched in May of 2018. All of Us is collecting genetic and health information from one million volunteers for a decades-long research project. By mid-December 2019, over 305,000 individuals consented to participate and over 235,000 have fully enrolled. More than 80 percent of those individuals were from groups historically underrepresented in research, such as seniors, women, Hispanics and Latinos, African Americans, Asian Americans and members of the LGBTQ community.[12] This program is creating an invaluable biomedical data set that is inclusive of all Americans and will inform the development of new personalized medicines. Program officials plan to begin returning individual genetic results to participants this year.[13]

All of Us will continue to refine and streamline participant enrollment while focusing on retaining current participants. The program also plans to give researchers access to additional data that include participants' genomic information, genetic propensity for disease or differential medication response, and visualization of basic electronic health record data for use in their research to improve the diagnosis, treatment, and prevention of disease. To facilitate the use of data from All of Us and other cohort studies, the NHGRI plans to establish a new research program developing cutting-edge data and informatics tools for genomic research.[14]

The Cancer Moonshot is a second initiative supported by the Cures Act. It aims to transform the way cancer research is conducted by supporting immunotherapy networks, such as the Partnership for Accelerating Cancer Therapies (PACT). Through PACT, the NIH is collaborating with 11 pharmaceutical companies and the Foundation for NIH to identify, develop, and validate biomarkers to advance new cancer immunotherapy treatments. Improvements in immunotherapy over the past decade have driven declines in mortality from lung cancer and melanoma; however, progress in reducing rates for other cancers, including colorectal, breast, and prostate cancers, has slowed.[15] These collaborations promise to discover new cancer treatments and harness the ability of the body's immune system to fight cancer.

The Cures Act authorizes funding for these initiatives through the Innovation Fund. The $3 billion increase requested by PMC in fiscal year 2021 would ensure that the $404 million authorized by the Cures Act this year would supplement the NIH's base budget, as Congress intended, and thereby allow these important initiatives to continue.

IV. CONCLUSION

PMC appreciates the opportunity to highlight the NIH's importance to the continued success of personalized medicine. The subcommittee's support for a $3 billion increase over the NIH's program level funding in fiscal year 2020, in addition to

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[10] https://www.nih.gov/news-events/news-releases/new-nih-funded-translational-research-centers-speed-diversify-alzheimers-drug-discovery.

[11] https://docs.house.gov/meetings/AP/AP07/20200304/110616/HHRG-116-AP07-Wstate-CollinsF-20200304.pdf.

[12] https://officeofbudget.od.nih.gov/pdfs/fiscal year 21/br/1-OverviewVolumeSingleFile-toPrint.pdf.

[13] https://officeofbudget.od.nih.gov/pdfs/fiscal year 21/br/1-OverviewVolumeSingleFile-toPrint.pdf.

[14] https://www.genome.gov/news/news-release/NHGRI-establishes-new-intramural-precision-health-research-program.

[15] https://www.cancer.org/latest-news/facts-and-figures-2020.html.

supplemental funding received from the Cures Act and COVID–19 emergency appropriations, will bring us closer to a future in which every patient benefits from an individualized approach to healthcare. PMC will gladly provide additional information on the programs described in our testimony upon request.

[This statement was submitted by Cynthia A. Bens, Senior Vice President, Public Policy, Personalized Medicine Coalition.]

PREPARED STATEMENT OF THE PHYSICAL SCIENCE EDUCATION POLICY COALITION

Dear Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee:

The Physical Science Education Policy Coalition (PSEPC) is a diverse group of scientific non-profit organizations that works to promote issues regarding all aspects of physical science education to benefit both students and teachers.

We urge you to reject the White House's budget proposal for the Department of Education to eliminate and replace the following programs:

—Supporting Effective Instruction State Grants
—Student Support and Academic Enhancement Grants
—21st Century Community Learning Centers

Congress has authorized these programs to receive funding under Title II and Title IV of Public Law No: 114–95, the Every Student Succeeds Act (ESSA). ESSA helps bolster this country's domestic STEM talent pipeline—and therefore our global competitiveness—by assisting States in seizing the greatest opportunity to strengthen their own physical science and STEM education programs. Therefore, we urge you to fund these programs at current fiscal year 2020 authorized levels in fiscal year 2021 appropriations.

Congress has shown that it appreciates the importance of high-quality high school physical science teachers and informal STEM learning programs by previously rejecting the White House's proposed abolition of these programs for fiscal year 2019 and fiscal year 2020. Instead, Congress funded them as part of the fiscal year 2019 Defense, Labor-HHS–ED Consolidated Appropriations Act, and the fiscal year 2020 Further Consolidated Appropriations Act (Public Laws 115–245 and 116–94 respectively).

The White House's proposal for fiscal year 2021 would consolidate 29 existing programs,[1] including the three listed above, into "a new $19.4 billion block grant to States." But according to the Department of Education,[2] only $6.8 billion would be appropriated for fiscal year 2021, while the remaining funds would serve as an advance for fiscal year 2022. Given that the Grants to Local Educational Agencies under Title 1 of the Elementary and Secondary Education Act of 1965 (Education for the Disadvantaged) alone is currently funded at $15.9 billion, it is clear that it will be impossible to maintain current funding levels for these programs in fiscal year 2021 should the White House's proposal be accepted. Furthermore, even in subsequent years when previously appropriated advances contribute to the Department of Education's total Budget authority, a $19.4 billion grant will still reduce the amount of money which States receive by $4.7 billion. Put simply, this proposed consolidation is ultimately a budget cut.

The Supporting Effective Instruction State Grants, Student Support and Academic Enhancement Grants, 21st Century Community Learning Centers programs exist to solve persistent and troublesome problems in education. In Missouri, the ESSA Consolidated State Plan published by the Missouri Department of Elementary and Secondary Education (MO–DESE) in 2019[3] states, "MO–DESE has a single area of critical need for state-level activities under Title IV, Part A, Subpart 1. A recent statewide analysis of advanced course offerings in mathematics and science indicated that a significant number of high schools do not offer, and consequently a significant number of students do not have access to, advanced coursework." Table 1 (below) presents data from the report that provides examples of courses that have limited availability to students. During 2016, 2017, and 2018, 3 years analyzed in a recent statewide study, 451 high schools in Missouri—or 86 percent of all high schools in the state—have failed to offer a single physics course. This equated to

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[1] The White House Budget Request https://www.whitehouse.gov/wp-content/uploads/2020/02/budget__fy21.pdf.

[2] Department of Education fiscal year 2021 President's Budget https://www2.ed.gov/about/overview/budget/budget21/21pbapt.pdf.

[3] Every Student Succeeds Act, Missouri's Consolidated State Plan 2019, p. 62 https://dese.mo.gov/sites/default/files/qs-ESSA-Plan-2019.pdf.

more than 26,000 junior and senior students lacking access to a physics course during the 2016–17 school year.

TABLE 1

Course	Number of high schools not offering the course in the last three years	Percentage of high schools not offering the course in the last three years	Number of Juniors and Seniors lacking access to course during the 2016-17 school year
Trigonometry	124	23.6%	10,508
Calculus	151	28.7%	3,833
Statistics	290	55.1%	13,537
Physics	451	85.7%	26,761
Advanced Biology	76	14.4%	2,211

In Oklahoma, the 2018 Oklahoma Educator Supply & Demand Report[4] found that the overall number of educators employed in Oklahoma's public schools who have certificates in math and science has consistently declined between 2012–13 and 2017–18. Certificates in math and sciences declined by 10 percent and 21 percent, respectively. Instead of loosening requirements for entry into the profession to solve this problem, the Oklahoma State Department of Education (OSDE) assembled a Teacher Shortage Task Force to implement changes that would strengthen the teacher pipeline, thereby bolstering recruitment and retention efforts in the state. The Oklahoma ESSA Consolidated State Plan[5] says, "The complete elimination of Title II, Part A funding would severely hamper the state's ability to achieve its goal of reducing its need for emergency certified teachers. Title II, Part A dollars are critical to Oklahoma's efforts to enhance meaningful professional development offerings, provide support to teachers in implementing rigorous academic standards and equip instructional leaders who can support teachers and ultimately increase academic achievement for all students." Unfortunately, the issues described are components of a larger, nationwide, problem. Across the United States, there is a significant shortage of highly qualified middle and high school physics teachers. In a nationwide survey of teachers in US high schools who taught at least one physics class, only 40 percent have a major or minor in physics or physics education.[6]

The solutions to the problems in Missouri, Oklahoma, and the country at large depend on Federal funding. The Supporting Effective Instruction State Grants (Title II–A) program helps by allowing States to fund grants for teacher preparation programs. Title II–A funded teacher preparation programs train teachers to deliver robust, high-quality STEM education. The Student Support and Academic Enhancement Grants (Title IV–A) and the 21st Century Community Learning Centers (Title IV–B) gives States funding for out of school STEM programs to enhance learning. Alongside organizations specifically dedicated to enhancing the training of educators, such as PhysTec for the physical sciences,[7] these programs can solve the teacher shortage issue and give American students world class educations in physical science and other STEM fields.

A strong physical science background prepares students for success in their university courses and careers, but this success is impossible without highly qualified teachers who have deep knowledge of physical science. We should all strive to ensure that our children receive the best education possible.

Endorsed by the following member organizations:

American Association of Physicists in Medicine
American Association of Physics Teachers
American Astronomical Society
American Institute of Physics
American Physical Society

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[4] 2018 Oklahoma Educator Supply & Demand Report, p. 52–63 https://sde.ok.gov/sites/default/files/documents/files/Oklahoma%20Teacher%20Supply%20and%20Demand%20Report%202018%20February%20Update.pdf.

[5] Oklahoma ESSA Consolidated State Plan, p. 146 https://www2.ed.gov/admins/lead/account/stateplan17/okconsolidatedstateplan.pdf.

[6] Who Teaches High School Physics? https://www.aip.org/sites/default/files/statistics/highschool/hs-whoteaches-13.pdf.

[7] About PhysTec https://www.phystec.org/webdocs/AboutPhysTEC.cfm.

OSA-The Optical Society

[This statement was submitted by Mr. Elborz D. Mazanderan, American Institute of Physics, Physical Science Education Policy Coalition.]

PREPARED STATEMENT OF THE PHYSICIAN ASSISTANT EDUCATION ASSOCIATION

On behalf of the 254 accredited physician assistant (PA) education programs in the United States, the Physician Assistant Education Association (PAEA) welcomes the opportunity to submit the following testimony regarding the critical need for continued investment in health professions education in fiscal year 2021. As illustrated starkly by the COVID–19 pandemic and other emerging health crises, ensuring that patients have access to timely, high-quality care is dependent upon a strong Federal commitment to improving the supply, distribution, and diversity of the national health workforce. As such, PAEA joins with our colleagues to request a total of $790 million in fiscal year 2021 for both the Title VII health professions and Title VIII nursing programs. As the health professions education community works to prepare the future health workforce, this level of support will represent the investment necessary for programs to address key challenges, pursue innovation, and promote quality patient care.

BACKGROUND ON PA PRACTICE/CURRENT ISSUES IN PA EDUCATION

Since the creation of the profession in the mid-1960s in response to growing physician shortages, PAs have played a critical role in the practice of medicine by ensuring timely access to quality care, particularly in rural and underserved areas. Following the completion of a rigorous, seven semester, curriculum consisting of both classroom-based and clinical education, PAs have broad flexibility to fill workforce gaps based upon their generalist training. During their clinical education, PA students are required to complete one calendar year of core rotations in family medicine, emergency medicine, internal medicine, surgery, pediatrics, women's health, and behavioral health—in addition to electives—providing them with the skill set necessary for flexible practice throughout their careers. Currently, a plurality of PAs practice in primary care, with over 25,000 primary care PAs practicing in communities throughout the United States.[1]

To meet the projected 31 percent growth in PA practice openings from 2018–2028, the number of accredited PA programs nationwide has grown significantly in recent years, rising from 149 in 2010 to 250 in 2020, with more than 50 additional programs in development.[2] While this remarkable expansion appropriately reflects demand for PA services, the rapid rate of growth has presented formidable challenges as PA educators work to provide high-quality education to students. The most acute concern is increased competition for clinical training sites and clinician preceptors—a supply that has significantly contracted as a result of COVID–19. Shortages of clinical training sites prior to the pandemic have resulted in a growing number of programs being forced to pay for training sites. According to PAEA's most recent survey of members, 52 percent of programs nationwide, up from 27.9 percent as of 2015, are now paying for some or all of their clinical rotations at an average cost of $245 per week, per student.[3] Given the current lack of dedicated Federal funding to support PA clinical training comparable to Graduate Medical Education for physicians, this cost has ultimately been borne by students in the form of higher tuition.

In the absence of a direct funding stream for PA clinical training, a small number of PA programs have traditionally relied upon existing Title VII programs to facilitate limited training opportunities. For example, Primary Care Training and Enhancement (PCTE) grants have long served as a critical resource for PA programs seeking to direct graduates to practice in primary care through curriculum development and clinical training experiences. In fiscal year 18, 577 PA students graduated from a PCTE-funded program, well in excess of the 200 student target set by

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[1] National Commission on Certification of Physician Assistants (2019). 2018 Statistical Profile of Certified Physician Assistants by Specialty. Retrieved from: https://prodcmsstoragesa.blob.core.windows.net/uploads/files/2018StatisticalProfileofCertifiedPAsbySpecialty1.pdf.

[2] Bureau of Labor Statistics. (2019). Physician Assistants. Retrieved from https://www.bls.gov/ooh/healthcare/physician-assistants.htm.

[3] Unpublished data. Physician Assistant Education Association. (anticipated publication 2020). By the Numbers: Program Report 35: Data from the 2019 Program Survey.

HRSA.[4] In addition to PCTE grants, Area Health Education Centers (AHECs) partner with PA programs, along with other health professions programs, to facilitate clinical rotations in rural and underserved settings. In fiscal year 2018, AHECs throughout the country supported clinical rotations for 12,385 health professions students, including PA students.[4] In fiscal year 2020, Congress also appropriated more than $26 million to establish a Mental and Substance Use Disorders Workforce Training Demonstration to support, among other priorities, clinical rotations in behavioral health. Given the severity of clinical training site shortages for PA programs, PAEA specifically urges the Subcommittee to prioritize increased appropriations for PCTE grants, AHECs, and the Mental and Substance Use Disorders Workforce Training Demonstration in fiscal year 2021.

COVID–19 AND MATERNAL MORTALITY

In addition to addressing the broader clinical training site crisis, PAEA is also committed to preparing the future PA workforce to respond to emerging public health issues, such as the COVID–19 pandemic and maternal mortality. As an organization, PAEA's vision is Health for All. The achievement of this vision requires the elimination of persistent health disparities, and PAEA is particularly concerned with both the elimination of clinical training opportunities for students as a result of COVID–19 and rising rates of maternal morbidity and mortality disproportionately impacting African American, Native American, and Alaska Native women. According to a 2019 report issued by the CDC, these women die from largely preventable pregnancy-related causes at a rate three times higher than white women.[5] PAs have a critical role in addressing maternal health disparities once they enter practice, however, competition for clinical training experiences in women's health has been a particular barrier to ensuring students are best-equipped to meet this challenge. According to a recent survey report of PAEA member programs, 83.5 percent of programs that pay for clinical sites currently pay for women's health rotations—the highest rate of any required PA specialty rotation.[6] Another report revealed that 83.9 percent of programs characterized women's rotations to be very difficult or difficult to obtain.[7] To begin addressing this issue, PAEA has endorsed H.R. 4995—the Maternal Health Quality Improvement Act—which would authorize the Rural Maternal and Obstetric Care Training Demonstration, a program which would support women's health clinical training experiences in rural areas for PA and other health professions students as a means of increasing access to care. In fiscal year 2021, PAEA urges the Subcommittee to provide appropriations at the proposed authorization level of $5 million.

PROMOTING DIVERSITY

PAEA strongly concurs with the body of evidence supporting the value of a diverse health workforce to address broader disparities through the provision of culturally competent care.[8] Traditionally, underrepresented minority students have faced daunting financial and other barriers in entering health professions education. According to PAEA's most recent Student Report, these barriers have resulted in only 4 percent of matriculating PA students being African American and 7.8 percent being Hispanic compared to 13.4 percent and 18.3 percent of the general population, respectively.[9] PAEA is grateful for existing Federal investments to promote diversity, such as Scholarships for Disadvantaged Students (SDS), which provides PA programs and other disciplines with the resources necessary to promote access to health professions education for disadvantaged students who are more likely to

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[4] Health Resources and Services Administration. (2020). Justification of Estimates for Appropriations Committees. Retrieved from: https://www.hrsa.gov/sites/default/files/hrsa/about/budget/budget-justification-fy2021.pdf.

[5] Centers for Disease Control and Prevention. (2019). Vital Signs: Pregnancy-Related Deaths, United States, 2011–2015, and Strategies for Prevention, 13 States, 2013–2017. Retrieved from: https://www.cdc.gov/mmwr/volumes/68/wr/mm6818e1.htm?s__cid=mm6818e1__w.

[6] Physician Assistant Education Association. (2018). By the Numbers: Curriculum Report 3: Data from the 2017 Clinical Curriculum Survey. Retrieved from: https://paeaonline.org/wp-content/uploads/2018/10/paea-curriculum-report-33-20181015.pdf.

[7] Physician Assistant Education Association, By the Numbers: 30th Report on Physician Assistant Educational Programs in the United States, 2015, Washington, DC: PAEA, 2015. doi: 10.17538/btn2015.001.

[8] Cohen, J.J., Gabriel, B.A., & Terrell C. (2002). The Case for Diversity in the Health Care Workforce. Health Affairs, 21(5). 90–102. https://www.healthaffairs.org/doi/pdf/10.1377/hlthaff.21.5.90.

[9] Physician Assistant Education Association. (2019). By the Numbers: Student Report 3: Data from the 2018 Matriculating Student and End of Program Surveys. Retrieved from: https://paeaonline.org/wp-content/uploads/2019/08/sr3-program-report-20190814.pdf.

practice in underserved areas following graduation. In fiscal year 2018, SDS awards supported the training of 3,155 health professions students, exceeding HRSA's target of 2,930 students.[4] Prior to matriculation, the Health Careers Opportunity Program (HCOP) plays a complementary role by investing in K–16 health education programs that help recruit diverse and disadvantaged students into the health professions pipeline. In fiscal year 2018, 4,082 disadvantaged students participated in structured HCOP programs, double HRSA's target of 2,000 students.[4] PAEA strongly supports continued and increased investments in the SDS and HCOP programs in fiscal year 2021.

FISCAL YEAR 2021 RECOMMENDATION

As PA education programs across the nation work to prepare the future PA workforce to address emerging health crises, continued Federal commitment to address challenges such as clinical training site shortages and workforce diversity is critical. To improve the supply, distribution, and diversity of the national health workforce, PAEA joins in the request of the health professions education community for $790 million to support the Title VII health professions and Title VIII nursing programs in fiscal year 2021. PAEA thanks the Subcommittee for the opportunity to submit testimony and looks forward to continuing to serve as a resource to members and staff.

[This statement was submitted by Howard Straker, EdD, MPH, PA-C, President, Physician Assistant Education Association.]

PREPARED STATEMENT OF THE PLANNED PARENTHOOD FEDERATION OF AMERICA

Dear Chairman Blunt and Ranking Member Murray,

Planned Parenthood is the nation's leading women's healthcare provider and advocate and a trusted, nonprofit source of primary and preventive care for women, men, and young people in communities across the U.S as well as the nation's largest provider of sex education. As experts in sexual and reproductive healthcare, we reach 2.4 million people in our health centers, 1.2 million people through educational programs, and see 177 million visits to our website every year. Backed by more than 13 million supporters, Planned Parenthood Action Fund works every day to defend access to healthcare and advance reproductive rights at home and abroad. Through our international arm, Planned Parenthood Global, we provide financial and technical support to over 100 innovative partners in nine countries in Africa and Latin America.

In the past decades, there has been considerable progress made related to sexual and reproductive healthcare. For example, a 2016 Guttmacher documented that the U.S. was currently experiencing the lowest level of unintended pregnancy in 30 years[1] and the lowest rate of abortion since Roe *v.* Wade was decided in 1973.[2] Much of this progress is due in part to increased access to healthcare services, driven by strategic investments in family planning, access to birth control, and other healthcare programs, and increased access to high-quality, comprehensive sex education.

However, there remain significant and unacceptable inequities in health outcomes that are the result of longstanding systems of oppression that deeply impact traditionally marginalized communities, including persons of color, those with low-incomes, those who identify as LGBTQ, and those who live at the intersection of structural racism, inequality, sexism, classism, xenophobia, and other systemic barriers to healthcare and other resources are among those most severely impacted. The recent outbreak of the novel coronavirus and subsequent COVID–19 pandemic is underscoring the inequities in access to healthcare worldwide and is very likely to further exacerbate the financial barriers to seeking care that is needed, including sexual and reproductive health services.

On behalf of Planned Parenthood Federation of America (PPFA), I respectfully request that while assembling legislation to provide appropriations for fiscal year 2021 that you protect critical domestic health and family planning programs while also increasing funding for key programmatic priorities, including by:

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[1] Guttmacher Institute. U.S. Unintended Pregnancy Rate Falls to 30–Year Low; Declines Seen in Almost All Groups, but Disparities Remain. March 2, 2016. https://www.guttmacher.org/news-release/2016/us-unintended-pregnancy-rate-falls-30-year-low-declines-seen-almost-all-groups. Accessed March 10, 2020.

[2] New York Times. America's Abortion Rate Has Dropped to Its Lowest Ever. September 18, 2019. https://www.nytimes.com/2019/09/18/health/abortion-rate-dropped.html. Accessed March 11, 2020.

1. Protecting and increasing funding for Title X—America's Family Planning Program

Prior to 2019, the Title X program served more than four million low-income individuals annually at nearly 4,000 health centers located in every state plus the District of Columbia.[3] The program provided those with low-income with access to affordable basic primary and preventive healthcare and family planning services, including contraception services and counseling, cancer screenings, and STI testing and treatment. Title X had a proven track record as being highly effective, for example helping to prevent nearly one million unintended pregnancies each year.[4]

Over the objection of more than 110 public health and medical organizations[5] and, most importantly, the American people, the Trump administration proposed and is now enforcing a gag rule that makes significant changes to the program. The gag rule prohibits Title X providers from giving their patients full and accurate information, eliminates a longstanding requirement that Title X providers offer a broad range of medically-approved contraception, and imposes onerous and unreasonable physical and financial separation requirements for abortion-related activities. It also contains a whole host of additional provisions designed to reduce access to quality family planning services in communities across the country, which effectively dismantle the program as it has been run for nearly 50 years. Since enforcement began in August 2019, the Guttmacher Institute recently estimated that 981 clinics have since been forced out of the program because of the gag rule which provided Title X-funded services to 1.6 million patients nationwide. Many states have seen drastic reductions in both the number of Title X provider sites and capacity to provide Title X services and today there are no longer Title X-funded services being provided in six states—Hawaii, Maine, Oregon, Utah, Vermont and Washington.

Now that Planned Parenthood health centers have been forced out of the program, Title X and its underserved patients remain at risk unless Congress acts to ensure the gag rule is blocked and Planned Parenthood and other family planning providers have a pathway back into the program. We strongly recommend that any increase in funding be paired with protective language blocking the gag rule. We urge you to adopt protective language similar to the fiscal year 2020 House language that blocks implementation of the harmful gag rule and permits existing and former Title X networks to rebuild and begin to reverse the damage caused by this rule. With that language in place, we recommend you appropriate $400 million for the program.

2. Providing Funding for STI and HIV Prevention at the Centers for Disease Control and Prevention (CDC)

Sexually-transmitted infections (STIs) are a serious and growing public health problem. In 2018, an annual CDC surveillance report identified nearly 2.5 million cases of syphilis, chlamydia, and gonorrhea diagnoses in the United States.[6] This marked the fifth consecutive year of increases in the rates of these STIs. Of particular concern were cases of congenital syphilis—syphilis passed from a mother to her baby during pregnancy—which increased 40 percent over the previous year. The overall rate has nearly tripled over the past 5 years. Similarly, while progress has been made in recent years to prevent new HIV infections, new data suggest that efforts have plateaued at 39,000 new cases per year since 2013, driven by disparities in progress amongst persons of color.

Despite the CDC recommendation that all pregnant women be tested for STIs, many women and other sexually active adults are not being adequately tested, in part because of limited resources for screening. The CDC's National Center for HIV/AIDS, Hepatitis, STIs and TB Prevention (NCHHSTP) conducts critical public health surveillance, but also funds screenings and other important activities. We

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[3] Fowler, C. I., Gable, J., Wang, J., & Lasater, B. (2017, August). Family Planning Annual Report: 2016 national summary. Research Triangle Park, NC: RTI International.

[4] Frost JJ et al., Contraceptive Needs and Services, 2014 Update, New York: Guttmacher Institute, 2016, https://www.guttmacher.org/report/contraceptive-needs-and-services-2014-update.

[5] Planned Parenthood Federation of America. More than 110 Family Planning and Public Health Organizations Urge HHS Not to Undermine Title X Family Planning Program Through "Domestic Gag Rule." May 16, 2018. https://www.plannedparenthood.org/about-us/newsroom/press-releases/more-than-110-family-planning-and-public-health-organizations-urge-hhs-not-to-undermine-title-x-family-planning-program-through-domestic-gag-rule?—ga=2.224895454.598872098.1553546518-807812785.1551206749 Accessed March 11, 2019

[6] Centers for Disease Control and Prevention (CDC). 2018 STD Surveillance Report. October 8, 2019. https://www.cdc.gov/nchhstp/newsroom/2019/2018-STD-surveillance-report.html. Accessed March 11, 2020.

ask that you fund CDC/NCHHSTP at $1.921 billion for fiscal year 2021, including $240.8 million for the Division of STD Prevention.

3. Protecting and Funding the Teen Pregnancy Prevention Program and the CDC's Division of Adolescent School Health, Eliminating Harmful and Ineffective Abstinence-Only-Until-Marriage Programs

As the nation's leading provider of sex education, Planned Parenthood works in and with communities across the country to provide outstanding sex education programs. Our educators see daily how vital it is for young people to have access to sex education programs that give them knowledge and skills they need to lead fulfilling, safe, and healthy lives. However, today less than 43 percent of all high schools and only 18 percent of middle schools provide education on all of the CDC's identified topics that are critical to ensuring sexual health.

Since fiscal year 2010, the Teen Pregnancy Prevention Program (TPPP) has supported projects and programs that deliver community-driven, evidence-based or informed, medically accurate, and age-appropriate approaches that incorporate involvement from parents, educators, and health providers. Currently, 84 organizations in 33 states, the District of Columbia, and the Marshall Islands receive TPPP funding. The positive outcomes of the program have been well-documented. In September 2017, the bipartisan Commission on Evidence-Based Policymaking, established by then-House Speaker Paul Ryan and Senator Patty Murray, highlighted TPPP as an model example of a Federal program that has developed evidence in support of good policy.

Despite this progress, the Trump-Pence administration proposes to eliminate the program and has diluted its impact by awarding funding to organizations and programs using abstinence-only-until-marriage (AOUM), or so-called "sexual risk avoidance" frameworks. This is despite an overwhelming body of evidence that has found that AOUM programs not only fail to deliver results, but are ineffective at their primary goal of young people delaying sex until marriage.

Planned Parenthood urges you to continue to provide $101 million for TPPP, in addition to $6.8 million for dedicated evaluation transfer authority. We also request additional bill and report language that protects the integrity of the program, which has been subject to unlawful attacks by the administration. Furthermore, urge you to eliminate funding for the abstinence-only-until-marriage "sexual risk avoidance" competitive grant program.

The CDC's Division of Adolescent and School Health (DASH) provides funding to local education agencies across the country to implement school-based programs and practices designed to prevent HIV and other STIs among young people, and also integrates approaches aimed at substance use and violence prevention. In addition, the program expands the research and evidence base of how to best meet the respective needs of young people, including LGBTQ youth and other adolescents. Currently, DASH provides funding to 28 school districts across the country. Providing a significant increase ($67 million over the fiscal year 2020 enacted level) to DASH funding would considerably expand the number served through this important program. We ask that you provide CDC/DASH with $100 million in fiscal year 2021.

4. Eliminating Harmful and Discriminatory Legacy Riders That Undermine Access to Abortion and Rejecting Any New Anti-Women's Health Provisions

Opponents of sexual and reproductive health and rights have long used the appropriations process to undermine women's access to comprehensive reproductive care, including access to abortion. Through policy riders in bills under the jurisdiction of multiple subcommittees, including the original Hyde amendment in the Labor/HHS bill, opponents have limited access for women on Medicaid. When elected officials deny certain categories of women insurance coverage for abortion, they either are forced to carry the pregnancy to term or pay for care out of their own pockets. The result is unfair and discriminatory policy that further exacerbates poor public health outcomes for those who already face significant barriers to care. We urge the Committee to eliminate all such coverage bans on women's access to abortion. In addition, the Committee should reject the multiple harmful new policy riders we have seen proposed in years past that would roll back progress for women, including proposals to "defund" Planned Parenthood.

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We welcome the opportunity to discuss these requests with you or your staff. If you have questions about any of the above requests, please don't hesitate to contact me jacqueline.ayers@ppfa.org). For more information about domestic priorities, please contact Jack Rayburn, Director, Legislative Affairs (jack.rayburn@ppfa.org).

Sincerely.

[This statement was submitted by Jacqueline Ayers, Vice President, Government Relations and Public Policy, Planned Parenthood Federation of America.]

PREPARED STATEMENT OF THE POPULATION ASSOCIATION OF AMERICA AND THE ASSOCIATION OF POPULATION CENTERS

Thank you, Chairman Blunt and Ranking Member Murray for this opportunity to express support for the National Institutes of Health (NIH), National Center for Health Statistics (NCHS), Institute of Education Sciences (IES), and Bureau of Labor Statistics (BLS). These agencies are important to the members of the Population Association of America (PAA) and Association of Population Centers (APC) because they provide direct and indirect support to population scientists and the field of population, or demographic, research overall. In fiscal year 2021, we urge the Subcommittee to adopt the following funding recommendations: $44.7 billion, NIH; $189 million, NCHS; $670 million, IES; and $658.3 million, BLS. Given the uncertainty of the ongoing COVID–19 pandemic, PAA and APC also urge the subcommittee to consider opportunities to provide necessary, additional funding for these agencies in fiscal year 2021.

NATIONAL INSTITUTES OF HEALTH

Demography is the study of populations and how or why they change. The health of our population is fundamentally intertwined with the demography of our population. Recognizing the connection between health and demography, NIH supports population research programs primarily through the National Institute on Aging (NIA) and the National Institute of Child Health and Human Development (NICHD). PAA and APC thank Chairman Blunt and Ranking Member Murray for their bipartisan leadership and for working together in recent years to provide the NIH with robust, sustained funding increases. As members of the Ad Hoc Group for Medical Research, PAA and APC recommend the Subcommittee continue to prioritize NIH funding by endorsing an appropriation of at least $44.7 billion for the NIH, a $3 billion increase over the NIH's program level funding in fiscal year 2020. We urge that NIA and NICHD, as components of the NIH, receive commensurate funding increases in fiscal year 2021.

NATIONAL INSTITUTE ON AGING

The NIA Division of Behavioral and Social Research (BSR) is the primary source of Federal support for basic population aging research. In January 2020, the NIA National Advisory Council on Aging (NACA) released a comprehensive review of the BSR Division The report reinforced the value of the Institute's investment in an array of population aging research activities, including large-scale, longitudinal studies, such as the Health and Retirement Study, and center programs, such as the Centers on the Demography and Economics of Aging, which are conducting research on the demographic, economic, social, and health consequences of U.S. and global aging at 11 universities nationwide. With additional funding in fiscal year 2021, the BSR Division could continue to support these activities as well as pursue recommendations that the NACA review identified, including expanding research opportunities to advance our understanding of the poor overall health of older people in America and the growing disparities in some parts of the country.

EUNICE KENNEDY SHRIVER NATIONAL INSTITUTE ON CHILD HEALTH AND HUMAN DEVELOPMENT

Since the Institute's inception in 1962, NICHD has had a clear mandate to support a robust research portfolio focusing on maternal and child health, the social determinants of health, and human development across the lifespan. The NICHD Population Dynamics Branch meets this mandate by supporting innovative and influential population science initiatives, including: (1) large-scale longitudinal surveys, with population representative samples, such as the National Longitudinal Survey of Adolescent Health and Fragile Families and Child Well Being Study; (2) a nationwide network of population science research and training centers; and, (3) numerous scientific research initiatives that have advanced our understanding of specific diseases and conditions, including obesity, autism, and maternal mortality, and, further, how socioeconomic and biological factors jointly determine human health. With additional support in fiscal year 2021, the Institute could continue supporting its large-scale data collection activities and its Population Dynamics Centers Research Infrastructure Program. Finally, with additional support to NIH overall, NICHD could help achieve the goals of the agency's proposed research initiative to reduce maternal mortality.

NATIONAL CENTER FOR HEALTH STATISTICS

NCHS is the nation's principal health statistics agency, providing data on the health of the U.S. population. Population scientists rely on large NCHS-supported health surveys, especially the National Health Interview Survey and National Health and Nutrition Examination Survey, to study demographic, socioeconomic, and behavioral differences in health and mortality outcomes. They also rely on the vital statistics data that NCHS releases to track trends in fertility, mortality, and disability. NCHS health data are an essential part of the nation's statistical and public health infrastructure. In order to support NCHS's continued work to monitor the health of the American people and to allow the agency to make much-needed investments in the next generation of its surveys and products, PAA, as a member of the Friends of NCHS, recommends NCHS receive at $189 million in fiscal year 2021. Our recommendation reflects an increase to NCHS's base budget of $14.6 million from its fiscal year 2020 appropriation, as well as the formalization of an ongoing $14 million transfer from Surveillance, Epidemiology, and Informatics as proposed in the President's fiscal year 2021 Budget Request. We urge the Subcommittee to reject the Administration's proposed $5.4 million cut to the agency, which would have a devastating impact on NCHS's ability to continue to provide timely, unbiased, and accurate data on Americans' health and could result in the elimination of one of its primary health surveys.

BUREAU OF LABOR STATISTICS

Population scientists who study and evaluate labor and related economic policies use BLS data extensively. The field also relies on unique BLS-supported surveys, such as the American Time Use Survey and National Longitudinal Surveys, to understand how work, unemployment, and retirement influence health and well-being outcomes across the lifespan. As members of the Friends of Labor Statistics, PAA and APC are very grateful for $40 million programmatic increase that BLS received in fiscal year 2020. It was the first meaningful increase that the agency had received since 2009. We are also pleased that BLS received $10 million in fiscal year 2020 to plan for a new youth cohort for the National Longitudinal Survey of Youth (NLSY). As the Subcommittee knows, the current NLSY 1979 and 1997 cohorts cannot provide adequate information about teens and young adults entering the labor market. PAA and APC hope that this planning process will provoke a new, necessary NLSY cohort in fiscal year 2021. We urge the Subcommittee to continue sustained support for the agency in fiscal year 2021 by supporting the Administration's request, $658.3 million, in fiscal year 2021.

INSTITUTE OF EDUCATION SCIENCES

PAA relies on the Institute of Education Sciences (IES), particularly the National Center for Education Statistics (NCES) within IES, for objective information on the condition of education in the United States, including topics ranging from K–12 to post-secondary education, teacher development, and school violence. PAA joins other social science organizations in expressing concerns about inadequate staffing at NCES and its adverse effect on the agency's ability to manage its broad array of surveys and assure data quality and program rigor. We urge the Subcommittee to exert careful oversight of this situation and consider whether legislative language could be adopted in the fiscal year 2021 bill to address it. Further, as members of the Friends of IES, we ask that agency receive $670 million in fiscal year 2021.

Thank you for considering our support for these agencies as the Subcommittee drafts the fiscal year 2021 Labor, Health and Human Services and Education Appropriations bill.

[This statement was submitted by Mary Jo Hoeksema, Director, Government and Public Affairs, Population Association of America and the Association of Population Centers.]

PREPARED STATEMENT OF POWER TO DECIDE

Dear Chairwoman Lowey, Ranking Member Granger, Chairwoman DeLauro and Ranking Member Cole:

Power to Decide respectfully requests the following funding levels within the fiscal year 2021 Labor, Health and Human Services, Education, and Related Agencies (LHHS) appropriations bill, as well as language protecting and restoring the integrity of key programs. Power to Decide is a non-profit, non-partisan organization that works to ensure that all young people-no matter who they are, where they live, or what their economic status might be-have the power to decide if, when, and under what circumstances to get pregnant and have a child. We do this by increasing information, access, and opportunity. Specifically, we request:

—$400 million for the Title X Family Planning Program accompanied by language that blocks the domestic gag rule and begins to undo its damage by allowing those entities that left the program a way to rejoin it.

—$101 million for the Teen Pregnancy Prevention (TPP) Program accompanied by language that ensures the program adheres to rigorous standards of evidence and avoids biased or incomplete information.

—$6.8 million under the Public Health Services Act for the evaluation of teenage pregnancy prevention approaches, including sufficient funding to support the Teen Pregnancy Prevention Evidence Review administered by the Assistant Secretary for Planning and Evaluation (ASPE).

TITLE X FAMILY PLANNING PROGRAM

We request $400 million in funding for the Title X program for fiscal year 2021. For five decades, Title X has played a critical role in preventing unplanned pregnancy by offering low-income and uninsured individuals' access to high-quality contraceptive services, preventive screenings, and health education and information. Title X patients are some of the most marginalized in the country. Two-thirds have incomes at or below the Federal poverty level and forty percent are uninsured.[1] The services Title X supports save taxpayers $7 for every $1 invested.[2] Despite the significant return on investment, the current $286.5 million funding level in fiscal year 2020 is $31 million lower than the fiscal year 2010 level, which was already inadequate to meet the need. Even prior to the devastating implementation of the domestic gag rule, reduced funding over the last several years has resulted in fewer patients served and more clinic closings. For example, in 2018, Title X clinics served nearly 4 million women and men, down 25 percent or 1.3 million patients from the 5.2 million patients served in 2010. The current funding level is already insufficient to meet the needs of those depending on Title X clinics, but the implementation of the domestic gag rule has made things dramatically worse. In addition to increased funding, we request language that blocks the domestic gag rule and that provides a pathway for entities forced out of the Title X program to rejoin. Nationwide, more than 19 million women in need of publicly funded family planning (with incomes at or below 250 percent of the Federal Poverty Level) live in contraceptive deserts, where they lack reasonable access to a clinic offering the full range of contraceptive methods.[3] The upheaval caused by the gag rule is only exacerbating these access gaps. The gag rule has forced clinics to make an impossible choice—reject funds that support their patients who might not otherwise be able to afford family planning care or withhold information from patients about abortion services. To date, 15 states have lost some or all of their Title X funding, and an additional 15 states have lost funding to individual clinics that are not replaceable in those communities leading to more than 900 clinics losing Title X funding. Nationwide, 8.8 million women in need of publicly funded contraception across 390 counties have lost Title X resources in their communities.[4] And it is not only those who receive services directly paid for by Title X who are losing access to birth control. Title X funds are critical to keeping clinic doors open for thousands of clinics that also serve patients who have insurance, such as Medicaid and Affordable Care Act plans. Insufficient funding and forcing high quality providers out of Title X both exacerbate disparities in access to family planning care, falling hardest on people of color, people living in rural areas, and people struggling to make ends meet. We urge you to help change this by funding Title X at $400 million, blocking the domestic gag rule, and beginning to reverse the damage done.

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[1] Fowler, C. I., Gable, J., Wang, J., Lasater, B., & Wilson, E. (2019, August). Family Planning Annual Report: 2018 national summary. Research Triangle Park, NC: RTI International.

[2] Frost J.J., Sonfield A., Zolna M.R., & Finer L.B. (2014). Return on investment: A fuller assessment of the benefits and cost savings of the US publicly funded family planning program. Milbank Quarterly, 92(4): 667–720.

[3] Power to Decide (February 2020). Contraceptive Deserts Research, Retrieved on February 19, 2020 from https://powertodecide.org/what-we-do/access/birth-control-access.

[4] Power to Decide (November 2019). Impacts of the Domestic Gag Rule, Retrieved on February 19, 2020 from https://powertodecide.org/what-we-do/information/resource-library/impacts-domestic-gag-rule.

TEEN PREGNANCY PREVENTION (TPP) PROGRAM

We request funding for the TPP Program at $101 million for fiscal year 2021, the same as its current fiscal year 2020 funding level. We also request that language be included that protects the program from ongoing Administration efforts to subvert congressional intent. Specifically, we request language that ensures the program adheres to rigorous standards of evidence, avoids biased or incomplete information, and provides accountability for the funding appropriated by Congress.

The first two five-year cycles of grants have already made vital contributions to the growing body of knowledge of what works for whom and under what circumstance to prevent teen pregnancy. This has included high quality implementation, rigorous evaluation (primarily randomized control trials), innovation, and learning from results. The September 2017 unanimously-agreed-to-report from the bipartisan Commission on Evidence-Based Policymaking established by House Speaker Paul Ryan and Senator Patty Murray highlighted the TPP Program as an example of a Federal program developing increasingly rigorous portfolios of evidence.[5] Yet since 2017 the U.S. Department of Health and Human Services (HHS) has repeatedly sought to eliminate or undermine the TPP Program. This includes shortening the second cohort of five-year grants (fiscal year 2015—fiscal year 2019) to only 3 years, until grantees prevailed in 11 lawsuits filed against the grant shortening. Despite numerous and repeated inquiries from Congress, attempts to remake the program continue, including a move away from implementation of evidence-based interventions and rigorous evaluation. We strongly urge appropriators to include language for fiscal year 2021 appropriations that both fully funds the TPP Program and includes language that protects the program from ongoing efforts to subvert congressional intent.

EVALUATION OF TEENAGE PREGNANCY PREVENTION APPROACHES

As part of the growing bipartisan commitment to evidence-based policymaking, there's a recognition of supporting high quality evaluation within Federal agencies. Congress has historically provided a modest amount of dedicated funding to evaluate teen pregnancy prevention approaches, including longitudinal evaluations. This funding, in conjunction with the TPP Program, has contributed to deepening our knowledge of what works to reduce teen pregnancy. However, HHS has not in recent years used this funding for high quality evaluations. That should be corrected in fiscal year 2021. Appropriators should also specifically include sufficient funding to continue the Teen Pregnancy Prevention Evidence Review administered by ASPE, as they did through report language for fiscal year 2020. This is an objective, systematic review using high quality evidence standards. Such evidence reviews are recognized as a hallmark of evidence-based policymaking and are an essential tool to compile and share a growing body of evidence.

ADDITIONAL PROGRAMS

In addition to funding for the aforementioned programs, we urge you to provide adequate funding levels for other important programs that contribute to improved reproductive well-being as part of broader efforts. These programs include the Maternal and Child Health Block Grant, the Centers for Disease Control and Prevention, and Community Health Centers.

The TPP Program and the Title X Family Planning Program enjoy broad bipartisan support.

In conclusion, 85 percent of adults support continued funding for the TPP Program, and 75 percent favor continuing the Title X program. These programs make sense. Helping to ensure that everyone has the power to decide if, when, and under what circumstances to get pregnant and have a child will improve opportunities for them and for the country. We appreciate the budget constraints appropriators face and respectfully urge you to support this request. If you have questions or need additional information, please contact Rachel Fey, Senior Director of Public Policy at rfey@powertodecide.org.

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[5] Nick Hart and Meron Yohannes (eds.) Evidence Works: Cases Where Evidence Meaningfully Informed Policy. (Washington, D.C.: Bipartisan Policy Center, 2019). Retrieved on February 19, 2020 from https://bipartisanpolicy.org/wp-content/uploads/2019/06/Evidence-Works-Cases-Where-Evidence-Meaningfully-Informed-Policy.pdf.

PREPARED STATEMENT OF PREVENT BLINDNESS

As the nation's leading nonprofit, voluntary organization committed to preventing blindness and preserving sight, Prevent Blindness appreciates the opportunity to submit testimony to the Subcommittee. We are pleased that the year 2020 represents a unique opportunity to draw attention to vision and eye health. As such, we respectfully request the following allocations in fiscal year 2021 to the Department of Health and Human Services Centers for Disease Control and Prevention (CDC), National Center for Chronic Disease Prevention and Health Promotion, to promote eye health and prevent eye disease and vision loss:

—$5,000,000 for the CDC's Vision and Eye Health program to update national prevalence estimates on vision impairment and eye disease using the National Health Nutrition Examination Survey (NHANES) and improve state and community-level interventions to help prevent avoidable vision loss; and

—$4,000,000 to allow the CDC's Glaucoma program to continue to improve glaucoma screening, referral, and treatment by reaching populations that experience the greatest disparity in access to glaucoma care.

VISION AND EYE HEALTH AND COVID–19

As our nation continues to respond to the current novel coronavirus pandemic, there is an increasing understanding of the need for sustained investments in public health surveillance to stay ahead of major disease outbreaks or crises. As we start to understand the long-term impacts of COVID–19, we are concerned our national vision and eye health problem will only become worse if patients cannot access eye care treatments due to a loss or lack of comprehensive healthcare coverage or if patients do not feel safe to seek treatment.

Additionally, as the majority of the United States is working from home or learning in a virtual environment, Americans face increased demands on their vision and eye health from prolonged, close exposure to electronic devices such as smart phones, laptop computers, and tablets. Additional research is needed to understand the long-term impacts that these devices may have on our eyes-such as increasing rates of myopia, dry eye, and eye strain-particularly as we may need to extend these virtual work and learning circumstances into the fall and winter.

We are still learning about this serious disease; however, we do know there is an intersection between those at high risk for complications of COVID–19 and those who live with eye disease or vision loss-including the elderly and people with underlying conditions like diabetes. Until we have assurance that a safe and affordable vaccination for COVID–19 is readily available and can safeguard our personal and public health, our only available proactive response to this disease is preparation.

With updated data that illustrates who currently lives with vision loss and eye disease, and who is most at risk for potentially blinding conditions, we can develop strategies to ensure that patients can safely seek eye care treatment without potentially exposing themselves, their loved ones, their caregivers, and front-line providers to this disease. We can ensure patients understand how to manage their eye care treatment should social distancing guidelines continue in the future. We can work with state and community leaders to develop cross-sector, multilevel collaborations and interventions on vision and eye health that ensure individuals living with vision loss can continue to safely function in their own communities while taking necessary precautions. We can also address the consequences of vision loss that overlap with COVID–19, including social isolation, inability to self-care and manage disease, improve telehealth and accessibility, improve access to COVID–19 services including screening, testing, and treatment, and ensure access to support services necessary for those with disability for which social distancing requirements effectively cuts off critical transportation.

Ultimately, we can develop guidelines based on evidence, experience, and foresight to ensure that patients do not have to make the choice between interruptions in their care (which, in some cases, could lead to irreversible vision loss) or exposing themselves and others to the serious risks of COVID–19.

OUR NATIONAL VISION AND EYE HEALTH PROBLEM

Vision and eye health enables many aspects of daily living no matter your age, racial and ethnic background, or socio-economic circumstances. With healthy vision, we can engage with the world around us, learn in school, earn a living, and age independently with a high quality of life. Public opinion polls conducted over the last 40 years indicate that Americans consistently fear losing their vision second only to fear of cancer. Yet, vision and eye health is often an afterthought until changes to eyesight become noticeable and lost vision is gone forever. Vision impairments and eye disease are chronic conditions: they require ongoing treatment and management over the course of one's lifetime. According to the Robert Wood Johnson Foundation, eye disorders are the fifth leading chronic condition among those aged 65 years and older and seventh across all age groups.[1] Recent estimates from the CDC indicate that, in 2017, 93 million Americans over the age of 18 (roughly 4 in 10) are at high risk for vision loss. Of this population, 37.2 million (40 percent) did not see an eye doctor or receive an eye exam in the last year. The CDC also found that 8 million adults (roughly 1 in 11) needed eyeglasses but could not afford them.[2] The reality is that 75 percent of vision loss is preventable with early detection and treatment; yet, patients continue to face significant barriers such as costs of treatment, coverage, lack of awareness of the importance of prevention, and gaps in the healthcare system. The programs we are here to discuss today are a critical first step in addressing these very preventable problems.

THE COSTS OF VISION LOSS AND EYE DISEASE

Vision problems are also incredibly costly, not just to the individual but to our national healthcare system. Accounting for private and public payments for medical care, long-term care, patients' out-of-pocket costs, direct and indirect costs, lost productivity and consequential lost tax revenue, our national costs on vision and eye health amounted to $167 billion in 2019. According to national forecasts, total expenditures on vision problems, due to an aging population and changes in demographics, will reach $385 billion by 2032 and $717 billion by 2050. With this, the proportion of these costs paid by government programs will increase from 32.6 percent to 41.14 percent by 2050.

Vision impairment and eye disease often contributes to several costly and chronic conditions, including: diabetes, injuries and death related to falling, stroke, depression and social isolation, cognitive decline, lack of mobility, and need for long-term care. Barriers in access to care resulting from high costs, lack of transportation, inability to prioritize eye care with other conditions, and poor health outcomes exacerbate vision problems. Patients with vision loss experienced longer hospital stays and high readmission rates, resulting in $500 million in excess costs.[3] With an aging population and a working adult population who faces a rise in chronic diseases that affect their vision and ability to maintain their own economic independence through sustained employment, now is the time to invest in our collective eye health.

VISION AND EYE HEALTH AT THE CDC: SAVING SIGHT AND DOLLARS

The CDC addresses our national vision impairment and eye disease burden by conducting public health surveillance, research, and evidence-based public health interventions designed to complement state and community health efforts. From 1999—2008, NHANES included visual examinations and from 2005—2008, it included ophthalmology examinations to measure rates of eye disease that led to vision loss. However, the 2005—2008 data set is the last collection of reliable prevalence estimates of vision impairment and eye disease[4] due to a consistent lack of resources allocated to the CDC's vision and eye health programs from fiscal year 2011 through fiscal year 2020. This means that our best available data on our national vision loss and eye disease burden is over a decade old with current state and community interventions based on 12–15 year-old data. Without updated and reliable data, we cannot begin to solve our burgeoning vision and eye health crisis.

With $5 million appropriated to vision and eye health in fiscal year 2021, the CDC can:

—Resume use of the NHANES to collect data on prevalence of diabetic retinopathy, glaucoma, and vision loss,

—Determine rates of vision and eye examinations, measure rates of visual acuity, screening tests, and visual functioning assessment to determine gaps in access and patient education, and

—Use this information to bolster state capacity to respond to the needs of their communities with collaborative interventions and targeted strategies to improve vision and eye health at the state, local, or systems level.

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[1] 1 "Chronic Care: Making the Case for Ongoing Care" Robert Woods Johnson Foundation, 2010. https://www.rwjf.org/content/dam/farm/reports/reports/2010/rwjf54583.

[2] Four in 10 US Adults Are At High Risk for Vision Loss, CDC Vision Health Initiative, March 2020. https://www.cdc.gov/visionhealth/resources/publications/high-risk-vision-loss.html.

[3] Morse AR, et al. JAMA Ophthalmology. 2019;doi:10.1001/jamaophthalmol.2019.0446. Accessed 20/01/23 from: https://www.ncbi.nlm.nih.gov/pubmed/30946451.

[4] Vision Health Initiative, CDC. National Health and Nutrition Examination Survey https://www.cdc.gov/visionhealth/vehss/data/national-surveys/national-health-and-nutrition-examination-survey.html.

We urge the Committee to direct $5 million to the CDC's Vision and Eye Health program to resume use of this gold standard surveillance instrument, and help ensure that we are doing everything we can to protect Americans' eye health and sight.

GLAUCOMA AT THE CDC

As well, we ask the Committee to maintain the CDC's work in improving glaucoma screening, referral, and treatment particularly for populations that face disparity in access to glaucoma care. The CDC conducts glaucoma detection programs designed to reach populations that are at highest risk for getting glaucoma. Two particular programs have proven essential in providing direct glaucoma detection, referral, and sustained eye care services through innovative service models that can be spread to other areas with high-risk populations.[1]

University of Alabama (UAB) EQUALITY (Eye care Quality and Accessibility Improvement in the Community): The UAB coordinated with local optometrists to provide comprehensive eye exams and send high-resolution retinal images to glaucoma specialists at the Department of Ophthalmology for review, diagnosis, and a developed treatment plan. Educational components included brochures, short consumer-oriented videos, and posters placed in the vision centers. This program successfully reached 651 participants with optometrists making 750 diagnoses by eye and 19 percent new detected cases of glaucoma. 88 percent of program participants were older than 40 years and 64 percent were African-American.

Willis Eye Hospital: Willis Eye Hospital transported eye care equipment to community sites (such as senior centers, residential housing for seniors, faith-based organizations, health fairs, and public health clinics) where a team of 4–7 technicians and a glaucoma specialist provided free eye examinations and laser treatment. Services were provided in 43 communities in Philadelphia with 1,649 people were screened for glaucoma and 1,709 glaucoma diagnoses were made by eye. This outreach also resulted in diagnosis of eye-related diseases in 1,462 eyes (1,140 of which were cataracts).

By maintaining the CDC's funding at $4 million in fiscal year 2021, Congress will ensure that this essential work will continue for Americans who need essential glaucoma care.

CONCLUSION

Earlier this year, over 83 organizations including Prevent Blindness sent a letter to this Committee with our collective endorsement of these critical investments to the CDC's vision and eye health programs. There is strong consensus among providers, researchers, public health practitioners, community organizations, and consumer and patient groups in the vision and eye health community that these investments are important for safeguarding our ability to see clearly, learn in school, engage with our communities, earn a productive living, and maintain our independence through the aging process.

On behalf of Prevent Blindness, our Board of Directors, and the millions of people whom we represent at risk for vision loss and eye disease, we stand ready to work with the Subcommittee and other Members of Congress to advance these and other policies that will prevent blindness and preserve sight.

[This statement was submitted by Jeff Todd, President & CEO, Prevent Blindness.]

PREPARED STATEMENT OF THE PUEBLO DE COCHITI

I write this testimony on behalf of the community members of the Pueblo de Cochiti. The Pueblo is located in north central New Mexico and a small Pueblo, rural in nature and an on-reservation population of less than 1000 members. The Indian Health Service provides a 2-day clinic per week in our reservation clinic. The Community Health Representatives (CHRs) are the 'Boots on the Ground' tribal health providers when no other health services are available in our Pueblo. The small staff is our medical providers after Indian Health Service staff leave. They provide prevention, intervention and direct services such as home visits, health education, EMS, partner with local, state and Federal health partners. They keep me informed of all health matters related to our community and serve as liaison with all health providers. The funding for this valuable community-based health program is funded from the Indian Health Service under the appropriations cited above. The elimination of such a service will leave Cochiti Pueblo with minimal health providers in our rural community. We encourage your support of the overall IHS budget and 2–3 percent yearly increases since 2008, however, we realize there is still a huge need for public health infrastructure in Native lands like the CHRs.

The current Coronavirus pandemic has deployed our CHRs in our Pueblo. The CHRs along with a Public Health Nurse have made home visits to each household on educating, communicating and referral contacts on Coronavirus. The tribal leadership has been informed in our native language on the Coronavirus public health concerns and possible actions necessary. At times of confusing information, we need our own tribal health staff to assure trust and plan of action necessary specific to our population. On Friday March 13, 2020 I put in place a Public Health Emergency on the Coronavirus–19 where the CHR's are working with the different tribal programs to get correct information to the community. This will be set in place for 30 days expiring

The President's budget request also proposes to combine funding for CHR ($ 62.8 million in fiscal year 2020), Health Education ($20.56 million in fiscal year 2020) and nationalization of the Community Health Aide Program ($5 million in 2020) into a new 'Community Health' line item funded at $44.1 million. By combining all three-line items to one would reduce the yearly funding by $44 million for all three combined. All three-line items should remain as stated in the Indian Health Care Improvement Act which authorizes the IHS budget and has been institutionalized as line items. All 3-line items should be increased as has been recommended by the Tribal Leaders IHS budget formulation workgroup for the past few years. The workgroup put the CHR program as priority in Native lands and the IHS budget should be funded $9.1 billion. As demonstrated by the Coronavirus pandemic, the public health infrastructure and services in our Pueblo communities need to be staff and developed with additional CHR and public health funding. In rural reservations, the CHRs and Community Health providers are the first to respond in public health practice and protocol. You are now seeing the confusion and misunderstandings of public health practices as this will continue to occur if such programs are not funded adequately.

Congress has a constitutional obligation to mandatory fund the Indian Health Service budget and not remain as discretionary funding. There is nothing discretionary about healthcare when lives are at stake. The Pueblo de Cochiti has submitted testimonies on funding healthcare in Native communities. As such, the Pueblo supports an indefinite appropriation and separate line item for the section 105(l) facility leases. This has forced IHS to take from services program accounts to pay for these leases. This also forces the budget to take from CHR, Health Ed and other line items from direct service tribes to pay other contracting/compacting tribes on leases at the expense of locally controlled public health services.

Although, not in the IHS budget, the Pueblo urge your immediate support of a five-year reauthorization of the Special Diabetes Program for Indians (SDPI). We have over 60 diabetics in our small community. The SDPI funding has had a major impact in keeping our diabetic numbers from increasing. SDPI has saved a lot of Medicaid and Medicare funding but more importantly bought awareness and lifestyle changes to our healthy residents.

We appreciate your continued support for Advance Appropriations to keep our healthcare facilities and programs open during government shutdowns. The IHS funded programs are direct service providers similar to the VA and should be funded with no regard to political grandstanding. My testimony highlights our Public Law 93–638 programs contracted by the Pueblo as we can we provide culturally sensitive services, but it also supports our tribal administration in administering these programs. Thank you very much for your efforts in protecting and promoting Native American healthcare.

Respectfully.

[This statement was submitted by Charles D. Naranjo, Governor, Pueblo de Cochiti.]

PREPARED STATEMENT OF THE PUERTO RICO FEDERAL AFFAIRS ADMINISTRATION

Dear Chairman Blunt and Ranking Member Murray:

Thank you for your essential support of Puerto Rico in the fiscal year 2020 appropriations process. The Committee's support of the island is invaluable as we continue our efforts to rebuild following the devastation of Hurricanes Irma and Maria in September 2017, as well as the earthquakes that impacted the southwest part of the island earlier this year. With the support of Congress, we have made great progress, but as you are aware, much remains to be done in order to rebuild Puerto Rico and set the island on a path to full recovery and reconstruction. With the shared goal of continuing the recovery and prosperity of Puerto Rico, I, on behalf of Governor Wanda Vázquez Garced, respectfully submit the following proposals for fiscal year 2021 Labor, Health and Human Services, Education, and Related Agencies appropriations.

Funding of Puerto Rico's Medicaid Program:

The Government of Puerto Rico urges the Subcommittee to continue to adequately fund Puerto Rico's Medicaid program by appropriating two additional fiscal years of increased statutory cap funding at $3 billion respectively for fiscal year 2022 and fiscal year 2023, and permanently establishing Puerto Rico's Federal Medical Assistance Percentage (FMAP) at 76 percent. As you are aware, Puerto Rico and the other U.S. territories are limited by statute for the FMAP at 55 percent and are subject to a capped block-grant funding from the Federal Government mandated as by Section 1108(g) of the Social Security Act (SSA). Unlike the states and Washington DC, which have open ended Federal Medicaid funding, Puerto Rico has its Federal Medicaid funding based on the annual rate of the Consumer Price index for all Urban Consumers (CPI–U).

However, following the enactment of the Further Consolidated Appropriations Act, 2020 (Public Law 116–94), Puerto Rico was allocated a temporary increase in its FMAP to 76 percent, and is eligible to receive up to $5.7 billion in capped funding for fiscal year 2020 and fiscal year 2021 combined. To retain this amount in Federal funding, Puerto Rico is required to meet certain program integrity benchmarks. If Puerto Rico fails to meet the benchmarks, the FMAP shall be reduced 2.5 percent for every fiscal quarter but such reduction shall not exceed 2.5 percent.

Puerto Rico's Department of Health (PRDOH) is working diligently to ensure that the integrity measures are punctual and Federal funds are properly spent for the Medicaid needs of the island. To ensure the continuity and longevity of program integrity measures and goals of the PRDOH, 2 years of additional funding would be required. Thus, Puerto Rico's Medicaid program would require an estimated $3 billion for fiscal year 2022 and fiscal year 2023 respectively, under a permanent 76 percent FMAP, to ensure the continuity of efforts and measures to safeguard Puerto Rico's Medicaid program.

Transition of Puerto Rico's Medicaid Program:

The Government of Puerto Rico urges the Subcommittee to direct the Secretary of the U.S. Department of Health and Human Services (HHS) to commission a study on the health, medical, and economic benefits of transitioning Puerto Rico's Medicaid program from a statutorily capped block-grant at a 55 percent FMAP, to a state-like Medicaid program for Federal funding purposes. The study should focus on the impacts of eliminating the section 1108(g) funding cap for Puerto Rico and allowing Puerto Rico's FMAP percentage to be based on Puerto Rico's per capita income relative to that of the United States.

Medicaid is designed to treat our nation's most vulnerable populations, including low-income families, the elderly, children, and individuals with disabilities. The U.S. citizens of Puerto Rico suffer from serious health conditions that require urgent care, including mental health issues and chronic diseases such as cancer, diabetes, Hepatitis C, and HIV. In the aftermath from the 2017 hurricanes and the recent earthquakes, serious disruptions to services at hospitals and other medical facilities have occurred. The exodus of providers and infrastructure damage is so dire that in certain circumstances, it has increased the risk from infectious diseases caused by unsanitary conditions.

Given all the Federal and local resources invested to alleviate the medical hardships faced by the U.S. citizens of Puerto Rico, we should ensure the long-term prosperity of Puerto Rico's Medicaid program. By examining the health, medical, and economic benefits of transitioning Puerto Rico's Medicaid program to a state-like program, we will have the information needed to provide the best healthcare results to Medicaid beneficiaries on the island with Federal funding.

Improvements to Medicare Advantage in Puerto Rico:

The Government of Puerto Rico urges the Subcommittee to direct the Centers for Medicare and Medicaid Services (CMS) to make improvements to Medicare Advantage (MA) in Puerto Rico. MA in Puerto Rico has the highest participation rate in the entire nation, at an estimated 75 percent, making MA in Puerto Rico the lowest payment rate with highest number of duals in a MA plan. Seniors on the island have indicated they appreciate MA's lower cost sharing, coordination of care, and other benefits that help to meet their special healthcare needs. As more than 40 percent of citizens on the island live below the poverty line, these factors are integral to beneficiaries.

To improve MA on the island, we urge the Subcommittee to direct CMS to maintain the zero claims adjustment to use its administrative authority to average geographic adjustment at .70. This would allow for a solution to MA funding disparities in Puerto Rico to resolve the persistent anomalies in the "Fee-For-Service" (FFS) program data. The FFS basis for MA rate setting is rapidly eroding in Puerto Rico and no longer aligns with the assumptions underlying its use for MA benchmarks.

Furthermore, we ask that the Subcommittee to direct CMS to expand MA coverage on the island to classify Part B premium support as a core A/B benefit or full benefit dual-eligible individuals in Duals—Special Needs Plans. This would enhance the capacity of MA plans to help dual-eligibles under 82 percent of the Federal Poverty Level with the payment of the Part B member premium. Allowing MA beneficiaries on the island to be covered similarly to situated citizens in the states. Thus, these improvements to MA will enable our more than 585,000 seniors to continue to get the necessary care they are entitled to receive.

The National Survey on Drug Use and Health and the Inclusion of Puerto Rico:

The Government of Puerto Rico urges the Subcommittee to fully fund the National Survey on Drug Use and Health (NSDUH) and require the inclusion of Puerto Rico in areas covered by the NSDUH. As you know, the NSDUH provides up-to-date information on tobacco, alcohol, drug use, as well as mental health related issues in the United States. Since its inception in 1971, the NSDUH is conducted every year in all 50 states and in DC. However, Puerto Rico is not included in the areas covered by the survey and is at a data deficit when developing treatment and prevention plans to address the health and well-being of the U.S. citizens on the island.

The collection of this data in Puerto Rico is urgently needed in the wake of Hurricanes Irma and Maria, as well as the recent earthquakes. The devastation caused by these natural disasters has presented historic challenges to the U.S. citizens of Puerto Rico, that will require a comprehensive approach to confront. Investment is not only needed in our infrastructure, but the mental health and well-being of the people of Puerto Rico. Therefore, fully funding the NSDUH and including Puerto Rico in the survey will allow the island to assess the actual substance abuse and mental health needs to adequately plan methods to address these issues.

Additional Federal Funding for the Puerto Rico Mental Health and Anti-Addiction Services:

The Government of Puerto Rico recommends that the Subcommittee to fully fund the Substance Abuse and Mental Health Services Administration (SAMHSA), which provides funding to Puerto Rico's Mental Health and Anti-Addiction Services (ASSMCA per its Spanish acronym). Following the 2017 hurricanes and the recent earthquakes, many of Puerto Rico's U.S. citizens are suffering from post-traumatic stress disorder (PTSD) and other mental health disorders. The goal of ASSMCA is to ensure high-quality, cost-effective, evidence-based, and integrated mental health services throughout the island. The development and implementation of their innovative strategies are further offered in an environment of respect and diversity. Thus, in order to meet the vital mental health services necessary to treat those affected by recent natural disasters in Puerto Rico, full funding of SAMHSA and ASSMCA is essential.

Federal Funding for Puerto Rico's Department of Education:

The Government of Puerto Rico asks the Subcommittee to provide adequate funding of $101,000,000 to Puerto Rico's Department of Education (PRDE) and allow for the fungibility of disaster funds from previous disaster supplementals to address the unmet educational needs throughout Puerto Rico. Following the aftermath of the 2017 hurricanes, several schools throughout the island remain unopened due to hurricane damage and lack of adequate funding. Recent earthquakes have further exacerbated the damage to educational facilities. The additional funding will allow for remedial education training and for renting of temporary facilities to begin courses. The fungibility of funding to meet the educational unmet needs will provide for the expedient use of already existing disaster funds to repair and alleviate the damage caused by the recent earthquakes. Allowing the interchangeable use of funds without limitation will enable the PRDE to continue its goals to reopen schools, provide alternative facilities, and begin courses.

Individuals with Disabilities Education Act:

The Government of Puerto Rico urges the Subcommittee to provide robust funding for the Individuals with Disabilities Education Act (IDEA). IDEA makes available free appropriate public education to eligible children with disabilities. IDEA allows students with disabilities such as hearing impairment, language impairment, down syndrome, cerebral palsy, autism, and other learning disabilities to receive individual-specific services, programs, and resources. In the aftermath of Hurricanes Irma and Maria, as well as the recent earthquakes, several schools lack the adequate facilities or personnel to meet the special education needs of students with disabilities. To assess and guarantee the effectiveness of efforts to educate children with disabilities, we must provide the proper tools to meet the individual needs of each student. Therefore, to ensure that educators and parents have the necessary tools to improve educational results for children with disabilities in Puerto Rico, we request robust funding of IDEA.

Third Party Fiduciary Agents' Scope on Grants Awarded to the Puerto Rico Department of Education:

The Government of Puerto Rico urges the Subcommittee to direct the Secretary of the U.S. Department of Education (ED) to commission an independent study to identify the scope of stipulations by third-party fiduciaries agent (TPFA), as well as establish specific timelines and conclusion of third-party oversight of Federal funds granted through ED to the PRDE. ED requires third-party fiduciary oversight, management, and administration of ED grant funds services to PRDE. PRDE's engagement of a TPFA is a specific condition established by ED for the receipt of grant funds. However, TPFAs have slowed the progress and recovery of schools throughout the island due to delay and uncertain deadlines. Following the displacements of students and teachers throughout the island as a result of this year's earthquakes, a thorough and specific scope of authority with established timelines is required for the expedient educational recovery of Puerto Rico.

The island-wide devastation suffered by Puerto Rico from Hurricanes Irma and Maria, as well as the recent earthquakes, present historic challenges to the 3.2 million U.S. citizens of Puerto Rico, the Caribbean economy, and the United States Government. A full recovery for Puerto Rico requires a sustained, comprehensive approach with support from the Federal Government to tackle the numerous issues we are now facing. On behalf of Puerto Rico, I thank you for your continued support and leadership in Congress. I have faith that with your support, Puerto Rico can and will make a full recovery.

If you require additional information or have any questions, please do not hesitate to contact me at jstoripan@prfaa.pr.gov.

Sincerely.

[This statement was submitted by Jennifer M. Storipan, Esq., Executive Director, Puerto Rico Federal Affairs Administration.]

PREPARED STATEMENT OF THE PULMONARY HYPERTENSION ASSOCIATION

Chairman Blunt, Ranking Member Murray and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the pulmonary hypertension (PH) community as you work to craft the fiscal year 2021 L–HHS Appropriations bill.

ABOUT PULMONARY HYPERTENSION

Pulmonary Hypertension (PH) is high blood pressure that occurs in the arteries of the lungs. It reflects the pressure the heart must apply to pump blood from the heart through the arteries of the lungs. As with a tangled hose, pressure builds up and backs up forcing the heart to work harder and less oxygen to reach the body. PH symptoms generally include fatigue, dizziness and shortness of breath with the severity of the disease correlating with its progression. If left undiagnosed or untreated it can lead to heart failure and death. In recent years, innovative treatment options have been developed and approved for PH. The effectiveness of current treatment options depends on accurate diagnosis and early intervention.

ABOUT PHA

Headquartered in Silver Spring, Md., the Pulmonary Hypertension Association (PHA) is the country's leading PH organization. PHA's mission is to extend and improve the lives of those affected by PH. PHA achieves this by connecting and working together with the entire PH community of patients, families, healthcare professionals and researchers. The organization supports more than 200 patient support groups; a robust national continuing medical education program; a PH clinical program accreditation initiative; and a national observational patient registry.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

Due to the serious and life-threatening nature of PH, it is common for patients to face drastic health interventions, including heart-lung transplantation. To ensure HRSA can continue to make improvements in donor lists and donor-matching please provide HRSA with an increase in discretionary budget authority in fiscal year 2021.

NATIONAL INSTITUTES OF HEALTH

Please provide NIH with meaningful increases—including at least $44.7 billion in program funding in fiscal year 2021—to facilitate expansion of the PH research portfolio so we can continue to improve diagnosis and treatment. NHLBI and PHA have partnered on a groundbreaking clinical study, the Redefining Pulmonary Hypertension through Pulmonary Vascular Disease Phenomics (PVDOMICS) program (RFA–HL–14–027 and RFA–HL–14–030). By collecting information from one thousand participants with various types of PH, and 500 participants without or at risk for PH, PVDOMICS hopes to find new similarities and differences between the current WHO classifications of PH, which could be a major step in learning about the disease and advancing patient care. This research is intended to lead to identification of both endophenotypes of lung vascular disease and biomarkers of disease that may be useful for early diagnosis or for assessment of interventions to prevent or treat PH.

PROPER HEALTH COVERAGE AND ACCESS

The PH community is concerned that the Centers for Medicare and Medicaid Services (CMS) is allowing insurance payers to refuse to accept charitable copay and premium assistance on behalf of patients with complex, chronic and life-threatening conditions like PH. Because of breakthroughs in research, PH patients are able to utilize life-sustaining treatments that allow them to manage this potential fatal condition and lead relatively normal lives. When patients are denied access to financial assistance they are forced to choose between necessities, between dramatically shortening their lives by giving up medication in order to afford housing and food or continuing medication while starting their families on the road to bankruptcy. We aware of the Subcommittee's continued requests for an explanation of this practice targeting rare disease patients. We ask that this Subcommittee once again ask CMS to explain this decisions and also encourage them to fix this problem that is greatly affecting the rare disease community.

PHA also asks the Subcommittee to urge CMS to increase incentives for the supply of oxygen that affects all oxygen modalities including both liquid and portable supplies. This increased flexibility will increase patient's quality of life at home and in their communities.

PATIENT PERSPECTIVES

Lori was approved for Social Security Disability Assistance 2 years ago as a result of her pulmonary hypertension. For the past 2 years, she has been in the "Medicare waiting period"—unable to work but not yet eligible for Medicare. Lori purchased coverage through her state's Health Insurance Marketplace during that time. Her plan fully covered the costs for her life-saving medication. Now Lori is finally eligible for Medicare, but she has been told that she will have to pay thousands of dollars each month for the same life-sustaining medication that was fully covered on her Marketplace plan. A financial grant from a non-profit organization may be Lori's only hope of making ends meet.

Diane has a genetic form of pulmonary hypertension. She has a younger sister with PH and they lost a brother to the disease. Recently, a generic version of one of the therapies Diane takes to manage her condition became available. Diane was automatically switched to the alternate version by her specialty pharmacy. Within a few weeks, Diane went from being able to comfortably walk more than seven miles a day to barely being able to walk a mile. She describes her health at that time as "just as bad as before I was diagnosed." Declines like the one Diane experienced are not always reversible. Fortunately, however, Diane appears to be regaining her normal level of functioning after returning to the original version of her therapy.

Before developing pulmonary hypertension, Doug was an architect specializing in historic preservation. Being an architect was the only thing he had ever wanted to do "when he grew up." Doug spent 2 years seeking an accurate diagnosis for his shortness of breath. During that time, he was misdiagnosed with depression, sleep apnea, altitude sickness and asthma. Ultimately Doug was diagnosed and treated, however he had to give up his career due to his PH.

Thank you again for your consideration of the PH community's priorities as you develop the fiscal year 2021 L–HHS Appropriations bill.

[This statement was submitted by Mr. Brad A. Wong, President and CEO, Pulmonary Hypertension Association.]

PREPARED STATEMENT OF REFUGEE COUNCIL USA

Chairman Shelby, Ranking Member Leahy, and members of the subcommittee, thank you for this opportunity to submit these funding and oversight recommendations for fiscal year 2021 on behalf of the 26-member organizations of Refugee Council USA (RCUSA)[1] dedicated to refugee protection, welcome, and integration, and representing the interests of refugees, refugee families, and volunteers and community members across the country who support refugees and resettlement. RCUSA recommends fiscal year 2021 funding levels of $4,692,446,000 for the Department of Health and Human Services' Refugee and Entrant Assistance (REA) account.

The REA account funds the Office of Refugee Resettlement (ORR) within the Administration of Children and Families. ORR funding provides critical Federal investments in the states and local communities that welcome refugees, and is a crucial component of fostering refugee integration and economic contributions. In addition to new refugee arrivals, ORR funding provides essential services to refugees who arrived in recent years, unaccompanied refugee minors, asylees, Cuban and Haitian entrants, Special Immigrants Visa (SIV) holders from Afghanistan and Iraq who served the U.S. mission in those countries, survivors of human trafficking, survivors of torture, and unaccompanied children. Through ORR programs and associated public-private partnerships, in fiscal year 2020 the account is projected to serve 171,420,[2] and in fiscal year 2021, 159,520.[3]

RCUSA recommends an increase for the Transitional Medical Assistance (TAMS) program; domestic and foreign-born trafficking survivor services; and, torture survivor assistance. TAMS funds critical initial assistance to refugees and other new arrivals; programs for vulnerable unaccompanied refugee children; and the highly effective Matching-Grant program, which leverages public funds with private donations, empowering refugees to secure employment within 6 months. RCUSA appreciates the small increase in funding from fiscal year 2020 to fiscal year 2021 for trafficking victims, to help serve trafficking survivors, given the 962 percent increase in identified victims in need of trauma-informed case management services since 2002.[4] RCUSA commends as a step in the right direction the increase in fiscal year 2019 and fiscal year 2020 to aid victims of torture, and yet the services gap remains extraordinary. Approximately 44 percent of the program's beneficiaries—refugees, asylees and asylum seekers—are torture survivors. Even with the increased appropriation many programs have wait lists and torture survivor populations across the country have no access to services at all. We urge continued increases for these urgent needs.

The U.S. is one of roughly 27 resettlement countries. The U.S. Refugee Admissions Program (USRAP) process begins with rigorous screening to determine that applicants qualify for refugee status and are not a security risk. The U.S. admits a small percentage of the world's refugees, often the most vulnerable, for resettlement (including unaccompanied refugee minors) through the USRAP. Refugees arriving through the USRAP, along with Iraqi and Afghan SIV recipients, are placed with one of nine voluntary nonprofit resettlement agencies that have signed a Cooperative Agreement with the State Department and have local affiliates in over 200 sites in communities around the country. Six of the nine voluntary agency networks are faith-based, and harness the energy of many faith communities to help welcome newcomers to their new communities. These community organizations ensure that a core group of services are provided during the first 30–90 days after a refugee's arrival, including the provision of food, housing, clothing, employment services, follow-up medical care, and other necessary services. After this initial period, ORR funds integration services through both the states and community partners around the country.

Once refugees arrive in the U.S., they are supported to become oriented to the community, learn English, enroll their children in school, and find employment. With this crucial support, they often are not only able to support themselves and their families but also become contributors to their new communities, integrating with and bringing innovation to our neighborhoods. The following highlights critical programs within the REA account, but does not include all program activities:

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[1] A list of RCUSA member organizations can be viewed at RCUSA.org.

[2] The FY20 figure includes: 18,000 refugees, 14,900 SIVs, 46,000 asylees, 22,520 Cubans/Haitians, 1,000 trafficking victims, and 69,000 unaccompanied children. We are on pace to assist 50,000 UCs, but trends indicate that the numbers could spike up to 69,000.

[3] The FY21 CBJ's figure includes: 90,520 new arrivals (incl. 18,000 refugees and 45,600 asylees). In addition, we estimate up to 69,000 UCs in FY21.

[4] This is based on the 2002 ORR report to Congress and the 2016 TIP report.

Transitional & Medical Services (TAMS)

Matching Grant Program: The Matching Grant Program, a public-private partnership, is ORR's most successful program to help refugees achieve early self-sufficiency. It empowers refugees and other eligible individuals to become self-sufficient within 6 months without needing to access Federal or state assistance programs. The program leverages public funds with private donations at a 2:1 ratio, with non-governmental agencies working hand-in-hand with local communities to match Federal government contributions with private resources.

Unaccompanied Refugee Minors: Unaccompanied refugee minors (URM) are among the most vulnerable of refugees, and the U.S. is the only country that permanently resettles them. URM have been lost or separated from their parents and families and have often suffered greatly not only in their home country but also in countries near their homelands where they have sought refuge. This is a small but crucial U.S. program to protect the most vulnerable of these at-risk children and provide them a new life in the U.S.

Refugee Support Services (RSS)

In fiscal year 2018, the Administration merged the administration of Refugee Social Services and Targeted Assistance into one new program, Refugee Support Services; Congress also continues to require funding for the Refugee Health Promotion program and ORR is providing it as an RSS set aside. Congress has not allocated less than $200 million cumulatively for these three programs in at least 15 years, not even taking inflation into account. RCUSA recommends a small increase in TAMS and RSS funding to account for cost of living, ongoing integration needs of ORR populations of concern, and to assure gap filling caused by reduced numbers of Reception and Placement sites.

RSS supports initial employability services and other integration services that address initial barriers to employment. It is provided to states and non-profit organizations based on formula pertaining to anticipated refugee and other arrivals and competitive grants. Additionally, school Impact funding, provided through a formula in the RSS program, supports impacted school districts with the funds necessary for activities, like English as a Second Language instruction, that will lead to the effective integration and education of vulnerable children.

RSS additionally, provides support to states with particularly high refugee arrivals, including via secondary migration, and services to refugees requiring longer term employment support. It also provides specialized services to meeting the unique needs of certain groups, such as youth programming and career development for higher skilled refugees looking to recertify in their field.

Finally, RSS supports critical healthcare investments by offering grants which helps refugees navigate the U.S. healthcare system. It is awarded competitively and helps fund State Refugee Health Coordinators, provide language access at Federal healthcare centers, and supports mental health screening of refugees, among other things. RCUSA strongly opposes the proposed elimination of RHP.

Survivors of Trafficking

Since the passage of the Trafficking Victims Protection Act in 2000, victims of human trafficking have received case management services through HHS's partnership with NGO providers, including assistance obtaining and referrals to medical and psychological treatment, housing, educational programs, life skills development, legal services, and other assistance. Funding is also utilized to promote public awareness, training, and coalition building to raise awareness about human trafficking among law enforcement, social services, medical staff, and other potential first responders, in addition to other to other faith-based and community groups. These grants are crucial to providing victims, including children, integrative aid and services once they have been identified as a victim of trafficking. Increased funding to $20 million for each domestic and foreign-born victim is requested to adequately serve trafficking survivors. This funding is critical due to the increases in victim identification efforts. In fact, there has been a 843 percent increase in the number of foreign-born individuals served by the program from 2003 to fiscal year 2016.

Survivors of Torture

The Services to Survivors of Torture grant program, which was first authorized with strong bi-partisan support in 1998 by the Torture Victims Relief Act (PL 105–320–OCT. 30, 1998), funds non-profit organizations to provide healing, legal, and social services to refugees, asylees and asylum seekers who endured torture abroad and now reside in the U.S. These holistic, trauma-informed services play a key role in helping survivors restore their dignity and health, rebuild their lives, and integrate into communities and economies. In particular, torture rehabilitation has proven to have significant positive impacts on employment and healthcare cost savings. RCUSA's proposed $28 million for torture survivor assistance reflects that many programs have wait lists and large survivor populations across the country have no access to services at all.

Unaccompanied Children (UCs)

In fiscal year 2017, 40,894 children were referred to the custody and care of the Office of Refugee Resettlement (ORR). ORR provides children in its care with food, shelter, and clothing as well as educational, medical, mental health, and case management services. For a limited number of children, ORR provides family reunification services by social services providers; specifically, "home studies" to help ensure children are released into safe placements and "post-release services" to facilitate family and community integration after reunification. Post-release social services by providers are an important means of assuring the continued well-being and adjustment of the children and preventing such dangers as human trafficking. Post-release services also help families to understand the child's legal obligations as well as provide critical protection and support to the families themselves as the children are integrated into their new communities. These practices not only promote child safety, but they can help reduce the need for involvement with the public child welfare system post-release. RCUSA recommends an increase to at least $1.983 billion in base UC funds for these programs that promote successful family reunification and stability, which serve the best interest of the children. RCUSA does not support an expansion of detention, including through use of large-scale institutional facilities, or efforts to support forced family separation.

Our nation's historic commitment to refugees through domestic resettlement provides lifesaving support and protection to the world's most vulnerable. Our nation's historic commitment to displaced populations helps us build strategic alliances and stabilize those regions most affected by the largest displacement crisis in global history. This helps keep America safe. Thank you for considering our funding recommendations for fiscal year 2021.

ORR Contingency Fund

Numerous times in the last decade, ORR has had to reprogram funds from within or outside the agency to maintain vital services for refugees, unaccompanied children and other populations of concern. This occurred for example in 2012 ($115 million), in 2014 ($94 million), in 2018 ($446 million), and in 2019 ($385 million). These major shortfalls in the last decade demonstrate that ORR and the vulnerable populations that it serves need stronger financial footing. To avoid future destabilizing reprogramming, RCUSA supports the Administration's request for a $2 billion contingency fund for UCs so that ORR can flexibly meet urgent and unanticipated needs of the vulnerable populations that it serves. However, RCUSA requests that the $2 billion be available for ORR to utilize in a single year and that $100 million of the contingency fund go toward replenishing the TAMS and RSS programs. To the extent Congress does not appropriate an ORR contingency fund, Congress should ensure that the $2 billion is added to base funding for UCs.

RCUSA Urges Congress to Support Stabilization of Resettlement Infrastructure

Finally, RCUSA urges Congress to encourage the Office of Refugee Resettlement (ORR) to ensure that resettlement agencies are able to maintain their infrastructure and capacity to continue to serve refugees and other populations of concern. RCUSA also expresses concern that the administration failed to conduct appropriate consultation with Congress regarding the fiscal year 2020 Presidential Determination and direct a report to assess the impact that the extended moratorium on refugee arrivals had on refugees in the pipeline. RUCSA urges Congress to hold the administration accountable in meeting the fiscal year 2020 Presidential Determination of 18,000, and returning the refugee admissions ceiling to the historic average of 95,000 in fiscal year 2021.

FY 2021 Office of Refugee Resettlement Funding Needs for the Refugee and Entrant Assistance (REA)Account

Program Areas	FY 2020 Enacted Funding	FY 2021 President's Request	FY 2021 RCUSA Needs Assessment *Assuming continued policies of incumbent Administration*[5]
Transitional & Medical Assistance (TAMS)	$354,000,000	$278,559,000	$404,000,000
Refugee Support Services (RSS)	$207,201,000	$150,821,000	$237,201,000
Subtotal (Resettlement Services)	**$561,201,000**	**$429,000,000**	**$641,201,000**[6]
Foreign-Born Trafficking Survivor Assistance	$19,500,000[7]	$27,755,000	$20,000,000
Domestic Trafficking Survivor Assistance	$8,255,0000[8]		$20,000,000
Services for Survivors of Torture Program	$16,000,000[9]	$16,000,000	$28,000,000
Unaccompanied Children	$1,303,245,000[10]	$1,983,245,000	$1,983,245,000
Supplemental/Contingency[11]	$0[12]	$2,000,000,000[13]	$2,000,000,000
Total	**1,908,201,000**	**$4,456,000,000**	**$4,692,446,000**

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[5] Given the number of refugees awaiting processing, including those already approved, RCUSA estimates that the U.S. could resettle up to 100,000 refugees in FY21 if there is a return to historic norms in terms of refugee resettlement policies and numbers. RCUSA's needs assessment in that scenario would be a resettlement services subtotal of $1.64 billion including $1.04 billion for TAMS and $528.6 million for RSS, both based on FY17 figures accounting for similar arrival projections, as well as $66.5 million that was reprogrammed in FY12 and never replenished.

[6] RCUSA recommends at least a 14% increase in TAMS and RSS funding to account for cost of living, ongoing integration needs of ORR populations of concern, and to assure gap filling caused by reduced numbers of Reception and Placement sites.

[7] RCUSA appreciates the small increases in funding for trafficking victims in FY19 and FY20, to help serve trafficking survivors, given the 962% increase in the number of victims identified and certified in need of services since 2002, based on the 2002 ORR report to Congress and the 2016 Trafficking in Persons (TIP) report.

[8] RCUSA recommends at least a small increase in domestic TIP funding to account for cost of living and increases in victims identified.

[9] RCUSA commends as a step in the right direction the increase in FY19 and FY20 to aid victims of torture, and yet the services gap remains extraordinary. Approximately 44% of the program's beneficiaries—refugees, asylees and asylum seekers—are torture survivors. Even with the increased appropriation many programs have wait lists and torture survivor populations across the country have no access to services at all. We urge continued increases for these urgent needs.

[10] RCUSA recommends at least $1.983 billion in base UC funds, based on relatively small increases beyond the actual ORR spending. Beyond the $1.3 billion enacted funds for UC in FY18, ORR transferred or reprogrammed an additional $463 million: $266 million (*CNN, 9/5/18*) from an internal LHHS transfer, $180 million (*Washington Post, 9/21/18*) from discretional health fund, and $17 million (*Newsweek, 7/19/18*) from funds that had been transferred but unspent in FY17. Then in FY19, beyond the $1.3 billion enacted for UC, HHS transferred or reprogrammed an additional $385 million (*The Hill, 3/8/19*) including $99 million in ORR funds.

[11] Even while being on track for $1.8 billion in spending for UC in FY19, Congress added $2.88 billion in emergency funds in FY19. RCUSA urges maintaining at least a total of $2 billion beyond $1.8 billion base funding for ORR to assure ORR can deal with large spikes in arrivals, such as the one that occurred as recently as 2019 with 69,000 UC. This chart shows it as a contingency fund. Another option would be to appropriate it as part of base funding for UC, i.e., as $3.983 billion.

[12] Funding for ORR from the FY 2019 Supplemental was authorized until spent, with much of the spending occuring in FY 2020.

[13] Over a three-year period.

PREPARED STATEMENT OF THE REGIONAL CENTERS OF EXCELLENCE IN VECTOR-BORNE DISEASES

Dear Chairman Blunt and Ranking Member Murray:

On behalf of the Regional Centers of Excellence in Vector-Borne Diseases, we the undersigned write to express our strong support for efforts related to vector-borne diseases (VBDs) at the Centers for Disease Control and Prevention (CDC). We urge you to provide at least $8.3 billion for CDC in the fiscal year 2021 Labor, Health and Human Services, Education, and Related Agencies appropriations bills, with full funding for VBD efforts authorized by the Kay Hagan TICK Act and the Pandemic and All Hazards Preparedness and Advancing Innovation Act.

Many notorious public health threats, such as the pathogens which cause Lyme disease, Zika, West Nile, and malaria, are transmitted by tick and mosquito arthropod vectors. Between 2004 and 2016, reported human cases of diseases transmitted through the bites of arthropod vectors tripled in the United States. Disease vectors also pose significant threats to both livestock and companion animals. These issues stem from not only native ticks and mosquitoes, but also the introduction of new species to our communities, as evidenced by the recent identification of the invasive Asian longhorned tick in the eastern US.

The five Regional Centers of Excellence in Vector-Borne Diseases were established by the CDC in December 2016 to support our public health infrastructure aimed at combatting these threats. We conduct applied research to develop and validate effective prevention and control tools to respond to VBD outbreaks, train current and future public health entomologists in the skills required to address VBD threats, and support effective collaborative relationships between academic and public health communities across our regions. Solutions to addressing the growing menace of VBDs in the United States are complex and require robust, dedicated, and sustained funding now more than ever.

As your subcommittee considers fiscal year 2021 funding levels for CDC, the Regional Centers of Excellence in Vector-Borne Diseases encourage you to include at least $66.195 million in funding for the CDC's Division of Vector-Borne Diseases (DVBD), as was proposed in the President's Budget Request for fiscal year 2021, to support VBD prevention, surveillance, testing, and response activities.

Our collaborative networks applaud the recent passage of the Kay Hagan TICK Act, a provision in the fiscal year 2020 Further Consolidate Appropriations Act, H.R. 1865, signed into law by the President on December 20, 2019 (Public Law 116–94); and the Pandemic and All Hazards Preparedness and Advancing Innovation Act, which in Section 607, Strengthening Mosquito Abatement for Safety and Health (SMASH), details support for important mosquito abatement activities. Providing the full level of funding authorized by these important pieces of legislation would be highly effective in facilitating the development and implementation of a national strategy to combat VBDs.

The Kay Hagan TICK Act authorizes $20 million to support the CDC Epidemiology and Laboratory Capacity (ELC) grant program. The ELC program is particularly important for efforts related to the surveillance, detection, response, and prevention of infectious diseases, including VBD. Last year the CDC's DVBD received requests for nearly $50 million from the state departments of health for VBD through the ELC program. However, the DVBD was only able to support $18.2 million, roughly a third of the needed resources to address VBDs across the nation.

The Kay Hagan TICK Act also authorizes $10 million per year to support the continuation of our five Regional Centers of Excellence in Vector-Borne Disease programs. Continued support will allow us to build on the successes achieved since 2016 in supporting surveillance efforts, translating research findings and information into public health action, and promoting outreach and education to empower our communities.

The CDC is the first line of defense for our nation's health, safety, and security, and it is crucial that the agency has the resources it needs to protect Americans from serious threats like VBDs. On behalf of our collaborative network of stakeholders invested in the mission to reduce the ongoing as well as emerging threats posed by ticks, mosquitoes, and other arthropod vectors, we thank you for your commitment to this critical issue.

Sincerely,

Lyric Bartholomay, PhD, Program Co-Director
Susan Paskewitz, PhD, Program Co-Director
Midwest Center of Excellence for Vector-Borne Diseases
Laura C. Harrington, PhD, Program Director
Northeast Regional Center for Excellence in Vector-Borne Diseases
Christopher M. Barker, PhD, Program Co-Director
William Walton, PhD Program Co-Director
Pacific Southwest Center of Excellence in Vector-Borne Diseases
Rhoel R. Dinglasan, PhD, MPH, Program Director
Southeastern Center of Excellence in Vector-Borne Diseases
Scott C. Weaver, PhD, Program Director
Western Gulf Center of Excellence for Vector-Borne Diseases

PREPARED STATEMENT OF RESEARCH!AMERICA

On behalf of Research!America and our alliance, which advocates for science, discovery, and innovation to achieve better health for all, thank you for this opportunity to submit testimony to the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies on fiscal year 2021 appropriations. We are grateful that for fiscal year 2020, the base budgets of the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and the Agency for Healthcare Research and Quality (AHRQ) were increased and the Subcommittee additionally provided dedicated funding for critical research programs. We again ask that you provide increased funding for NIH (least $44.7 billion), CDC ($8.3 billion), and AHRQ ($471 million) in fiscal year 2021.

THE NATIONAL INSTITUTES OF HEALTH

Each year, more than 125,000 Americans lose their lives by age 45 to physical and mental illness. Because personal loss is a tragedy, not a statistic, it is impossible to fully capture the devastating impact of so many lives cut short. However, it is possible to deploy science to successfully fight back. The research that NIH funds delivers health, social, and economic benefits that endure and multiply as time goes on. With the current level of investment, NIH is only able to fund 20 percent of the meritorious grant proposals it receives. The steadfast commitment of Federal policymakers from both sides of the aisle to rebuild the NIH budget over the past decade has helped restore our nation's place at the cutting edge of medical progress. It is essential that we keep up that mantle and gain the upper hand over diseases that rob us of time, independence, and loved ones.

The NIH is the world's leading funder of basic biomedical research, and Americans recognize the value this research delivers. According to a national survey Research!America commissioned in January 2020, 88 percent of Americans believe it is important for Congress and the President to assign a high priority to faster medical progress. As it stands, our nation spends about 5 cents of each health dollar on research to prevent, cure and treat disease. Some 61 percent of Americans say that this level of investment is not enough. Americans want medical progress, and they want the U.S. to do more to drive it.

More than 80 percent of NIH funding is awarded through almost 50,000 competitive grants to more than 300,000 researchers at over 2,500 universities, medical schools, and other research institutions in every state. Research supported by NIH is typically at the early, non-commercial stages of the research pipeline; NIH funding works in tandem with critical private sector investment and development while delivering significant economic benefits. Basic research funded by the NIH fuels the entry of new drugs into the market, providing an estimated return on public investment of $1.43 for every dollar invested. The Human Genome Project has produced $1 trillion of economic growth—a 178-fold return on investment. The NIH also plays an integral role in educating and training America's future scientists and medical innovators by sponsoring fellowships and training grants.

NIH advances the interests of America and Americans in other crucial ways. For example, NIH is funding a new genome center for the All of Us Research Program, which will enable researchers to better understand the value, including the strengths and limitations, of long-read sequencing as it relates to exploring more elusive parts of the genome. The Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative, of which NIH is a part, is aimed at revolutionizing our understanding of the human brain. The Initiative is working to accelerate the development and application of innovative technologies, through which researchers will be able to draw a new picture of the brain that, for the first time, shows how individual cells and complex neural circuits interact in both time and space.

We believe it is in the strategic interests of the U.S. to increase funding for NIH to at least $44.7 billion in fiscal year 2021, an increase of $3 billion over fiscal year 2020 enacted. Research!America believes this funding increase is warranted by the ever-growing magnitude of our health challenges, including the ongoing COVID–19 pandemic, the tangible and intangible costs of inaction, and the undeniable return on medical progress.

THE CENTERS FOR DISEASE CONTROL AND PREVENTION

We urge you to fund the Centers for Disease Control and Prevention (CDC) at a level of $8.3 billion in fiscal year 2021, a 4.8 percent increase. As demonstrated by the ongoing COVID–19 pandemic, public health threats do not respect international borders, and in our increasingly globalized world, we are more vulnerable than ever to emerging, deadly infectious diseases.

CDC's work is also crucial to combating the opioid epidemic, which is claiming approximately 130 American lives each day, and to tackling antimicrobial resistance. Our public health surveillance infrastructure is vital to a secure and prosperous future for our nation as are our roads and highways—we cannot afford to ignore it.

CDC is tasked with protecting and advancing the nation's health, and over the past 70 years it has worked diligently to thwart deadly outbreaks, costly pandemics, and debilitating disease. Moreover, CDC plays a key role in research that leads to life-saving vaccines, bolsters our nation's defense against and response to bioterrorism, and improves health tracking and data analytics. CDC's work has benefited Americans in myriad ways, including investigating an outbreak of acute lung injury from use of e-cigarette or vaping products, supporting our national surveillance infrastructure to detect and prevent antimicrobial resistant infections, providing accurate and accessible health information, and preventing millions of hospitalizations.

Ebola, Zika, influenza, the opioid epidemic, measles outbreaks, and, most recently, the ongoing, novel COVID–19 outbreak have shown just how critical CDC is to the health of our nation and have also revealed the enormity of the challenge the agency faces as it works to safeguard American lives. To protect us, CDC scientists must be on the ground fighting public health threats wherever and whenever they occur. But there is a growing gap between the funding provided to CDC and the demands and challenges placed before the agency. We request that CDC receive at least $8.3 billion in fiscal year 2021, $380 million over fiscal year 2020 enacted, to carry out its crucially important responsibilities.

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

AHRQ is the lead Federal agency that is tasked with making sure our nation is not just making medical progress but that this progress translates into more effective, efficient, and affordable healthcare for Americans across the country. The health services research that AHRQ conducts and supports has reduced medical errors, ensured that providers in rural areas have the same access to cutting-edge medicine as those in urban areas, identified ways to squeeze out costly duplication and waste from the healthcare system, and benefited patients and taxpayers in numerous other ways. AHRQ has historically been grossly underfunded relative to the need and potential for cost- and life-saving improvements in American healthcare delivery. We urge you to fund AHRQ at a level of $471 million, a 39 percent increase over fiscal year 2020 enacted, in fiscal year 2021.

AHRQ is one of the Federal agencies responsible for ensuring medical progress translates into better patient care. The value of medical discovery and development hinge on smart healthcare delivery. Out of the $3.82 trillion in annual spending on healthcare, an estimated 25 percent could be prevented by addressing errors and inefficiency.

AHRQ-funded research identifies and addresses this waste of limited healthcare dollars, empowering patients to receive the right care at the right time in the right settings. For example, AHRQ-funded research has helped identify methicillin-resistant Staphylococcus aureus (MRSA), which causes 80,000 invasive infections each year in the U.S., in long-term care facilities to address the increase of hospital patients affected by healthcare-associated infections. This research showed that MRSA infections and hospitalizations were reduced by 30 percent in patients using a treatment that cleansed the bacteria from their skin or noses. AHRQ-funded research has played a pivotal role in reducing hospital-acquired conditions by nearly 1 million from 2014–2017, saving lives and $7.7 billion in healthcare costs.

AHRQ is a nimble and critical healthcare investment. If we underinvest in AHRQ, we are inviting unnecessary healthcare spending and wasting the opportunity to ensure patients receive the quality care they need.

We appreciate your consideration of our funding requests and thank you for your stewardship over these critically important Federal spending priorities.

Sincerely.

[This statement was submitted by Mary Woolley, President and CEO, Research!America.]

PREPARED STATEMENT OF THE RESTLESS LEGS SYNDROME FOUNDATION

Chairman Blunt, Ranking Member Murray, and distinguished members of the Subcommittee, as you work to develop the fiscal year 2021 Labor-Health and Human Services Appropriations bill, thank you for considering the views of the community of physicians, researchers, patients, and caregivers affected by Restless Legs Syndrome (RLS). Please keep the needs of this community in mind, especially as you continue to work to address the opioid crisis.

ABOUT THE RLS FOUNDATION

The Restless Legs Syndrome Foundation is a nonprofit § 501(c)(3) organization dedicated to improving the lives of men, women, and children living with this often-devastating neurological condition. The Foundation works to increase awareness, improve treatments, and support research to find a cure. From a few volunteers meeting in a member's home in 1992, the Foundation has grown steadily; it now has members in every state, local support groups, and a track record that includes over $1.8 million provided to support translational research.

ABOUT RLS

Restless legs syndrome (RLS) is essentially an irregular biological drive, like hunger or thirst, that forces affected individuals to keep moving, thus reducing their ability to rest. Patients with this disease experience a deep, viscerally-irritating sensation in the legs that continues to increase until they are literally forced to move their legs or get up and walk; and this sensation only abates so long as the individual keeps moving. RLS is best characterized as a neurological, sensory-motor disorder with symptoms that are triggered from within the brain itself. It is estimated that up to 5 to 7 percent of the U.S. population may have RLS, of which half will have moderate to severe stages of the disease. RLS impacts men, women, and children, though it is 3 to 4 times more common in women and twice as common in older Americans.

Due to the inability to sleep and work, RLS can cause disability, depression, and suicidal ideation, as well as increased risk for co-morbid conditions such as heart attack, stroke, and Alzheimer's. There is no cure, and the current standards of care features several medications, which do not provide life-long coverage. One of the established effective treatment options for this disease is low-total daily dose opioid medications. These are commonly used when all other drug classes have failed. Research and clinical experience indicates that the dose of opioids typically used to manage RLS effectively without addiction or drug tolerance issues is significantly lower than dosages used to treat chronic pain.

FISCAL YEAR 2021 APPROPRIATIONS RECOMMENDATIONS

The RLS Foundation joins the broader medical research community in thanking Congress for continuing to support the National Institutes of Health with sustainable growth. Please continue to advance scientific progress through proportional funding increases by providing at least a $3 billion funding increase for fiscal year 2021 to bring NIH's budget up to $44.7 billion.

In this regard, please provide proportional funding increases for all NIH Institutes and Centers, including, but not limited to the National Institute of Neurological Disorders and Stroke (NINDS), the National Heart, Lung, and Blood Institute (NHLBI), the National Institute on Drug Abuse (NIDA), and the National Institute of Mental Health (NIMH). Research on RLS and similar neurological movement disorders is directly related to efforts targeting the opioid epidemic, as many patients with these disorders utilize very low total daily doses of opioid therapies to manage their condition. Additionally, related sleep disorders research activities impact many conditions and are studied across various Institutes and Centers at NIH.

RLS AND THE OPIOID CRISIS

While you consider the Committee's work to address the opioid epidemic through this fiscal year's appropriations bill, the RLS Foundation asks that you protect the needs of patient communities who depend on appropriate access to low total daily doses of opioid therapies to manage their debilitating condition. RLS is not a chronic pain condition, and many in our community utilize these medications to treat underlying neuropathology issues and not sensations of pain. Studies have shown that appropriate access to these therapies allows patients to live productive lives without an increased risk of developing opioid use disorder. As you consider various legislative proposals and work with Federal agencies, please consider the needs of patients who rely on the regular use of low total daily doses of opioids to manage RLS by supporting a diagnosis-appropriate safe harbor for RLS patients, so they do not face arbitrary barriers.

I would like to share with you the experience of Lewis M. Phelps from California, a 76 was 76-year old member of the RLS Foundation and former chairman of the RLS Foundation board of directors.

"I have had RLS for more than 30 years. After many years of treatment by doctors around the country (as I moved for professional purposes), I finally got decent control over my symptoms about 10 years ago with Mirapex, a dopamine-enhancing drug. Unfortunately, that didn't last. Over time, I began to experience what RLS experts call "augmentation," which means that the symptoms not only return, they are stronger, they start earlier in the day, and they affect more of my body. The doctor's response was to increase my dosage and keep adding additional drugs that he thought might help. That just kept making things worse. Finally, I consulted with a physician in my area who is one of the nation's leading experts on RLS. 'Lew,' he said, 'you are the poster child for augmentation. We need to get you off dopamine drugs.' He immediately withdrew me from all of the drugs I was taking and started me on a low daily dose of methadone. It has been amazingly helpful for me. My RLS symptoms are completely controlled. I have been on the same dose ever since I started on Methadone 5 years ago. I have no side effects. Methadone has made it possible for me to live a normal life again."

It's worth noting that the cost of my monthly drug treatment has fallen from $600 per month to less than $40 per month with this approach. Methadone is not only much more effective for treating my RLS, it is much more cost-effective.

"The only problem I have right now is that pharmacists are becoming afraid to fill my prescription, even though it is for only 10 mg of methadone per day—far lower than the maximum safe dose level. Over-reaction to the opioid crisis by the medical and pharmaceutical industries, and by some regulators, is very worrisome to me. I know from personal contacts that many people who suffer from RLS can't get an opioid prescription, even when they have no other viable alternatives. If I were to lose access to methadone, my life would become living hell. There are no other medications available that will prevent me from suffering very badly with RLS."

Lew's story is emblematic of the need for increased medical research, access to treatment, professional education, and public awareness. Thank you for your time and consideration of our requests.

[This statement was submitted by Karla M. Dzienkowski, RN, BSN, Executive Director, Restless Legs Syndrome Foundation.]

PREPARED STATEMENT OF JENNIFER D. ROSE

Dear Senators,

I am writing as the sister of a 29-year-old man who is suffering and disabled by his severe Bipolar 1 illness.

My brother is a deeply good and kind person, and works hard to collaborate with his psychiatrist and other medical professionals.

He is very consistent with medications, and yet—despite all his efforts and the support of his family—he continues to suffer profoundly from his bipolar illness. The medications he is on have terrible side-effects (diarrhea, nausea, confusion, headaches, depression, etc.) and yet he chooses to suffer through them because he prioritizes his brain's stability.

These past few weeks (despite the fact that he has been in therapeutic range for his lithium) as the result of another prescribed medication, he ended up in a severe manic episode that led to him going missing for 12 hours this past weekend. This was horrific for my family, as he was without sleep for roughly 96 hours and was experiencing severe psychosis, lost touch with reality, and vulnerable to risk-taking behaviors.

Again, this is a person who is trying to be well and stay well, and has the unwavering support of his family. During his episode, four of his family members, including myself, ensured he was consistently taking his meds, which he could not handle on his own due to confusion and loss of focus.

We are lucky he is still alive and was voluntarily admitted into a psychiatric hospital.

We should not have to rely on being "lucky." This is a profoundly painful, horrifying and disabling illness, and individuals and families like ours are not receiving enough basic support to survive this kind of illness. Medications are not anywhere near where we need them to be, and the only medication that works well for my brother (lithium) has long term implications for his thyroid and kidneys. We need better options for medications with fewer side effects.

Without question, we need more research for the cure and treatment of serious mental illness. This is a top priority.

I am urging NIMH's priority to be focused on the cures and treatment for serious mental illnesses like schizophrenia and bipolar.

Sincerely.

PREPARED STATEMENT OF ROTARY INTERNATIONAL

Chairman Blunt, members of the Subcommittee: Rotary appreciates the opportunity to encourage continuation of funding for fiscal year 2021 to support the polio eradication activities of the U.S. Centers for Disease Control and Prevention (CDC). The CDC is a spearheading partner of the Global Polio Eradication Initiative (GPEI), an unprecedented model of cooperation among national governments, civil society and UN agencies which reach the most vulnerable children through the safe, cost-effective polio immunization. Rotary International requests the Subcommittee provide $176 million for the polio eradication activities of the CDC—level funding—to ensure we end polio transmission, protect polio free areas, and leverage the resources developed through this global effort for value-added impact.

The 325,000 members of Rotary clubs in the US appreciate the United States' generous support and longstanding leadership. Rotary, including matching funds from the Gates Foundation, has contributed more than US$2.1 billion and thousands of hours of volunteer service to protect children from polio; and will continue this work until the world is certified polio free. Continued US leadership remains vital to achieve the goal of a polio free world and ensure that the investment in polio eradication infrastructure and resources lives on to benefit other health efforts.

PROGRESS IN THE GLOBAL PROGRAM TO ERADICATE POLIO

Since the launch of the GPEI in 1988, eradication efforts have led to more than a 99.9 percent decrease in cases. Over 18 million people have been spared disability, and over 900,000 polio-related deaths have been averted. In addition, more than 1.5 million childhood deaths have been prevented, thanks to the systematic administration of Vitamin A during polio campaigns.

Type 2 (WPV2) was declared eradicated in September 2015 and the certification of the eradication of wild poliovirus type 3 (WPV3) was announced in October 2019. Eradicating strains of the polio virus is further proof that a polio-free world is achievable.

Only two countries, Afghanistan and Pakistan, confirmed cases of wild polio in 2019. Wild poliovirus type 1 caused all the wild virus cases and these are found in high risk areas of

Afghanistan (29 cases) and Pakistan (146 cases). Nigeria, which experienced an outbreak in 2016, has not confirmed any new cases since August of 2016 despite humanitarian crises. It has now been more than 3 years since the last case of wild polio in Africa, paving the way for that region to be the next to be certified free from wild polio virus.

2019 also saw several outbreaks due to genetically-distinct circulating vaccine-derived poliovirus type 2. These outbreaks are not a failure of the vaccine, but result from a failure to sustain sufficiently high levels of routine immunization which causes the live, but weakened form of the virus used in the vaccine to revert over time to a more virulent, wild-like form.

The combination of progress in the midst of challenges underscores the urgency of continued focus to stop polio virus transmission in these most complex environments while sustaining high levels of population immunity in polio free areas. Continued support for global surveillance is also essential to monitor and detect cases and virus transmission and also provide confidence in the absence of cases.

CDC'S VITAL ROLE IN GLOBAL POLIO ERADICATION PROGRESS

The United States is the leader among donor nations in the drive to eradicate polio globally.

Congressional support has enabled CDC to provide the following:

—Provide $66.6 million to WHO for surveillance, technical staff and immunization activities' operational costs, primarily in Africa; and $3 million to UNICEF to support operational costs for National Immunization Days (NIDs) in all polio-endemic and outbreak countries.

—Provide $28.3 million to UNICEF for the expansion of a Community Based Vaccinator Program in Pakistan that now includes over 24,000 workers (nearly 90 percent of which are women) who reach 4 million children annually with approximately 60 million doses of oral polio vaccine, and 2.9 million doses of inactivated polio vaccine.

—Train global virologists in advanced poliovirus research and public health laboratory support. CDC's Atlanta laboratories serve as a global reference center and training facility.

—Support the international assignment of 19 technical staff on direct, 2-year assignments to WHO and UNICEF to assist polio-endemic and polio-reinfected countries.

—Provide technical leadership through three international polio consultants in Pakistan and one in Afghanistan; and build capacity through eight national polio consultants in Afghanistan.

—Assign 489 public health professionals who completed CDC's Stop Transmission of Polio (STOP) training program to support critical national immunization functions in 42 at-risk countries in 2018. In 2019, the STOP program deployed 254 professionals to 42 countries.

—Train 339 staff at the Local Governing Area level in the highest risk states of Nigeria in CDC's National STOP program. These staff play a key role in interrupting transmission of wild polio. Nigeria's polio legacy planning will transition those workers to build lasting improvements in Nigeria's immunization system.

—CDC has also trained 83 NSTOP officers in high risk districts in Pakistan who support the tracking of high risk and mobile populations.

The CDC also provides the following global surveillance, virologic and other technical expertise:

—Provides expertise in virology, diagnostics, and laboratory procedures, including quality assurance, and genomic sequencing of samples obtained worldwide.

—Houses the leading specialized polio reference lab in the world which provides the largest volume of operational (poliovirus isolation) and sophisticated (genetic sequencing of polio viruses) lab support to the 146 laboratories of the global polio laboratory network.

—Provides scientific and technical expertise to WHO on research issues regarding: (1) laboratory containment of wild poliovirus stocks following polio eradication, and (2) when and how to stop or modify polio vaccination worldwide following global certification of polio eradication.

—Leads the efforts to raise awareness of the importance and urgency of transition planning amongst donors, country governments and other stakeholders to begin polio legacy planning to ensure that key polio functions, including immunization, comprehensive vaccine-preventable disease surveillance, outbreak response and biocontainment, will be in place post-eradication.

In 2019, CDC also collaborated with Voice of America (VOA) to produce programs with scientifically accurate information about polio and the need for vaccinations to fight against early childhood diseases. The programs address identified vaccine issues and concerns through radio and television programming formats, including PSA's, radio dramas (if feasible), and field news reports to millions of Pashto-speaking Afghans and Pakistanis. VOA also trains journalists on "best practices" in covering polio, tracks stories written and compiles data for monitoring and evaluation.

Rotary and GPEI partner agencies are working with CDC to assess use of polio assets, consisting of thousands of polio workers and an extensive laboratory and surveillance network, while continuing critical polio eradication activities to the extent possible to avoid backsliding during the current 2020 COVID–19 pandemic response. Rotary is confident that CDC's commitment to polio eradication is firm and knows that CDC's polio eradication program operates in some of the most vulnerable places in the world, the agency is determined to do its part in defeating the COVID–19 pandemic.

FISCAL YEAR 2021 BUDGET REQUEST

We respectfully $176 million in fiscal year 2021 for the polio eradication activities of CDC, the level appropriated by Congress in fiscal year 2020. With Congress' continued support for polio eradication in fiscal year 2021, CDC's priorities are to stop virus transmission in the remaining polio endemic and outbreak countries; reaching all children, particularly those in high risk areas with vaccine, and support rapid case response. CDC will also continue to work to strengthen surveillance for polioviruses. CDC also continues planning for a post-polio transition to advance additional global vaccine-preventable diseases (VPD) control and elimination/eradication targets as outlined in CDC's Strategic Framework for Global Immunization 2016–2020.

BENEFITS OF POLIO ERADICATION

Since 1988, tens of thousands of public health workers have been trained to manage massive immunization programs and investigate cases of acute flaccid paralysis. Cold chain, transport and communications systems for immunization have been strengthened. The global network of 146 laboratories and trained personnel established by the GPEI also tracks measles, rubella, yellow fever, meningitis, and other deadly infectious diseases and will do so long after polio is eradicated.

Besides the savings of more than $27 billion in health costs that has resulted from eradication efforts since 1988, a sustained polio free world will generate $14 billion in expected cumulative cost savings by 2050, when compared with the cost countries will incur for controlling the virus indefinitely. Polio eradication is a cost-effective public health investment with permanent benefits. On the other hand, as many as 200,000 children could be paralyzed annually in the next 10 years if the world fails to capitalize on the more than $17 billion already invested in eradication. Success will ensure that the significant investment made by the US, Rotary International, and many other countries and entities, is protected in perpetuity.

[This statement was submitted by Anne L. Matthews, Chair, Rotary's Polio Eradication Advocacy Task Force.]

PREPARED STATEMENT OF THE RYAN WHITE MEDICAL PROVIDERS COALITION

Chairman Blunt, Ranking Member Murray, and members of the Subcommittee my name is Dr. Ernie-Paul Barrette, and I serve as Medical Director of the HIV Clinic for the Washington University School of Medicine, in St. Louis, Missouri, the largest providers of medical care for patients with HIV/AIDS in Missouri. I am pleased to submit testimony on behalf of the Ryan White Medical Providers Coalition (RWMPC), a national coalition of medical providers and administrators who work in healthcare clinics supported by the Ryan White HIV/AIDS Program in the HIV/AIDS Bureau (HAB) at the Health Resources and Services Administration (HRSA).

I want to thank the Subcommittee for increasing funding in fiscal year 2020 for both the Ryan White Program and the Bureau of Primary Health Care at HRSA by funding the bipartisan Ending the HIV Epidemic (ETE) initiative. Supporting the ETE initiative will help target jurisdictions scale up their ability to end the HIV epidemic by increasing access to HIV testing, prevention, care, and treatment services critical to reducing HIV transmission. However, increasing support for the Ryan White Program now would help jurisdictions nationwide continue to address ending the HIV epidemic while also meeting the new challenges COVID–19 presents. For fiscal year 2021, RWMPC requests $225.1 million (a 10 percent or $24 million increase) for Ryan White Part C, which supports approximately 350 HIV medical clinics nationwide. RWMPC also requests $500 million across the parts of the Ryan White Program in the next COVID–19 response bill to respond to a range of urgent patient and provider needs during the COVID–19 pandemic.

Additionally, RWMPC supports the Administration's fiscal year 2021 request for additional resources for the ETE initiative to expand access to HIV prevention, care, and treatment. RWMPC continues to supports the fiscal year 2021 ETE proposal that includes $302 million for HRSA, including $165 million for the Ryan White Program to provide additional HIV care and treatment, as well as $137 million for the Bureau of Primary Health Care to support HIV prevention services, including providing Pre-Exposure Prophylaxis (PrEP), medication to prevent HIV.

It is especially important now that any fiscal year 2021 increases for Ryan White Part C or for the ETE initiative be new, additional funding and not a repurposing of current resources. The additional pressure that the COVID–19 epidemic is placing on the public health infrastructure and medical facilities, including Ryan White clinics, is significant and limited resources cannot be further stretched. As of May 14, 2020, the Barnes Jewish Children's hospital network (of which my institution is a member) has completed 21,667 COVID–19 tests with 2,596 positives (12 percent). Almost 30 percent of the COVID–19 positive patients were admitted and discharged home. COVID–19 is a critical reason to strengthen the public heath infrastructure and medical clinics serving people living with HIV. Ryan White clinics are being pulled into wider COVID–19 response as experts in infectious diseases, while caring for vulnerable patients.

Finally, as successful HIV prevention for individuals at risk for HIV is available now through education, routine HIV screening, and ready access to PrEP, post-exposure prophylaxis (PEP), harm reduction services, and other prevention tools, both known and yet to be discovered, RWMPC supports HRSA/HAB to allow Ryan White

Program grantees to use their program income to reduce new HIV infections and for services that improve care and treatment outcomes for people living with HIV as long as the use of that program income does not reduce access to current or critical HIV care and treatment services provided by the grantee.

How the Ryan White Program is Responding to the COVID–19 Pandemic

Ryan White Program providers and community-based organizations nationwide are on the frontlines of the COVID–19 pandemic, and they need additional funding both in fiscal year 2021 and in the next COVID–19 response bill to meet the pressing current needs of their patients and clients. Ryan White clients are both vulnerable to the dangers of COVID–19 infection given their HIV status as well as low income—in 2018, more than 61 percent of Ryan White Program clients were living at or below 100 percent of the Federal Poverty Level. The health and economic dangers of COVID–19 impact every aspect of patients' lives. Ryan White clinics nationwide have shifted care to telehealth to protect patients during the pandemic but providing access to phones with sufficient minutes for patients and telehealth equipment for providers and clinics has been an immediate cost that clinics must support. Additionally, clinics are providing significantly more case management services to support a growing number of patients who are experiencing increased or new impoverishment from the dramatic economic downturn over the last 2–3 months. Ryan White programs are covering new costs, including medications (prescription as well as over-the-counter medications to help treat COVID–19), behavioral health services, and access to basic necessities, such as food and shelter that is appropriate during COVID–19.

As infectious diseases experts, Ryan White program teams are on the frontlines of both the HIV and COVID–19 pandemics, often doing multiple jobs at once now, and they need safety and protection, including PPE and mental health support, as well as the security that their team will continue to be employed during this dramatic economic disruption. Changes in program income based on the move to serve patients via telehealth, the loss of insurance coverage, and other budget cuts in the wake of COVID–19 make the need for Federal resources more critical than ever. Additional funding across the program's parts is needed to help people living with HIV stay in care and on treatment; maintain access to care and treatment during the economic downturn; meet the new needs of people who now are without health insurance; and prevent and contain the spread of COVID–19. Without this additional support, the Ryan White Program will fail to meet the immediate needs of its patients and clients while losing ground on responding effectively to COVID–19 and HIV.

Washington University in Missouri is Leading the Way

Washington University's Ryan White-funded clinic has served as the leading source of HIV primary care in Missouri for over 30 years. Each year our Ryan White clinic serves more patients with more complex needs. In 2019, the HIV Clinic at Washington University served 2,095 patients, a 3 percent increase over 2018 in its number of patients living with HIV. Over the past fourteen years the clinic has seen a 109 percent increase in patients living with HIV. Additionally, approximately 1 in 8 patients were fully uninsured and relied heavily on the Ryan White Program to fund their care, and a significant portion experienced housing insecurity. I expect the number of patients relying on the Ryan White Program for support to increase this year as a result of the significant economic downturn.

Washington University, like most Ryan White Part C clinics, receives support from several parts of the Ryan White Program—including parts A, B, C and D—that provide medications and services, including additional medical care, dental services, mental health services, peer health coaches, case management, and transportation—all key components of the comprehensive Ryan White care model that produces outstanding outcomes. In 2019, we started a new program called Rapid Start in which newly diagnosed patients are seen quickly and offered treatment at their first appointment. This program has significantly decreased the time it takes for most patients to achieve viral suppression or HIV treatment success. Additionally, Washington University provides dedicated services for women who are pregnant and for patients reentering care after being out of care for over a year. Both services include nurses and social workers that accompany patients to appointments and do home visits during these critical times.

Washington University also provides Pre-Exposure Prophylaxis (PrEP) services. This critical HIV prevention tool is integrated as part of prevention and primary care delivery. However, more support for the PrEP program is needed to scale up these services to meet patient and community needs, since Ryan White Program funding (including program income) currently is not permitted to support these key prevention services for individuals who are HIV negative.

Ryan White Part C Clinics are Effective Medical Homes and Public Health Programs

Ryan White Part C directly funds approximately 350 community health centers and clinics that provide comprehensive HIV medical care nationwide, serving more than 300,000 patients each year. These clinics are the primary method for delivering HIV care to rural jurisdictions—approximately half of all Part C providers serve rural communities. The program's comprehensive services engage and keep people in HIV care and treatment. This is critical, because HIV disease is infectious, so identifying, engaging, and retaining individuals living with HIV in effective care and treatment saves lives and benefits public health by stopping HIV transmission when individuals are virally suppressed.

In 2018, over 87 percent of Ryan White patients were virally suppressed—a 25 percent increase in the program-wide viral suppression rate since 2010. Washington University aligns with this national average—in 2019, 87 percent of Washington University patients were virally suppressed. Also, 90 percent of HIV patients remain in care at Washington University—a critical fact since HIV disease is infectious, so identifying, engaging, and retaining persons living with HIV in effective care and treatment is an essential public health outcome.

Ryan White Clinics Are Saving Lives and Reducing Costs

Early access to HIV care and treatment helps patients with HIV live healthy and productive lives and is cost effective. A study from the University of Alabama at Birmingham's Ryan White clinic found that patients treated at later stages of HIV disease required 2.6 times more healthcare dollars than those receiving earlier treatment meeting Federal HIV treatment guidelines.

Part C Clinics Are on the Frontlines of the Opioid Epidemic and Provide SUD Treatment

Ryan White clinics serve a significant number of individuals living with both substance use disorder (SUD) and HIV. Part C clinics are able to deliver a range of medical and support services needed to prevent and treat substance use disorder as well as related infectious diseases, including HIV, HCV, and sexually-transmitted infections. The Washington University HIV Clinic has been a leader in expanding HIV testing to identify cases; has improved linkage-to-care services; and has used social media to improve engagement, retention, and medical outcomes among youth and young adult patients.

However, the opioid epidemic continues to hit Missouri and other parts of the U.S. hard. Washington University patients struggle not only with HIV, but also with SUD and related infectious diseases, such as hepatitis C, with Missouri experiencing a dramatic increase in hepatitis C cases.[1] The Washington University HIV Clinic started a hepatitis C clinic in order to treat this infection earlier. Additionally, as a result of the increased need for SUD treatment and overdose prevention services, the Ryan White clinic now offers Medication Assisted Treatment (MAT) with buprenorphine and naltrexone and access to naloxone (which reverses drug overdoses). Finally, the clinic received a CDC grant to treat opioid use disorder in HIV negative patients with complicated infections. We work to blend all of these services in order to keep our high-risk patients HIV free. The experience and expertise of Ryan White clinics should be supported to effectively respond to the opioid epidemic and more rapidly expand access to SUD services. This is especially important now during the COVID–19 pandemic when we are seeing increased risk for and anecdotal evidence of rising drug overdoses.

Increased Funding for Prevention at CDC and Research at NIH Also is Critical

The ability to effectively respond to the syndemics of HIV, substance use disorder, and related infectious diseases such as HCV; sexually transmitted infections; and skin, soft tissue, and endovascular infections depends on CDC funding to enhance surveillance and prevention activities, and on NIH to continue to improve the tools to prevent and treat HIV and SUD and to learn how to effectively implement them. We support the Administration's fiscal year 2021 request for $371 million for CDC to provide surveillance, response, and other HIV prevention services as part of the ETE initiative, and the Administration's fiscal year 2021 request for $58 million for CDC to address the infectious diseases consequences of the opioid epidemic. We also request $58 million through CDC's opioid and infectious diseases program in the next COVID–19 response package to support access to harm reduction services, in-

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[1] Missouri Department of Health and Senior Services. Online at: https://health.mo.gov/data/hivstdaids/pdf/HepCKnownRisksFactSheets.pdf.

cluding syringe services programs, that prevent overdose and infectious diseases transmission and connect individuals to SUD treatment and medical care. Finally, we support continued robust funding for NIH. This funding supports discoveries that will help end the HIV, HCV, and opioid epidemics.

CONCLUSION

Thank you for your time and consideration of these requests, and please don't hesitate to contact me or Jenny Collier, Convener of the Ryan White Medical Providers Coalition, at jcollier@colliercollective.org if you have any questions or need additional information.

[This statement was submitted by Ernie-Paul Barrette, MD, Medical Director, HIV Clinic for the Washington University School of Medicine, Member, Ryan White Medical Providers Coalition.]

PREPARED STATEMENT OF THE SAC AND FOX NATION

Chairman Blunt and esteemed members of the Committee, on behalf of the Sac and Fox Nation I thank you for the opportunity to submit this testimony for the record of our requests for the fiscal year 2021 budgets and matters for consideration for Health and Human Services and Education. The Sac and Fox Nation looks forward to building a positive relationship with your committee and enhancing the future of our Tribal citizens.

DEPARTMENT OF EDUCATION REQUESTS

- Child Care Providers, Schools and Institutions of Higher Education should receive Federal funds due to closures impacting Native students;
- Provide $5 million for Title VI, Part A, Subpart 3, Every Student Succeeds Act (ESSA) (Language Immersion Grants)

DEPARTMENT OF HEALTH AND HUMAN SERVICES REQUESTS

- Ensure Tribes Have Equal Access to Resources and Programs to Prevent and Mitigate COVID–19
- Increased Funding for Head Start to Include Indian Head Start
- Increase Funding to Social Services in Indian Country Through Health and Human Services
  - Restore $281 million to Child Welfare Services Program (Pre-sequestration level)
  - Increase to $38 million—Child Abuse Discretionary Activities, Innovation Evidence-Based Community Prevention Program.
  - Increase to $70 million—Promoting Safe and Stable Families.
  - Increase funding to the Substance Abuse and Mental Health Services Administration—Children and Family Programs (includes Circles of Care)
  - Increase to $50 million—Tribal Behavioral Health Program
- Increase Funding for Part A, Grants for Indian Programs and Part B, Grants for Native Hawaiian Programs. Increase the Level of Funding for Programs like the Title VI Elders Program Food Delivery
- Restore the President's Proposed Elimination of the Low-Income Home Energy Assistance Program, Community Services Block Grants, and Preschool Development Grants.

The Sac and Fox Nation currently has an enrollment of over 4,000 people, with a jurisdictional area covering all or parts of Payne, Pottawatomie and Lincoln counties in Oklahoma. We are a Self-Governance Tribe in both the Department of the Interior and the Department of Health and Human Services. The Sac and Fox Nation is home of Jim Thorpe, one of the most versatile athletes of modern sports who earned Olympic gold medals for the 1912 pentathlon and decathlon.

DEPARTMENT OF EDUCATION REQUESTS

Child Care Providers, Schools and Institutions of Higher Education should receive COVID–19 Federal funds due to closures impacting Native Students: Public schools continue to close across the country, disproportionately impacting Native students who live in rural and remote areas, and those who live on or near Tribal lands; 42 states have closed schools statewide and according to the National Center for Education Statistics, 37 percent of Native students do not have access to Internet in the home compared to 12 percent of their white peers and the 14 percent nationwide average.

Provide $5 million for Title VI, Part A, Subpart 3, ESSA (Language Immersion Grants): The Ester Martinez Native American Languages Programs Reauthorization Act was enacted on December 20, 2019 and Congress must build on its bicameral work and continue to advance language immersion. The Sac and Fox Nation supports funding for this critical program above and beyond the 20 percent set aside through National Activities. The ESSA promotes co-existence of Immersion Schools through Section 6133, which recognizes the unique educational and culturally related academic needs of Native children.

DEPARTMENT OF HEALTH AND HUMAN SERVICES REQUESTS

Ensure Tribes Have Equal Access to Resources and Programs to Prevent and Mitigate the COVID–19 Virus: Tribes must be provided adequate access to the resources and programs described herein and set forth in Public Law 116–123, the Coronavirus Preparedness and Response Supplemental Appropriations Act.

Increased Funding for Head Start with Funding Parity for Indian Head Start: Head Start has been and continues to play an instrumental role in Native education by providing early education to over 24,000 Native children. This vital program combines education, health, and family services to model traditional Native education, which accounts for its success rate. Current funding dollars provide less for Native populations as inflation and fiscal constraints increase, even though research shows that there is a return of at least $7 for every single dollar invested in Head Start. Congress should increase funds to Head Start and Early Head Start with funding parity to ensure that Indian Head Start can reach more Tribal communities and help more Native recipients by activating the Indian special expansion funding provisions.

Increase Funding to Social Services in Indian Country Through Health and Human Services: Our children are a critical resource that we must protect and the great work that is done by the Administration for Children and Families and all the Indian Child Welfare departments across the Nation should be fully funded. These programs are in dire need of funding to ensure that they are running at the best capacity and efficiency possible. Protecting our Native youth is paramount in our eyes. We strongly encourage you to consider this increase and to help us fight to make sure that critical services are reaching those who are most in need. In fiscal year 2021, we recommend:

—Restore $281 million to Child Welfare Services Program (Pre-sequestration level). Tribes need to have access to increased flexible Child Welfare Services Program funds for their child welfare programs. Studies show that culturally tailored programs, resources and case management result in better outcomes for American Indian and Alaska Native (AI/AN) children and families involved in the child welfare system.

—Increase to $38 million—Child Abuse Discretionary Activities, Innovation Evidence-Based Community Prevention Program. Tribes are now eligible for these funds through a competitive grant process. An accurate understanding of successful child abuse and neglect interventions for AI/AN families allows child abuse prevention programs to target the correct issues, provide the most effective services and allocate resources wisely.

—Increase to $70 million—Promoting Safe and Stable Families. The Nation requests the discretionary funding portion of the Social Security Act, Title IV–B, Subpart 2 be increased to $70 million in order to provide ad currently not eligible to apply based on the funding formula.

—Increase $8 Million to the Substance Abuse and Mental Health Services Administration—Children and Family Programs (includes Circles of Care). Increase the overall budget category funding to $8 million and ensure that $6.5 million is reserved for the Tribal community Circles of Care program.

—Increase to $50 million—Tribal Behavioral Health Program. AI/AN youth are more likely than other youth to have an alcohol or substance abuse disorder. There is growing evidence that Native youth who are culturally and spiritually engaged are more resilient than their peers. These funds must be used for effective and promising strategies to combat substance abuse and suicide and promote the mental health of our youth.

Increase Funding for Part A, Grants for Indian Programs and Part B, Grants for Native Hawaiian Programs: Increase the Level of Funding for Programs like the Title VI Elders Program Food Delivery. At the Sac and Fox Nation, just as throughout Indian Country, we are seeing a great increase in the number of elders who need help getting meals. We request an increase in funding for this program and implementation with more flexibility. With an increase in funding, more meal centers could be opened to provide for the care of our growing population of elders. This is no small issue to us.

Restore the President's Proposed Elimination of the Low-Income Home Energy Assistance Program, Community Services Block Grants, and Preschool Development Grants.

[This statement was submitted by Justin F. Wood, Principal Chief, Sac and Fox Nation.]

PREPARED STATEMENT OF THE SAFER FOUNDATION

My name is Victor Dickson and I am submitting testimony on behalf of the Safer Foundation. For almost 50 years, Safer has provided a comprehensive continuum of workforce development and reentry services for individuals with arrest and conviction records seeking employment. There is dignity in work, and Safer Foundation believes that individuals who have made mistakes in the past should have the opportunity to be self-sufficient and contribute to their families and communities through gainful, living wage employment. Clients come to Safer because they want and need to work. Safer Foundation helps clients discover career paths that provide personal fulfillment while allowing them to earn a living. A critical Federal program that supports these efforts is the Reintegration of Ex-Offenders (RExO) program within the Employment & Training Administration of the U.S. Department of Labor. I thank the Subcommittee for providing RExO with $98 million in fiscal year 2020. Given the skills gap and need to train individuals in jobs our economy requires—such as healthcare workers, technology, and logistics—and to help employers identify the qualified workers they need, I request $105 million for the RExO program in fiscal year 2021. Additionally, given the dramatic economic downturn and the fact that states and localities nationwide are releasing people from incarceration to address COVID–19, I urge Congress to allocate $350 million for the RExO program in the next COVID–19 response bill. This funding would support community-based organizations and nonprofit providers in addressing the significant increase in need for reentry and workforce development services. Expanding services now would enable organizations and providers to serve those who are reentering earlier than expected or who have records and are facing unexpected job loss, as well as adjust services and training to better meet the needs of existent and emerging employers in the evolving economy.

The COVID–19 Pandemic's Impact on the Employment of Individuals with Criminal Records

1 in 3 adults in the U.S. has a criminal record that interferes with their ability to find a job.[1] The unemployment rate for formerly incarcerated individuals nationwide could be as high as 47 percent after the COVID–19 pandemic (based on unemployment data for this population from the last recession and current unemployment data and trends). The RExO program supports the collaboration of workforce development providers and businesses in training and credentialing individuals with criminal records for career path employment that meets the current needs of local and regional employers. Congress should proactively improve employment outcomes of individuals with records during this dramatic economic downturn by strengthening and expanding the RExO program.

To immediately meet these needs, Congress should provide supplemental RExO program funding in the next COVID–19 relief bill. $350 million for RExO would support reentry, education, and workforce development services for approximately 25,000–30,000 individuals (10.5–12.75 percent of formerly incarcerated individuals estimated to be unemployed after the pandemic), and this funding should support reentry and workforce development services, including wage replacement funding, training stipends, and earn and learn strategies and internships.

Additionally, this funding would provide Safer Foundation and other organizations with critical resources to help train and certify healthcare providers who are greatly needed as the country grapples with the pandemic. Safer Foundation created a program called the Safer Demand Skill Collaborative (SDSC)—an employer-driven initiative of public and private partners that work together to train and credential skilled workers across five industries, including healthcare. SDSC builds on Safer Foundation's successful workforce development programming by adding vocational training in high-growth sectors that leads to industry-recognized credentials. SDSC

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[1] "Research Supports Fair-Chance Policies" (March 2016), National Employment Law Project, footnote 1 on p. 7. Available at http://www.nelp.org/publication/researchsupports-fair-chance-policies.

provides career pathways within the healthcare sector for the jobs of certified nursing assistant, certified medical assistant, and registered nurses. In fiscal year 2017–2019, Safer Foundation successfully placed 158 individuals who faced barriers to a healthcare career because of their criminal record in critical frontline healthcare jobs with an average employee retention rate of 92 percent. With additional RExO program resources, organizations such as Safer Foundation would be able to help train and certify a portion of the healthcare workforce required to respond to COVID–19 and other pressing industry challenges, such as long-standing workforce shortages.

A substantial investment in the workforce system now must emphasize subsidized employment and "earn-as-you-learn" models such as transitional jobs that target those with barriers to employment such as criminal records. Time-limited, wage-paying jobs that combine real work, skills development, and supportive services help participants transition successfully into the labor market. Transitional jobs are an effective model for individuals impacted by the justice system and support employers to meet the demands of the workforce. RExO funding should support this model in this specific economic environment.

Employment Reduces Recidivism and Improve Reentry Outcomes

Research shows that sustained, living wage employment and life skills are critical components to long-term reentry success. One study found that individuals who were employed and earning higher wages after release were less likely to return to prison within the first year.[2] Unfortunately, finding this type of employment can be prohibitively difficult for Americans who have any history of justice system involvement. The RExO program helps individuals overcome employment barriers by preparing participants for jobs in local high-demand industries through career pathways and industry-recognized credentials.

Increasing RExO funding would expand access to comprehensive workforce development and reentry services that assist individuals with criminal records in navigating obstacles to employment while improving employment and reentry outcomes. Authorized by section 169 of Workforce Innovation and Opportunity Act (WIOA), the RExO program provides workforce preparation services for both adults and young people. RExO includes a $25 million set-aside to provide services to prepare formerly incarcerated young adults for employment, including those who have not completed school or other educational programs. Research has found that incarceration reduces the average formerly incarcerated individual's earning potential by more than 27 percent over a lifetime,[3] making workforce development services for young people essential for their long-term employment and reentry success. In light of the costs of the criminal justice system at the state, local, and Federal levels, the RExO program is crucial to incubating community-based models of successful reentry through employment.

Safer's RExO Services Increase Employment by Working with Employers and Employees

Safer Foundation offers a full spectrum of workforce development and reentry services that train individuals, address their reentry obstacles and needs, and help them obtain sustained employment. This holistic approach has rendered outstanding results for participants and employers. In 2006, decades of experience and success led Safer to become one of the original RExO grantees.

In addition to working with reentering individuals and their communities, Safer also works closely with employers to identify what types of trained employees they need. In November 2019, the National Federation of Independent Business (NFIB) reported that 53 percent of businesses overall (and 88 percent of those hiring or trying to hire) reported few or no "qualified" applicants for the positions they were trying to fill. 67 percent of construction firms reported few or no qualified applicants. Safer can be responsive to employer needs by tailoring its programs to develop skilled workers for specific employment sectors and has partnered with hundreds of employers to meet their workforce needs.

Safer's Training to Work (T2W) program, that was funded by a RExO grant, improved long-term employment prospects for clients at Safer's Adult Transition Centers (ATC). Program participants received case management, education, and training that lead to industry-recognized credentials for in-demand employment, such as

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[2] Visher, C., Debus, S., & Yahner, J. Employment After Prison: A Longitudinal Study of Releasees in Three States. Washington, DC: Urban Institute (2008).

[3] Holwell, P., & Gardner, D. (2014). Workforce centers: Successful labor market reentry for justice involved ex-offenders. Centennial, CO: Arapahoe/Douglas Works, p. 2: http://www.adworks.org/pdf/Supporting__Successful__LM__Reentry__for__Justice__Involved.pdf.

forklift operation, foodservice and sanitation, welding, computer numerically control (CNC), CDL training, and Microsoft technologies. Given the program's strong employer and credentialing components, RExO is uniquely positioned to assist local organizations in developing and providing services that meet the needs of both the local business community and reentering individuals. Increased RExO funding in the next COVID–19 response bill and in fiscal year 2021 appropriations, including the funding of earn and learn apprenticeship opportunities for in demand skills development, would allow these efforts to expand, and could help match more employers with qualified employees who are trained, talented, motivated to work.

Safer's RExO Grant Produced Outstanding Employment Outcomes and Reduced Recidivism

Safer's RExO grant for the Training to Work (T2W) program significantly outperformed employment targets and dramatically reduced recidivism. For the first cohort of RExO T2W participants, 69 percent of participants obtained employment—15 percent higher than the grant's employment target. Given the success of this first cohort of participants, T2W was extended to a second cohort who did even better with an employment rate of 78 percent—30 percent higher than the grant's target. Safer's RExO T2W grant also reduced recidivism rates beyond original targets. A 2014 report published by the Bureau of Justice Statistics, which studied recidivism across 30 states for 5 years, determined that the recidivism rate 1 year after release from prison was 43.4 percent.[4] T2W's first participant cohort had an 11 percent recidivism rate, and its second participant cohort had a 9 percent recidivism rate—respectively 75 percent and 80 percent lower than the national recidivism rate.

Program evaluation has shown that such successful outcomes are related to the comprehensive service model that grantees such as Safer provide. Effective, comprehensive services can include interventions such as relationship building between staff and participants, employment verification, trauma informed training, life skills training, employment preparation, mentoring, intensive case management, strong training provider relationships and support, family involvement, and post-release follow-up and support. These comprehensive services are cost-effective—a 2016 Illinois study found that for every $1 invested in community-based employment and training programs, tax payers saw a net benefit of $20.26, and found that employment and training programs had the highest cost-benefit ratio for reducing recidivism.[5] Another study found that individuals who were employed and earning higher wages after release were less likely to return to prison within the first year.[6] By increasing and improving employment outcomes, the RExO program invests in formerly incarcerated individuals and their families, while improving public safety.

Conclusion

By making effective workforce development and reentry services a priority, we fulfill labor market demands, contribute to the economy, and build strong and safe communities. Given the skills gap and workforce shortages that persist in industries such as healthcare, the significant return on investment related to reduced incarceration costs and reduced crime costs borne by victims, families, and communities, I urge Congress to allocate $350 million to the RExO program in its next COVDI–19 response bill as well as $105 million to the RExO program in fiscal year 2021. Thank you so much for your time and consideration of this important program. If you have questions or need additional information, please feel free to contact me at victor.dickson@saferfoundation.org or Jenny Collier at jcollier@colliercollective.org.

[This statement was submitted by Victor Dickson, President and CEO, Safer Foundation.]

PREPARED STATEMENT OF THE SCHIZOPHRENIA AND RELATED DISORDERS ALLIANCE OF AMERICA

The Schizophrenia and Related Disorders Alliance of America appreciates the opportunity to provide written testimony on the National Institute of Health fiscal year 2021 budget appropriations.

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[4] Durose, Matthew R., Alexia D. Cooper, and Howard N. Snyder, Recidivism of Prisoners Released in 30 States in 2005: Patterns from 2005 to 2010 (pdf, 31 pages), Bureau of Justice Statistics Special Report, April 2014, NCJ 244205.

[5] Illinois Sentencing Policy Advisory Council (2016). A Cost-Benefit Tool for Illinois Criminal Justice Policymakers, pp. 2–3: http://www.icjia.state.il.us/spac/pdf/Illinois__Results__First__Consumer__Reports__072016.pdf, pp. 2–3.

[6] Visher, C., Debus, S., & Yahner, J. (2008). Employment After Prison: A Longitudinal Study of Releasees in Three States. Washington, DC: Urban Institute.

The Schizophrenia and Related Disorders Alliance of America is a national nonprofit dedicated exclusively to Improving and saving lives affected by serious neuropsychiatric brain (mental) illnesses such as schizophrenia and bipolar disorder. Our organization promotes laws, policies and practices for the delivery of psychiatric care and supports the development of treatments for and research into factors of serious neuropsychiatric brain illnesses that have the potential for reducing suffering, saving and improving lives of individuals living with these illnesses.

The National Institute of Mental Health (NIMH) is the main Federal Government agency for research into mental illness. The NIMH was authorized through the passage of the National Mental Health Act in 1946 to better help individuals with mental health disorders through better diagnosis and treatments. With a budget of almost $2 billion in 2020, the NIMH conducts research and funds outside investigators to better understand mental illness and develop new treatments to reduce the burden these disorders have on individuals.

Unfortunately, the NIMH has a recent history of diminishing the work to impact those with the most severe mental illnesses. According to Dr. E. Fuller Torrey in Psychiatric Times earlier this month:

> “Congress awarded the National Institute of Mental Health an additional $98 million as part of the National Institutes of Health budget resolution in December 2019, which brings the NIMH budget to just under $2 billion and represents a 35 percent increase since 2015, one of the largest increases in the history of the NIMH. Yet, during the 5 years from 2015 through 2019, NIMH funded a total of 2 new drug treatment trials for schizophrenia and bipolar disorder, according to clinicaltrials.gov. This contrasts with the 5-year period from 2006 through 2010 when NIMH funded 48 such trials. NIMH has thus almost entirely given up its role of evaluating drugs for the treatment of 2 disorders (emphasis added).”

In December 2019, the NIMH released a draft of their five-year strategic plan for public comment. They reported receiving more than 6,000 responses over the winter holidays, including from our organization identifying concrete examples of research initiatives the NIMH could be pursuing today to help people with serious mental illness recover and live better lives. Despite this robust response, NIMH made no substantive changes to the research goals or objectives in the final version released to the public earlier this week.

The NIMH research goals for 2020–2025 increase the existing imbalance in NIMH research. In doing so, they offer little hope for new or better treatments for individuals who are currently afflicted with a a serious mental illness.

Schizophrenia and Related Disorders Alliance of America recognizes the profound importance of discovering the etiology of the syndromes to allow for precise targeted treatments, however, that will not provide for individuals currently suffering and dying. It is vitally important for NIMH to study what the pharmaceutical industry will not, that is what can be developed in the very short term to help individuals seriously ill now.

The pharmaceutical industry will not compare a “gold standard” medication, clozapine, to new medications or study the elements of clozapine that currently provide the most effective outcomes for people affected by psychosis thus improving life success and reducing suicide. Refine even further what is reasonable as well as safe Risk Evaluation and Mitigation Strategy (REMS) for clozapine to increase the use and accessibility of the currently most effective medication. NIMH must prioritize research and discover what will relieve the suffering of people currently seriously ill.

Future NIMH funding must be used to correct the existing imbalance, not worsen it, especially now that the COVID–19 pandemic has distressed the mental health treatment system and has resulted in an exacerbation of symptoms in people currently affected and will cause an increase in serious mental illnesses among Americans. Those with the most severe forms of neuropsychiatric brain (mental) illness deserve to be prioritized.

Thank you for your consideration of this request.

Sincerely.

[This statement was submitted by Linda Stalters, Chief Executive Officer, Schizophrenia and Related Disorders Alliance of America.]

PREPARED STATEMENT OF THE SCLERODERMA FOUNDATION

THE FOUNDATION'S FISCAL YEAR 2021 L–HHS APPROPRIATIONS RECOMMENDATIONS

- —$8.3 billion in program level funding for the Centers for Disease Control and Prevention (CDC), which includes budget authority, the Prevention and Public Health Fund, Public Health and Social Services Emergency Fund, and PHS Evaluation transfers.
  - —A proportional fiscal year 2019 funding increase for CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP).
- —At least $44.7 billion in program funding for the National Institutes of Health (NIH).
  - —Proportional funding increases for NIH's National Heart, Lung, and Blood Institute (NHLBI); National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS); National Center for Advancing Translational Sciences (NCATS).

Chairman Blunt, Ranking Member Murray and distinguished members of the Subcommittee, thank you for your time and your consideration of the scleroderma community's priorities while working to craft the fiscal year 2021 L–HHS Appropriations Bill.

ABOUT SCLERODERMA

Scleroderma is a chronic connective tissue disease affecting approximately 300,000 Americans. The word scleroderma means hardening of the skin, which is one of the most visible manifestations of the condition. The cause of this progressive and potentially fatal disease remains unknown. There is no cure, and treatment options are limited.

Symptoms vary greatly and are dependent on which organ systems are impacted. Prompt diagnosis and treatment by a qualified physician may improve health outcomes and lessen the chance for irreversible damage. Serious complications of the disease can include pain, skin ulcers, anemia and pulmonary hypertension.

ABOUT THE FOUNDATION

The Scleroderma Foundation is dedicated to the concerns of people whose lives have been impacted by the autoimmune disease scleroderma, also known as systemic sclerosis, and related conditions. The foundation's mission is to 1) support individuals affected, 2) promote education and public awareness, and 3) advance critical research and improve scientific understanding to improve treatment options and find the causes and a cure. The foundation has a research program that funds basic, translational and clinical research through a peer review process to find the cause and cure for scleroderma and related conditions.

CENTERS FOR DISEASE CONTROL AND PREVENTION

Early recognition and an accurate diagnosis of scleroderma can improve health outcomes and save lives. CDC in general and the NCCDPHP specifically have programs to improve public awareness of scleroderma and other rare, life-threatening conditions. Please increase funding for CDC and NCCDPHP so that the agency can invest in additional, critical education and awareness activities that have the potential to improve health and save lives. The Foundation supports the establishment of a Chronic Disease Education and Awareness Program, this program seeks to provide collaborative opportunities for chronic disease communities that lack dedicated funding from ongoing CDC activities. Such a mechanism allows public health experts at the CDC to review project proposals on an annual basis and direct resources to high impact efforts in a flexible fashion.

NATIONAL INSTITUTES OF HEALTH

NIH continues to work with the Foundation to lead the effort to enhance our scientific understanding of the mechanisms of scleroderma with the shared-goal of improving diagnosis and treatment, and ultimately finding a cure. Since scleroderma is a systemic fibrotic disease it is inexorably linked to other manifestations of fibrosis such as cirrhosis, pulmonary fibrosis, and the fibrotic damage resulting from heart attack. Scleroderma is a prototypical manifestation of fibrosis as it impacts multiple organ systems. In this way, it is important to promote cross-cutting research across such Institutes as NIAMS and NHLBI.

Please provide NIH with a significant funding increase to the scleroderma research portfolio can continue to expand and facilitate key breakthroughs.

—NIH continues to support the Trans-NIH Working Group on Fibrosis which is working to promote cross-cutting research across Institutes.

—NHLBI, which is leading Scleroderma Lung Study II, is comparing the effectiveness of two drugs in treating pulmonary fibrosis in scleroderma.

—NIAMS, is leading efforts to discover whether three gene expression signatures in skin can serve as accurate biomarkers predicting scleroderma, and investigations into progression and response to treatment to clarify the complex interactions of T cells and interleukin-31 (IL–31) in producing inflammation and fibrosis, or scarring in scleroderma.

Patient Perspective

My constantly aching hands begged for mercy of just one day without pain. My joints started to feel like they were being torn away from my body. Anytime I touched something cold, my hands would tingle and burn. Painful sores started appearing on my knuckles. You stole my skin color and with that went my confidence. It was like I was turning into a mummy as my skin tightened with collagen, day by day. I was beginning to need help performing small tasks. Opening a water bottle or turning a key in the door started to become difficult. Standing for long periods of time made my hips radiate with pain. In 2012 I had to stop working, at 24 years old. The definition of normal as I knew it was being torn down and built into something completely new. And so was my soul.

I now need help with everything! Getting dressed, washing my hair, cleaning, doing laundry; pretty much anything I have to use my hands for. You stole my independence. I had to learn to swallow my pride and ask for help. It's a tough thing to do, especially when you're at an age that's supposed to be your prime. Friends and family around me have blossomed into caregivers and helping me has become second nature to them. It's a beautiful thing when those surrounding you automatically adapt to your disability. Support is the lifeboat that keeps me afloat."

—Excerpt from "My Letter to Scleroderma"
Jessica Messingale
Coconut Creek, Florida

[This statement was submitted by Mr. Robert J. Riggs, Chief Executive Officer, Scleroderma Foundation.]

PREPARED STATEMENT OF CYNTHIA SCOTT

Here's how I have lived my life. Standing on a cliff, with my arms opened wide, trying to keep my loved ones from running off. I was born into a bipolar family. Bipolar disorder is not listed as the official cause of death for any of them, but this brain disease is picking off my family one by one. They drink and drug themselves to death in an attempt to poison the beast. They end up poisoning themselves and shattering their own lives in the process. I have spent my life trying to keep alive brilliant people gripped by madness. It's been an abject failure. Bodies keep hitting the floor one by one. This is a genetic, biological condition. They are born with bipolar, and it lives in their brain like a terrorist cell waiting to activate. It is a complex condition, and the triggers that activate it are complex and unique to the individual sufferer.

Why do they suffer? They are trapped in a hell mind. They hate themselves, because they can't find their way out. They project this self-loathing onto their safe people. My son, who is in and out of recovery and now back in, originally began his drug abuse to self-medicate his bipolar condition. Years after his first taste of a prescribed opioid, he told me, "It was the first time in my life that my brain felt calm." With that first taste, he fell down the dark rabbit hole. He tells me he did the drugs, because, "I just wanted to make my brain feel normal."

Love is not enough in the face of such suffering. I recently participated in a webinar for family members with addicted loved ones. The presenter offered this beautiful closing that left me weeping: "We don't believe in brokenness. We believe in forgetfulness, and we must remind them of who they are." It caused me to reflect on why we hang in there. We call them up, and we call them out, because we know they are still in there, but they are lost. Because we love them, and because we are brave and have big hearts, we are helping them find their way back home.

It is really since I sent my son to his first rehab more than 2 years ago that I started to open up about having a family afflicted by mental illness. Until then, I held that close to my chest, as an ache in my heart, as my secret sorrow. Mental illness is an intergenerational trauma for our family. Of all the grandchildren in my family of origin, only one is mentally healthy. The rest have bipolar disorder. All are brilliant and talented beyond belief. And all are cursed.

I feel raw with emotion right now writing this letter, because I just emerged from a harrowing five days, where I mounted a rescue operation from 1400 miles away to pull my son back from the edge of hell again. I would have caught the first plane to Costa Rica to find him if I could have, but the borders are closed. As I feared, the quarantine had destabilized him, and he disappeared for several days. When he resurfaced incoherent, I was able to pull enough details from him to send people to find him. For now, he is safe in recovery in Costa Rica. For how long? I don't know. The tragedy of loving someone with bipolar disorder is knowing your love is not strong enough to spare them and that their suffering does not truly end until the grave. Only a warrior can live with it for long.

Why is my son recovering 1400 miles away in Costa Rica? Because we could not afford long-term care for him in America, and I sent him down there initially for rehab. He is now on his fifth round of rehab there, because each time he has ever gone into rehab in America or abroad, they inadequately target the problem. The why behind his addiction. His bipolar disorder. Co-existing conditions like bipolar disorder and other serious mental illnesses are driving our problem with drug addiction. Before COVID–19 hit, drug addiction was the plague threatening to take our economy down. Currently, America has the highest rate of drug overdose deaths in the world. We also lead the world in having the highest percentage of our citizens incarcerated. For many of our mentally ill citizens, they do not receive adequate mental health treatment until they go to prison. Currently, our prison system is considered the largest mental health provider in the country. We should hang our heads in shame for this as a nation.

People suffering with substance use disorders end up on an insane merry-go-round of rehab and relapse. Why do so many relapse as soon as they leave rehab? For one, in most cases, insurance will only pay for 30 days, and this is laughable. There is no research to support this arbitrary number. Most rehabs offer inadequate treatment, because under our current backwards model, they try to cure them with a quasi-religious philosophy called The Twelve Steps. While this program has its benefits, it is not a medical cure for a medical problem. What addicts with co-existing conditions like bipolar disorder need are medicines that don't make them want to die. They often refuse to stay on the meds beyond initial stabilization because of their horrid side effects. My son says the meds numb him emotionally, make him feel like a zombie. They make him feel like he is living a miserable half-life as a human. If he cannot live fully and embrace the full range of his emotions, then why live at all? This is how he feels. For a bipolar person, their full range of emotions is dangerous and carries them away into the streets, prison, insanity or an early grave. The loss to our society is incalculable. The people afflicted with bipolar disorder are often brilliant. Bipolar disorder is referred to as the "artist's disease," because the sufferers are often highly creative. Those afflicted with this condition have made some of the greatest contributions to humanity. But they did so at the cost of intolerable psychological pain.

It is difficult to impossible to get many bipolar people to commit to care. They get stuck in a self-destructive cycle. Of all the brain illnesses, bipolar is the one that demands medication to survive. There is no "natural cure" for bipolar disorder. Sure, alternative and integrative therapies can help and be wonderful, but my son, for example, is not going to talk his way out of it, surf his way out of it, forest bathe his way out of it, pray his way out of it, think his way out of it, will his way out of it, or weight lift his way out of it. All of those things can and do help reduce the suffering but not to the point to keep the madness in check. Not. Even. Close. My son will continue to live like a homeless man even when he has a home if he does not get on proper meds that he can tolerate, and his life will continue along this wasted, tragic trajectory before it ends too soon.

Nobody hates Big Pharma more than I do. Because of their irresponsibility and greed, they have killed millions and almost took my son down, too. They go unpunished. I consider the Sackler family, who unleashed the opioid epidemic on America, to be mass murderers. They should all be arrested and carted off to prison where they rot forever. But no. Not how it works. They're now the world's most successful living drug dealers enjoying the high life with their blood-money billions, while my son's in Costa Rica trying not to die. His drug addiction began with a legal prescription for opioids at a time when doctors-aligned with Purdue Pharma marketing-claimed addiction to opioids was rare and prescribed these deadly drugs like Skittles.

Having said that, my son needs pharmaceuticals to live. Bipolar meds are not pretty. No one takes an anti-psychotic and shouts, "Good times!" Anyone who takes these meds without a dose of wisdom fear is a fool. This is a pick your poison scenario. On the one hand, they can choose barely tolerable meds with potentially horrendous side effects that can keep them alive but will probably destroy their kidneys in the process OR refuse treatment and live a tragic wasted life only to face an early death. It's a double-edged sword. This is a brutal choice and requires courage. Why do our mentally ill citizens, already enduring so much suffering, have to endure even more as guinea pigs while doctors spend months and years trying to find the right combination of meds that will help make their lives worth living? We can do better. We can be a nation that cares for the mentally ill instead of marginalizing them.

Bipolar disorder is a bleak condition I would not wish on my worst enemy if I had one. For untreated bipolar people, their bottom is death. When my untreated bipolar sister ran her car off the road, across a field, and crashed it into a building in a suicide attempt, that was not her bottom. She survived it but persisted in self-destruction, including her refusal to be properly medicated. She finally drank herself to death to stop the pain. Her son would do the same three short years later. He refused medication, too. These were not stupid people. Both had genius level IQs. High intelligence does not protect against the bipolar beast unless it is trained to target the beast. Their tragic fate is the same fate grinning back at my own son if he does not surrender to proper treatment, however inadequate. Even when bipolar people accept treatment, for many it is only temporary. Once they start feeling good, they ditch their meds, because they think they're cured (which is delusional) or because of the side effects. This brain disease is one unforgiving hellhound. Only a warrior will survive it.

We are still in the Dark Ages in our understanding of this brain disorder. Currently, we only know about 10 percent of what we can know about it, so we only have a primitive understanding. What leading experts and researchers do say is that this is not a psychiatric illness, but a medical one. It is not about character but about chemicals. This makes sense to me, because when my son is properly medicated, he is a different person—rational, sane, steady, thoughtful. Off his meds, he is a tornado impossible to lasso. The switch is that fast. Before the discovery of insulin, people also believed diabetes was a mental illness. A person's blood sugar would crash, and they would act drunk and irrational. People thought they were insane. Since insulin, we now understand that diabetes is a medical problem, not a psychiatric one. The problem is that while insulin can manage diabetes 100 percent, bipolar meds can only manage bipolar illness about 50 percent. The rest has to come from lifestyle choices and a continued course of therapeutic treatment. Left untreated, their pre-frontal lobe, the seat of their executive functioning, remains impaired, so they continue to make irrational choices about treatment and their own lives. It's a vicious cycle.

The majority of sufferers will end up with substance abuse disorders in a desperate attempt to normalize their brains. It is considered the most dangerous of any psychiatric illness (although it is still misunderstood as such), because it carries the highest suicide rate. It also carries the highest addiction rate.

Mental illness can strike any one of us or our loved ones at any time. No one is immune. There are no antibodies for mental illness. Like so many other families with mentally ill loved ones, I live on the ropes, but I don't give up easily. I would be forever grateful for caring advocates in Congress to join this battle, too.

The NIMH now has $2 billion in taxpayer funds to finance this fight. Congress can begin by ensuring that NIMH's priority is the development of cures and treatments for serious mental illnesses like schizophrenia and bipolar. With proper support, there is hope on the horizon. According to a recent article in the Psychiatric Times entitled "Riches Abound, So Where Are the Trials for Schizophrenia and Bipolar Disorder?" there are promising findings from small studies that show that immune modulatory drugs have potential for the treatment of schizophrenia and bipolar disorder. These should be followed up with larger scale studies. Also showing promise and deserving of exploration are neuro-hormones like estrogen and probiotics and other agents that regulate the microbiome and gut-brain axis. Clozapine is the last new psychiatric drug approved for psychosis. It was approved 30 years ago. Why has progress in the development of psychiatric drugs slowed to such a snail's pace even as the numbers of the mentally afflicted continue to rise exponentially in our country? It is time for Congress to declare a Manhattan Project for the mentally ill.

So many families display a quiet heroism and "unyielding love" for the mentally ill members of their tribes. It is an impossible, Sisyphean ordeal. It is purgatory. The afflicted and their families need an assist. They need a hand up out of hell.

PREPARED STATEMENT OF STEPHEN SEGAL

My name is Stephen Segal and I am a resident of Philadelphia. I am writing to encourage you to require NIMH to provide more support for trials for medications to treat bipolar disorder and schizophrenia.

My son has bipolar disorder. He was diagnosed at the age of 19 in the 1999 and continues to live with it to this day. At times, his journey has been heartbreaking. At other times, he manages well.

He has had numerous treatments, including ECT, TMS and ketamine infusions, and has tried different drugs over the years. He had to discontinue lithium, a foundation drug for him, because it was endangering his kidneys. For him and the millions who also suffer from these severe mental illnesses, the options are not sufficient when a medication either doesn't work or stops working or the side effects are too onerous to bear.

I am shocked that NIMH has actually reduced its support of drug treatment trials for bipolar disorder and schizophrenia by 96 percent since 2006! This is a disgrace. There is way too much suffering by the millions of Americans with these illnesses and their families to justify such diminished support. In addition, a person who is ill and not successfully treated is both a threat to society and a drain on society. People with untreated severe mental illness fill our jails and emergency rooms. They comprise a large number of the homeless population and they are more likely to be both victims of violent crime and perpetuators of violent crime. They also account for many of our nation's suicides. We all lose when someone is untreated or not treated successfully.

However, when treated successfully as many are, they can be productive and positive member of society. For those with bipolar illness who are treated well, they are indistinct from anyone else.

Please use your influence to require more spending on drug trials for bipolar disorder and schizophrenia. You will be saving lives and families. Thank you.

PREPARED STATEMENT OF THE SLEEP RESEARCH SOCIETY

FISCAL YEAR 2021 APPROPRIATIONS RECOMMENDATIONS

—SRS joins the broader medical research community in thanking Congress for providing a $2.6 billion funding increase for the National Institute of Health (NIH) for fiscal year 2020 and in requesting a subsequent increase of at least $3 billion for fiscal year 2021 to bring total agency funding up to a minimum of $44.7 billion annually.

  —Please provide proportional funding increases for all NIH Institutes and Centers, including in particular the National Heart, Lung, and Blood Institute (NHLBI), which houses the National Center on Sleep Disorders Research (NCSDR), and the National Institute of Neurological Disorders and Stroke (NINDS). Sleep impacts nearly every body system and the progress of many illnesses. As a result, nearly every NIH Institute and Center conducts sleep research, and NCSDR helps coordinate sleep research activities across (and not just across NIH, but across the Federal Government, including the Department of Defense and the Veterans Administration).

—SRS joins the broader public health community in thanking Congress for providing the Centers for Disease Control and Prevention (CDC) with a modest funding increase for fiscal year 2020 and in requesting a subsequent increase of at least $600 million in discretionary resources for fiscal year 2021 to bring total agency funding up to a minimum of $8.3 billion annually.

  —Please also provide a dedicated, line-item appropriation of at least $5 million to for a "Chronic Disease Education and Awareness Program" at CDC (as proposed in the fiscal year 2020 House LHHS Appropriations Bill).

Chairman Blunt, Ranking Member Murray, and distinguished members of the Subcommittee, thank you for considering the views of the sleep, circadian, and sleep disorders advocacy community as you work on fiscal year 2021 appropriations for relevant medical research and public health programs. We would like to take this opportunity to thank you for providing meaningful investment in fiscal year 2020 for NIH and CDC and to request that this investment continue in fiscal year 2021 considering recent progress and emerging opportunities.

ABOUT THE SLEEP RESEARCH SOCIETY

The Sleep Research Society (SRS) was established in 1961 by a group of scientists who shared a common goal to foster scientific investigations on all aspects of sleep, circadian rhythmicity, and sleep disorders. Since that time, SRS has grown into a professional society comprising over 1,300 researchers nationwide. From promising trainees to accomplished senior level investigators, sleep and circadian research has expanded into areas such as psychology, neuroanatomy, pharmacology, cardiology, immunology, metabolism, genomics, and healthy living. SRS recognizes the importance of educating the public about the connection between sleep, circadian rhythmicity, and health outcomes. SRS promotes training and education in sleep and circadian research, public awareness, and evidence-based policy, in addition to hosting forums for the exchange of scientific knowledge pertaining to sleep and circadian rhythms.

ABOUT PROJECT SLEEP

Project Sleep is a 501(c)(3) non-profit organization raising awareness about sleep health and sleep disorders by working with affected individuals and families across the country. Believing in the value of sleep, Project Sleep aims to improve public health by educating individuals and policymakers about the importance of sleep health and sleep disorders. Project Sleep will educate and empower individuals using events, campaigns, and programs to bring people together and talk about sleep as a pillar of health.

CDC SLEEP DISORDERS ACTIVITIES

For nearly a decade, CDC has supported the National Healthy Sleep Awareness Project (NHSAP) with discretionary resources at about $250,000 annually. Despite the severity and prevalence of sleep-related health issues, NHSAP represented the only public health activity at CDC devoted to sleep. This project has been highly successful by leveraging voluntary contributions from leading sleep centers and organizations to generate numerous research advancements, awareness campaigns, professional publications, and peer-reviewed articles.

Despite the overwhelming support for the NHSAP and the request to continue its core functions through key committee recommendations, CDC terminated these activities for fiscal year 2019 (effectively halting sleep-related public health efforts). The fiscal year 2020 House LHHS Appropriations Bill proposed establishing a line item program for “Chronic Disease Education and Awareness”. The sleep community is highly supportive of this program and requests that it be included again for fiscal year 2021 with an initial investment of $5 million. Such action will allow organizations to compete for funding and for the CDC to support timely and meritorious public health efforts.

NIH SLEEP DISORDERS ACTIVITIES

Over recent years, NIH has seen a meaningful infusion of essential funding. This investment has improved grant funding pay lines, led to significant scientific advancements, and helped to prepare the next generation of young investigators. Due to the high quality of the science, the sleep research portfolio has done well as a result of this additional funding. In fact, NIH supported research was critical to the circadian research project that received the 2017 Nobel Prize in Physiology and Medicine. However, while the sleep portfolio overall is strong, one area of potential improvement is investment in individual sleep disorders. The research portfolios for specific conditions at NIH, including Restless Legs Syndrome, circadian rhythm disorders, and Narcolepsy, remain relatively modest. The research done in these portfolios has a direct and sometimes immediate impact on patient health and wellness.

Recently, the committee reports accompanying the L–HHS appropriations bills have featured timely recommendations that emphasize the value and importance of sleep, sleep disorders, and circadian research. Moving forward, please continue to recognize the progress made by NCSDR and the need to continue to advance this research portfolio in a way that capitalizes on emerging opportunities for patient benefit. Please also recognize the leadership of NINDS on sleep disorders research activities.

BRITTANY MATTHEWS FROM ILLINOIS

One February afternoon during Brittany Matthews’ senior year of high school, she awoke on her bedroom floor to her mom frantically screaming at her for skipping school for the 20th time that year. Brittany hadn’t moved from the spot on the floor where she was doing her makeup at 7 am when her mom left for work. However, Brittany was confused because just a few minutes before this, she had thought she actually was at school and this “hypnopompic hallucination” experience felt just as real as now finding herself still at home. When the school informed Brittany’s parents that she needed to go to court for her truancy issues and was not likely to graduate on time, Brittany was sent to live with her dad, who thought he could “straighten her out.” That was one of the last straws in a sequence of events that finally led Brittany to receiving a diagnosis of narcolepsy at age 19, which was about 12 years after she began experiencing symptoms at the young age of 7. Narcolepsy is a misunderstood and under-diagnosed chronic neurological disorder affecting the brain’s ability to regulate the sleep/wake cycle with a prevalence of 1 in 2,000 people worldwide.

During the 5 years that followed, Brittany struggled in every aspect of her life until eventually finding a more effective treatment regimen, which allowed her to re-consider her dream of finishing college. Last year, Brittany graduated with her Bachelor of Science degree at the age of 26. Now, she is working full-time and is in the process of applying for graduate school programs for speech language pathology. Despite the progress she has made, Brittany still grapples daily with excessive daytime sleepiness, as well as cataplexy (sudden muscle weakness brought on by emotions). Advancements in research, treatments, and awareness are critical to improve the lives of those living with narcolepsy and other sleep disorders.

[This statement was submitted by Andrew Krystal, MD, MS, President, Sleep Research Society.]

Prepared Statement of Yvonne Smith

Dear Members of the NIMH Senate Committee,

This letter is to appeal on behalf of vulnerable members of our society, those with serious mental illnesses such as Schizophrenia or Bi-Polar disease. The population suffering from severe mental illness is growing and their needs are acute. NIMH has consistently overlooked this population in its efforts to find cures and treatments. This is not acceptable.

So I am asking that you direct a portion of the 2021 budget specifically to address the need for research to find cures for serious and debilitating mental illness and to mandate that the NIMH pursue a robust effort to find cures and effective treatments using the specific budget allocated to these efforts.

Thank you so much for considering my request.

Prepared Statement of the Society for Healthcare Epidemiology of America, the Association for Professionals in Infection Control and Epidemiology, and the Society of Infectious Diseases Pharmacists

The Society for Healthcare Epidemiology of America (SHEA), the Association for Professionals in Infection Control and Epidemiology (APIC), and the Society of Infectious Diseases Pharmacists (SIDP) urge appropriators to prioritize investments in the following Federal programs:

LHHS Programs	Agency	Fiscal Year 2021 Funding Request
National Healthcare Safety Network	CDC	$25 million
Antibiotic Resistance Solutions Initiative	CDC	$200 million
Advanced Molecular Detection	CDC	$57 million
Data Modernization	CDC	$100 million
Patient Safety Research	AHRQ	$100.4 million
Healthcare-Associated Infections	AHRQ	$50.2 million
Combating Antibiotic-Resistant Bacteria	AHRQ	$13.9 million
Investigator-initiated Research	AHRQ	$73.8 million
Biomedical and Advanced Research and Development Authority	ASPR	$230 million

Congress has not appropriated new funding for the above listed Federal programs for at least 10 years. These programs are critical for preventing healthcare-associated infections (HAIs) and the spread of antibiotic resistance (AR). New investments in these programs must be prioritized to improve the quality of care delivered to every American and to ensure advancements made possible by medical research and innovation can be sustained.

Although dedicated prevention and infection control efforts have helped reduce the number of infections and deaths caused by antibiotic resistance, the 2019 Antibiotic Resistance Threats in the United States report, published by the Centers for Disease Control and Prevention (CDC), concludes that we are now in a post-antibiotic era where some drugs no longer cure the infections they were designed to treat. In the United States, 2.8 million antibiotic-resistant infections occur each year resulting in 35,000 deaths. Suboptimal antibiotic use and prescribing practices have led to nearly 223,900 C. difficile infections, of which at least 12,800 people died in 2017.

We urge you to invest $25 million in the National Healthcare Safety Network (NHSN). Although significant progress has been made in preventing some HAIs, about one in 31 hospitalized patients (3.2 percent) develops at least one HAI. NHSN collects data on antibiotic prescribing and the prevalence of HAIs. The NHSN is also continuing its efforts to implement the antibiotic use and resistance module in hospitals, which would help monitor the use of certain antibiotics and the appearance of multidrug-resistant organisms in facilities. This funding includes providing technical support to more 65,000 users representing about 22,000 healthcare facilities across the continuum of care. There have been no new investments in the NHSN for at least 10 years despite the exponential expansion of its utilization since its inception. Increased funding is critical to ensure CDC's continued efforts toward eliminating HAIs and optimizing antibiotic prescribing practices.

We urge you to invest $200 million in the Antibiotic Resistance Solutions Initiative (ARSI). To combat the post-antibiotic era in which we now find ourselves, aggressive strategies must be adopted to make meaningful progress against the threat of AR. The ARSI supports 50 state health departments, six large city health departments, and Puerto Rico to detect, respond, and contain antibiotic-resistant pathogens. Increasing investments in ARSI would enable them to sustainably expand epidemiology, laboratory, and diagnostics capacity. The ARSI also includes the Antibiotic Resistance Lab Network which is comprised of seven regional labs that monitor and detect organisms that are resistant to most or all antibiotics.

We urge you to invest $57 million in the Advanced Molecular Detection (AMD) Initiative. AMD supports collaborative relationships between academic research institutions and public health to facilitate the development of new tools that detect disease faster, identify outbreaks sooner, and protect people from emerging and evolving disease threats. It informs vaccine and diagnostics development for new and emerging diseases as well as identify and track AR. Right now, AMD plays a critical role in the response to the growing global outbreak of COVID–19. An increased investment in AMD will empower state and local health departments with the ability to quickly develop targeted prevention and control strategies during an outbreak caused by emerging pathogen.

We urge you to invest $100 million in Public Health Data and IT Modernization. Congress recognized that our nation's public health data and infrastructure was dangerously antiquated by appropriating $50 million in new investments in fiscal year 2020. This new investment allows CDC to support state, local, tribal, and territorial health departments to begin the process of moving away from sluggish, manual, paper-based data collection to seamless, automated IT systems as well as recruit and retain skilled data scientists to use them. However in order to fully meet the current needs of our nation's public health data infrastructure, Congress will need to invest $100 million every year for the next 10 years to ensure public health professionals are consistently able to get ahead and stay ahead of emerging and urgent HAI and AR threats. These sustained investments will also allow policymakers to make better decisions informed by the expertise of the public health workforce and enabled by strong data and health information systems.

We urge you to invest $100.4 million for the Agency for Healthcare Research and Quality's (AHRQ's) patient safety and research portfolio. Specifically, we are seeking $50.2 million for research and preventative strategies for healthcare-associated infections, $13.9 million for research and strategies to combat antibiotic resistant bacteria, and $73.8 million to support investigator-initiated research grants. AHRQ is the only Federal agency that funds research to study the most efficient way to deliver healthcare while also improving the quality of patient care and outcomes across the healthcare continuum. Much of this research is conducted by leading medical investigators at academic centers and other institutions of research across the country. Congress has prioritized medical research investments for treatment and cures over the last several years. While we commend these investments in innovation, Congress must also prioritize research in discovering the best methods for preventing HAIs and AR to ensure a safe environment for delivering treatments and cures. AHRQ also provides tools and training to implement research findings for the everyday care of patients.

We urge you to invest $230 million for Broad Spectrum Antimicrobials and CARB–X at the Biomedical Advanced Research and Development Authority (BARDA). The BARDA Broad Spectrum Antimicrobials program and CARB–X, programs within the office of the Assistant Secretary for Preparedness and Response (ASPR), have demonstrated that successful development of new FDA approved antibiotics is possible. Without this investment, modern medical advances that have become standard practice, such as chemotherapy and organ transplantation which can only be sustained by the availability of antibiotics, may become unavailable due to the high risk of infection.

The importance of investing in preparing for and responding to emerging infectious disease threats has been highlighted in the ongoing COVID–19 pandemic. The challenges we are facing today with the growing prevalence in AR will get worse without new investments. Preventing infections, improving antibiotic use, detecting threats, and implementing interventions are essential to ensuring public health. The societies thank you for this opportunity to submit testimony on behalf of clinicians and researchers who champion infection prevention and antibiotic resistance.

Prepared Statement of the Society for Maternal-Fetal Medicine

On behalf of the Society for Maternal-Fetal Medicine (SMFM), I am pleased to submit testimony in support of the important work related to women's and infants' health being conducted at the U.S. Department of Health and Human Services for fiscal year 2021. SMFM urges Congress to ensure that the Centers for Medicare and Medicaid Services (CMS), Centers for Disease Control and Prevention (CDC), National Institutes of Health (NIH), Health Resources and Services Administration (HRSA) and Agency for Healthcare Research and Quality (AHRQ) are adequately funded in fiscal year 2021. Specifically, SMFM urges the Committee to support a total of $44.7 billion for the NIH, with $1.7 billion of that total to fund the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), $8.3 billion for the CDC, including $76 million for the Safe Motherhood Initiative, $8.8 billion for the HRSA, including $715 million for the Title V Maternal and Child Health Services Block Grant, $189 million for the National Center for Health Statistics (NCHS), $471 million for AHRQ, and continued, sustained, broad support for the U.S. Department of Health and Human Services and programs relevant to pregnant and post-partum people and their children.

Established in 1977, SMFM is the national voice for clinicians and researchers with expertise in high-risk pregnancies. A non-profit association representing more than 5,000 individuals, the core of SMFM's membership is comprised of maternal-fetal medicine (MFM) subspecialists. MFM subspecialists are obstetricians with an additional 3 years of formal education and who are board certified in maternal-fetal medicine, making them highly qualified experts and leaders in the care of complicated pregnancies. Additionally, SMFM welcomes physicians in related disciplines, nurses, genetic counselors, ultrasound technicians, MFM administrators, and other individuals working towards optimizing the care of women with high-risk pregnancies.

SMFM members see the most at-risk and complex patients, with the goal of optimizing outcomes for pregnant people and their children.

NATIONAL INSTITUTES OF HEALTH/NICHD

The Eunice Kennedy Shriver National Institute for Child Health and Human Development (NICHD)'s investment in maternal and child health outcomes is essential to understanding the rising maternal mortality and severe morbidity rates and to optimize maternal and child health.

Task Force Specific to Pregnant Women and Lactating Women (PRGLAC): SMFM urges Congress to continue its strong support for the PRGLAC Task Force, housed at NICHD. PRGLAC submitted its report to the Secretary in the fall of 2018 with 15 recommendations on including pregnant and breastfeeding people in clinical trials and broad research initiatives and is now in the midst of creating its implementation plan, which is expected in the summer of 2020. SMFM urges Congress to continue to support the implementation of the PRGLAC recommendations. It is essential that Congress support broader inclusion of pregnant and lactating people in research, so that lifesaving interventions and treatments can be addressed for this population.

Maternal-Fetal Medicine Units Network (MFMU): SMFM urges continued strong support of the MFMU and ask that Congress allocate $30 million to support the

Network's continued work. Established in 1986 to achieve a greater understanding and pursue development of effective treatments for the prevention of preterm births, and reduce low birth weight infants, fetal growth abnormalities, fetal mortality and medical complications during pregnancy the MFMU is a critical resource to addressing the nation's growing maternal health crisis. We hope that the NICHD will leverage the MFMU to build on its success by ensuring its highly efficient structure of multicenter collaborative research. The MFMU has a strong history of changing and improving clinical practice and obstetric management, improving outcomes of pregnant people and babies in the United States, and is extremely successful, as 25.6 percent of all publications from the network are cited in clinical practice guidelines. These guidelines are relied upon by Medicaid and Medicare programs to define evidence-based services covered under the plans. The work of the network is even more urgent given the increase in maternal mortality and severe morbidity in the US. We urge Congress to ensure stable and sustained funding and infrastructure for the MFMU, and to ensure that any proposed change in the funding mechanism or structure for the MFMU not compromise the ability of the network to remain nimble and directly address the changing landscape of women's health, including to reduce health disparities.

Preterm Birth: Delivery before 37 weeks' gestation is associated with increased risks of death in the immediate newborn period as well as in infancy and can cause long-term complications. About 20 percent of premature babies die within the first year of life. Although the survival rate is improving, many preterm babies have lifelong disabilities including cerebral palsy, mental retardation, respiratory problems, and hearing and vision impairment. Preterm birth costs the U.S. $32.5 billion annually. Great strides are being made through NICHD-supported research to address the complex situations faced by mothers and their babies. One of the most successful approaches for testing research questions is the NICHD research networks which allow researchers from across the country to collaborate and coordinate their work to change the way we think about pregnancy complications and change medical practice across the country. These networks deal with different aspects of pregnancy the problem of preterm birth and its consequence.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

The CDC's Division of Reproductive Health (DRH) as well as the National Center for Birth Defects and Developmental Disabilities (NCBDDD) are doing important work related to pregnancy. The data collection efforts related to pregnancy outcomes, maternal mortality and medications in pregnancy must continue. The support from CDC to states related to data collection and especially maternal mortality review committees will go a long way toward tackling this growing public health problem. According to the NCHS, the maternal mortality rate in 2018 was 17.4 deaths per 100,000 live births and racial disparities persisted with a maternal mortality rate of 37.1 per 100,000 live births among non-Hispanic black women compared to 14.7 among non-Hispanic white women. SMFM fully supports Congress' attention to reducing maternal mortality through CDC's Safe Motherhood Initiative, supporting the highest possible allocation for this work. We ask Congress to allocate $30 million for the maternal mortality review committees (MMRCs) and their continued work. Funding for perinatal quality collaboratives (PQCs) and other initiatives that would investigate and transparently report on maternal mortality causes while reducing health disparities are essential in tackling our nation's rising maternal mortality rates. We also ask Congress to allocate $100 million for the CDC's Surveillance for Emerging Threats to Moms and Babies initiative.

HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

The work of HRSA is critical to maternal and child health. HRSA's initiatives reduce infant mortality, improve maternal health and wellbeing, and serve more than 50 million people through the MCH block grant. The MCH block grant is critical to ensure that women and their children have access to quality care. These funds provide and ensure access to comprehensive prenatal and postnatal care to women—especially low income and at-risk pregnant people. The Title V MCH Block Grant programs save Federal and State Governments money by ensuring delivery of preventive services to avoid more costly chronic conditions later in life. Additionally, HRSA's family planning initiatives ensure access to comprehensive family planning and preventive health services for more than 4 million people, thereby reducing unintended pregnancy rates. Finally, HRSA's support for the Alliance for Innovation in Maternal Health Care (AIM) reduces maternal mortality through implementation of care bundles at the state and institutional level. These bundles help reduce maternal mortality through quality improvement in various areas including postpartum hemorrhage and hypertension. We encourage Congress' support for this important program that will help reduce maternal mortality nationally.

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY (AHRQ)

Projects conducted at the Agency for Healthcare Research and Quality (AHRQ) are critical to ensuring that research is translated from bench to bedside through comprehensive implementation in the everyday practice of medicine. Unfortunately, over the past decade, AHRQ's existence has been under threat. AHRQ is the only Federal agency that funds research on "real-life" patients—those with comorbidities and co-existing conditions, including high-risk pregnant people. In 2000, an estimated 60 million Americans had multiple chronic conditions. By 2020, an estimated 81 million people will have multiple chronic conditions, and the costs of their care will consume 80 percent of publicly funded health insurance programs, such as Medicare and Medicaid. SMFM hosted a workshop in February 2020 on implementation practices in maternal mortality. AHRQ's support in ensuring widespread uptake among providers, public health officials, health systems and states is essential to ensuring that best practices and guidance is implemented broadly to reduce maternal mortality and severe maternal morbidity.

Prioritizing Maternal Health During COVID–19: The COVID–19 pandemic has exposed the existing inequities and gaps within our healthcare system for people across the country, including pregnant people. It is now more important than ever to ensure that pregnant and lactating people are being included in clinical research related to COVID–19 and vaccine and therapeutic development. We urge HHS to prioritize and adequately fund efforts for maternal health that aim to reduce maternal mortality and severe morbidity during and after the pandemic.

CONCLUSION

With your support of vital HHS programs, researchers, clinicians and patients can continue to peel away the layers of complex problems of pregnancy that have such devastating consequences and truly improve the health and wellbeing of mothers and babies.

[This statement was submitted by Dr. Judette Louis, MD, MPH, President, Society for Maternal-Fetal Medicine.]

PREPARED STATEMENT OF THE SOCIETY FOR NEUROSCIENCE

Mr. Chairman and members of the Subcommittee, I am Barry Everitt, President of the Society for Neuroscience (SfN) and it is my honour to present this testimony on behalf of the Society in strong support of at least $44.7 billion, a $3.0 billion increase over fiscal year 2020, in funding for the National Institutes of Health (NIH) for fiscal year 2021, including the release of the 21st Century Cures funding. As both a researcher and as a Professor in the Department of Psychology at Cambridge University, I understand the critical importance of Federal funding for neuroscience research in the United States.

My own research focuses on the neural and psychological basis of drug addiction and is dedicated to understanding the maladaptive engagement of the learning, memory, and motivational mechanisms that underlie compulsive drug use. Drug abuse and addiction are critical issues in my country as in yours, having devastating consequences at the individual, family, and society levels. My research group has made significant advances in showing that structural and neurochemical changes in the brain associated with behavioral impulsivity confer a major risk on the vulnerability to develop cocaine addiction. We have also demonstrated the neural circuit basis of the transition from recreational to the compulsive use of opioids, stimulants and alcohol, revealing commonalities as well as differences in the neural basis of addiction to these drugs. This understanding has opened the door to the development of novel pharmacological and psychological treatments for addiction that may promote and maintain abstinence from drug use. For example, we have shown that a novel opioid receptor antagonist greatly decreases opioid, cocaine, and alcohol use in animal models, as well as showing its efficacy and safety in experimental studies in humans. We have further revealed that reducing the impact of maladaptive drug memories can promote abstinence from drug use, as well as being effective in the treatment of anxiety disorders and post-traumatic stress disorder (PTSD). The NIH, especially NIDA and NIAAA, supports the great majority of the global research on addiction and its treatment and this is a shining example of how governmental funding for research in the US leads the world and inspires related and collaborative research internationally on this major brain disorder.

SfN believes strongly in the research continuum: basic science leads to clinical innovations, which lead to translational uses that impact the public's health. Basic science is the foundation upon which all health advances are built. However, basic research depends on reliable, sustained funding from the Federal Government. SfN is very grateful to Congress for its appropriations and increases for NIH over the last 5 years. Growing the NIH budget over $11 billion in that period is exactly the kind of sustained effort that is needed, and your continued support will pay dividends for years to come.

SfN stands with the more than 335 organizations and institutions in the biomedical research community supporting an increase in NIH funding of at least $3.0 billion above the final fiscal year 2020 level, including the release of the 21st Century Cures funding. This increase is consistent with those provided by this committee for the past few years and provides certainty to the field of science, allowing for the exploitation of more scientific opportunity, more training of the next generation of scientists and more improvements in the public's health.

Equally as important as providing a reliable increase in funding for biomedical research is also ensuring that funding is approved before the end of the fiscal year. Your success in 2018 in completing appropriations prior to the start of the fiscal year was a tremendous benefit to research. Continuing Resolutions have significant consequences on research, including restricting NIH's ability to fund grants. For some of our members, this means waiting for a final decision to be made on funding before knowing if their perfectly scored grant would in fact be realized, or operating a lab with 90 percent of the awarded funding until appropriations are final. All of this has real and negative impacts on research and all of the positive benefits that research provides in this country. Meeting the example you set in 2018 would be another substantial benefit to science.

I would also like to express my and the Society's appreciation for your support of the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative. While only one part of the research landscape in neuroscience, the BRAIN Initiative has been critical in promoting future discoveries across neuroscience and related scientific disciplines (see an example below). By including funding in 21st Century Cures—and note that it is only part of the funding that the BRAIN Initiative will require—Congress helped maintain the momentum of this endeavor. Note however, using those funds to supplant regular appropriations would be counterproductive. There is no substitute for robust, sustained, and predictable funding for NIH.

The deeper our grasp of basic science, the more successful those focused on clinical and translational research will be. We use a wide range of experimental and animal models that are not used elsewhere in the research pipeline. These opportunities create discoveries—sometimes unexpected discoveries—that expand knowledge of biological processes, often at the molecular level. This level of discovery reveals new targets for research to treat all kinds of brain disorders that affect millions of people in the United States and beyond.

As the leading scientific society dealing with the brain and the central nervous system, SfN hosts one of the largest annual scientific meetings and publishes two highly-rated scientific journals where scientific discoveries are put on display. Some recent, exciting advancements include the following:

Decoding Speech From the Brain

The BRAIN Initiative has been key for developing new technologies that may one day be used in the clinic. For patients suffering from a stroke and other neurological disorders, the loss of speech due to paralysis in the muscles in their face and neck can be devastating and leaves few ways to communicate quickly or easily. While there are devices that allow the use of head or eye movements to produce speech, these currently rely on choosing individual words or letters one at a time and are consequently very slow. Researchers hoping to close this communication gap recorded the brain activity of volunteers when speaking, including their muscle movements associated with speech. They were then able to use machine learning techniques to decode these brain signals, creating simulated movements of the vocal track that could be turned into synthesized speech. Testers asked to transcribe these sentences were able to accurately determine the phrases more than half of the time. While further refinement and testing is needed before this technology can be used with patients, it provides a path towards restoring speech those who have lost the ability.

Generating a Library of New Molecules

The discovery of new molecules and compounds is critical to developing new drugs to treat mental illnesses and other neurological disorders. To facilitate this, scientists funded by NIH have created an expanding virtual library of what will soon be 1 billion new molecules that can be tested for compatibility with specific receptors in the brain. Using this expansive library, researchers were able to model how each molecule would interact with the receptor they were interested in blocking and then choose the most likely candidates to test in the lab. Through this method, they were able to generate six new molecules that interacted specifically with a dopamine receptor type linked to schizophrenia, ADHD, Parkinson's disease, and other neurological conditions. The creation of this extensive, publicly available library will allow researchers around the world to expand their search for new treatments.

SUMMARY AND CONCLUSION

NIH funding is not only critical for the future of biomedical research and for training researchers at the bench, but is also a key economic driver of science in the United States through funding universities and research organizations across the country. For this nation to remain a leader in biomedical research, Congress must continue to support basic research that fuels discoveries as well as the economy.

To reiterate, the Society for Neuroscience strongly supports the appropriation of at least $44.7 billion for the National Institutes of Health for fiscal year 2021, including the release of the 21st Century Cures Act funding. Like the Subcommittee, we also strongly support the appropriation of this funding in a timely manner, one that avoids delays in approving new research grants or causes reductions in funding for already approved research funding.

Thank you for your strong and continued support and I look forward to working with you to ensure that research remains central to the economy and remains a priority of the Congress. The trinity created among Congress, the NIH, and the scientific research community has created great benefits for the United States, its people, and those suffering from diseases and disorders. As an international researcher, I also see clearly the global impact of your funding of the NIH. On behalf of the Society for Neuroscience, I urge you to continue it.

[This statement was submitted by Barry Everitt, Sc.D., F.R.S., President, Society for Neuroscience.]

PREPARED STATEMENT OF THE SOCIETY FOR WOMEN'S HEALTH RESEARCH

On behalf of the Society for Women's Health Research (SWHR), I am pleased to submit testimony to the Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies. We will highlight important work related to women's health being conducted at the U.S. Department of Health and Human Services (HHS) for fiscal year 2021. With that in mind, SWHR urges Congress to ensure the Centers for Medicare and Medicaid Services (CMS), Centers for Disease Control and Prevention (CDC), National Institutes of Health (NIH), Health Resources and Services Administration (HRSA) and Agency for Healthcare Research and Quality (AHRQ) are adequately funded in fiscal year 2021.

We specifically urge the Committee to support a total of $44.7 billion for the NIH, including proportional increases to fund the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) and Office of Research on Women's Health (ORWH). We support at least $8.3 billion in funding for the CDC; $8.8 billion for HRSA, including at least $715 million for the Title V Maternal and Child Health (MCH) Services Block Grant; and $471 million for AHRQ. We encourage continued, sustained, broad support for HHS and programs relevant to women's health and women's health research.

Founded in 1990, SWHR is the thought leader in promoting research on biological sex differences in disease and improving women's health through science, policy, and education. An appropriately funded, robust Federal research agenda that is committed to furthering women's health research is critical for the U.S. to address gaps in knowledge and achieve equity in healthcare for women.

NATIONAL INSTITUTES OF HEALTH (NIH)

The NIH is America's premier medical research agency and the largest source of funding for biomedical and behavioral research in the world. As such, its public health mission is vital to promote the overall health and well-being of Americans by fostering creative discoveries and innovative research, training and supporting researchers to ensure continued scientific progress, and expanding the scientific and medical knowledge base.

Multiple initiatives within the NIH are aimed at improving the health of women. The agency released its Trans-NIH Strategic Plan for Women's Health Research in April 2019, which laid out broad agency goals to complement its more targeted women's health programs. The NIH's emphasis on improving standard research methodologies to better address sex and gender and funding relevant women's health research makes continued strong support of this agency fundamental to supporting women's health.

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

Housed within the NIH, the NICHD has achieved extraordinary feats in research on women's health throughout the lifecycle. The NICHD conducts critical and timely studies that support the health of women and children—such as the recently launched study analyzing the effects of the COVID–19 pandemic on pregnancy and delivery nationwide. It is only with adequate resources that the NICHD can build upon new and existing initiatives to address knowledge gaps and identify solutions to benefit women, children, and families throughout the U.S. Several of these initiatives are detailed below.

Reproductive Sciences: The NICHD's reproductive biology research is vital in improving treatment options for serious gynecologic conditions. Research on many of these conditions is broadly underfunded in proportion to their significant burden on millions of women. For example, more than 11 percent of reproductive-aged women are living with endometriosis, and more than 80 percent of African American women and almost 70 percent of white women will develop uterine fibroids at some point in their lifetime. Despite the prevalence of these diseases and their potentially severe effects on women, their families, and society, a clear understanding of the basic biology behind these conditions is lacking, resulting in delayed diagnosis and limited treatment options. Given the history of limited funding allocated to research on these conditions, it is imperative that the NICHD receive robust funding to continue and expand upon this essential work.

Task Force on Research Specific to Pregnant Women and Lactating Women (PRGLAC): The NICHD is leading the field in supporting inclusion of pregnant and lactating women in clinical trials. Pregnant women historically have been excluded from research—even in studies that would advance knowledge of medical conditions and treatments in pregnancy. The PRGLAC task force is now in the second phase of its efforts to develop a strategy to implement 15 recommendations outlined in its mandated report to Congress and HHS. The NICHD must have sufficient resources for PRGLAC to continue its important work in this area.

PregSource®: The NICHD's PregSource initiative allows pregnant women to track health data from gestation to early infancy and access evidence-based information about normal and abnormal pregnancy experiences. This program encourages researchers to use aggregated data and recruit pregnant and postpartum women in clinical trials. It is making important headway in eliminating knowledge gaps and imbalances in care for these understudied patient populations.

Maternal Mortality: The NICHD's Pregnancy and Perinatology Branch plays a pivotal role in supporting research to improve the health of women before, during, and after pregnancy. Its work is central in continuing to reduce the number of preterm births and pregnancy and delivery complications, and in ensuring the long-term health of mothers and their children. Approximately 10 percent of births in the US are preterm, and rates are much higher in some minority populations. The 2018 US maternal mortality rate was 17.4 deaths for every 100,000 live births—meaning the US is faring much worse than comparatively wealthy countries. Research conducted in these areas by the NICHD and other agencies will be crucial in limiting the number of pregnancy-related complications and deaths in the US.

Office of Research on Women's Health (ORWH)

As the NIH focal point for coordinating women's health research, the ORWH ensures women are appropriately represented in biomedical and behavioral research supported by the NIH. SWHR has long supported the idea that studying, analyzing, and reporting on sex differences should be standard practice across all research. It is well-known that sex differences exist at all levels: cellular, molecular, and systems. Furthermore, it is understood that these differences affect research outcomes in a variety of significant ways.

In 2015, the NIH announced a policy (NOT–OD–15–102) to factor sex as a biological variable (SABV) into research designs, analyses, and reporting for NIH-funded vertebrate animal and human studies. The ORWH leads collaborations across the NIH to implement this policy and develop research programs such as Building Interdisciplinary Research Careers in Women's Health (BIRCWH), an initiative that aims to increase the number and skills of investigators who conduct research on sex and gender influences on health and disease. The Specialized Centers of Research Excellence (SCORE), another signature ORWH program, is designed to expedite the development and application of new knowledge to human diseases that affect women, to learn more about the etiology of these diseases, and to foster improved approaches to treatment and/or prevention. The ORWH needs adequate funding to continue these initiatives and to support scientists across the country who are conducting groundbreaking research on sex differences.

National Institute on Minority Health and Health Disparities (NIMHD)

The NIMHD serves as the leader on scientific research initiatives dedicated to improving minority health and reducing health disparities—differences in the incidence and outcome of health conditions among specific populations defined by race or ethnicity, sex and gender, disability status, geographic location, or other sociodemographic classifications. The NIMHD invests in critical research on minority health and health disparities. Its work informs practice and policy to increase the scientific community's focus on equally important non-biological factors such as socioeconomics, discrimination, culture, and environment in relation to health disparities.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

The CDC's Division of Reproductive Health (DRH) and its goals of improving women's health from menarche to menopause; improving pregnancy health and care; and improving fetal, newborn, and infant health are areas of fundamental importance to women and their families. The DRH's work to address issues of chronic disease among women of reproductive age and its data collection efforts related to pregnancy outcomes, maternal mortality, and medications in pregnancy must continue. Funding for maternal mortality review committees (MMRCs), perinatal quality collaboratives (PQCs), and other initiatives that investigate and transparently report on maternal mortality causes while reducing health disparities are essential in tackling our nation's rising maternal mortality rates.

Additionally, the CDC's work will be vital to continued disease monitoring and prevention during the novel coronavirus outbreak. Studying sex and gender differences in COVID–19 infection rates and outcomes will help us to figure out why the virus is affecting men more severely and to understand how we can better improve our responses to future pandemics. Increasing CDC funding for pandemic response will improve the agency's ability to collect reliable, consistent data about COVID–19, including sex and gender differences in deaths, symptoms, risk factors, and virus exposure.

HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

The work of HRSA is crucial to women's health. HRSA's initiatives reduce infant mortality and improve maternal health and wellbeing through its support of pregnant women, mothers, and their families. The Title V Maternal and Child Health (MCH) Block Grant is specifically tailored to address the needs of pregnant women and their families by providing access to comprehensive prenatal and postnatal care to women—especially low-income and at-risk pregnant women. HRSA support saves Federal and State Governments money by ensuring delivery of preventive services to avoid more costly chronic conditions later in life.

Agency for Healthcare Research and Quality (AHRQ)

AHRQ ensures that research is translated from bench to bedside through comprehensive implementation in the everyday practice of medicine. AHRQ is the only Federal agency that funds research on "real-life" patients—including women with comorbidities and co-existing conditions and high-risk pregnant women. Approximately 38 percent of women have a least one diagnosed chronic disease, as compared to 30 percent of men, making this a topic of particular relevance to women's health, as individuals with complex comorbidities are typically excluded from research studies. Budget cuts in recent years have led to termination of various disease programs and portfolios, limiting the impact of AHRQ's important work. Increasing AHRQ's funding will lead to better care for women and for all Americans.

CONCLUSION

In conclusion, I would like to thank the Chair, Ranking Member, and the Committee for their support for medical and health services research and their commitment to the health of the nation. Thank you in advance for consideration of this HHS fiscal year 2021 funding request and the rationale behind it. If you have questions, please contact Melissa Laitner, PhD, MPH, Director of Science Policy, at melissa@swhr.org.

[This statement was submitted by Kathryn G. Schubert, President & CEO, Society for Women's Health Research.]

PREPARED STATEMENT OF TEXAS FAMILIES AND FRIENDS FOR CHOICE

Chairman Blunt, Ranking Member Murray, and Committee Members,

Thank you for your service and for affording families the opportunity to present testimony.

INTEREST AND REQUEST OF TEXAS FAMILIES AND FRIENDS FOR CHOICE

I am Debra Wallace of Red Rock, Texas and mother of Justin Wallace, aged 39, who is severely autistic and profoundly communicatively and behaviorally impaired. I am submitting this testimony not only on behalf of my child, but for all residents of the Texas state centers and their families, who view those same centers as a safe and supportive community that is uniquely theirs. The Texas Families and Friends for Choice (TFFC) is comprised of those guardians who choose to place their loved in one of our thirteen (13) Texas centers.

Justin lived at home for 18 years with me, my husband and his four siblings. All therapies were attempted, and doctors were consulted to help our precious child. When our autistic little boy morphed into a strong young man, we realized our greatest fear; we were no longer physically capable of managing his care and safety. Initially, we were pushed to place him in a group home situation, but the outcomes for those individuals with a high level of need in "community" homes were often troubling and even tragic.

Today, he happily resides at the Austin State Supported Living Center, where he participates in activities, and, like many other residents, works at the sheltered workshop for his weekly paycheck. Like the many members of TFFC, we chose to place our severely disabled child in a facility that would keep him safe and provide a community that would truly understand his needs. Unlike the understaffed and isolating group homes, the Intermediate Care Facility (ICF) staff meet our severely disabled loved ones where they are, rather than forcing them into a world that overwhelms and misunderstands them. The centers provide twenty four (24) hour medical care, field trips, computer, swimming, gardening, holiday events, choir, music therapy and so much more.

After years of struggle and fighting for our children, families believed we had found the best life for them. But that was not to be. The funds that have flowed from the Federal Government have created a battlefield in many states, closing many facilities, denying IDD people their safe havens or even their lives. Families are bankrupting themselves in order to oppose the skewed ideology of "community first" that is being funded by the Federal Government. Therefore, TFFC is requesting relief from the Department of Health and Human Services (HHS) programs and policies which undermine Texas ICF centers and attempt to deny guardians their right to chose the best program/placement for their loved ones.

HHS DD ACT PROGRAMS IN TEXAS

As a parent I have witnessed first hand the propaganda used against the ICF centers and the families that support them by recipients of DD Act funds. Health and Human Services (HHS) through its grants to programs created under the Developmental Disabilities Assistance and Bill of Rights Act (Public Law 106–402—the DD Act) has been responsible for many of the groups intent on closing Texas' larger residential centers for persons with cognitive deficits and other developmental disabilities.

Health and Human Services (HHS) through its grants to programs created under the Developmental Disabilities Assistance and Bill of Rights Act (Public Law 106–402—the DD Act) has been responsible for many of the groups intent on closing Texas' larger residential centers for persons with cognitive deficits and other developmental disabilities. The DD Act programs are: (1) State Councils on Developmental Disabilities, (2) Protection and Advocacy (P&A) systems, (3) National Network of University Centers for Excellence in Developmental Disabilities Education, Research and Service (UCEDD) programs and (4) Projects of National Significance (PNS).

There have been no Congressional hearings on the DD Act in over 20 years. It was last reauthorized in 2000 for a period of 7 years. Why does Congress continue to fund programs without opportunity for families adversely affected to provide testimony? How will this subcommittee protect Justin and his peers from destructive policies and activities promoted and carried out by those who are on the Federal payroll? Each legislative session, the Arc, the Protection and Advocacy group, Disability Rights, and the Coalition for Texans with Disabilities have testified that our life-saving centers should be closed, forcing our most vulnerable loved ones into unstable and treacherous situations. In fact, during a 2014–2015 attempt to close centers in Texas by HHS, fifty (50) IDD men were evicted from the Austin State Supported Living Center, and subsequently a minimum of twenty percent of them died within a short span. One resident, who was placed there by his parents, had lived at the center for fifty years due to a severe seizure disorder. Following the death of his parents, his guardianship was given to an agency who clearly had a conflict of interest, as it was a community group home provider. He passed away two weeks after his move. His family's wishes were ignored, because of an aggressive push from these federally funded ideologues. Often, TFFC families must drive across our vast state to counter the "advocates" testimony and attempt to halt closures and save lives. As there is no agency funded to defend these facilities against closures, families have to find ways to mount a legal defense on their own. Advocacy groups do not protect those who move into the perfect mythological community, as it would deny their very purpose for existence.

Families have also witnessed the testimony of "advocates" to limit or sunset guardianships. After many years of loving, sacrificing for, and fighting for a beloved child, families hardly need a professional advocate who has a "one size fits all" outcome in mind to take control of their child's/sibling life. Guardians are under siege in Texas, and I have witnessed suggestions to legislators that guardianships be "sunsetted". What better way to expedite the closing of care facilities and eliminate choice than to vacate guardianships? Again, the agency pushing this strategy, is partially funded by the Texas Council on Developmental Disabilities (TCDD).

The Texas Advocates, who are funded by the Texas Council on Developmental Disabilities, made an initial visit to the Austin SSLC in February of 2019. I attended the meetings their director and grant writer had set up for residents of the facility. It was evident that the objective of the program was to persuade residents of the facility to leave and live in a group home setting. During their meeting, the mentors instructed the peer advocates to get permission from the residents to participate in the program, and if the resident was incapable of responding, they could state that a blink was consent. If this was challenged by the guardian, a hearing could be set up to override the guardian's decision. When I asked for a copy of the grant, everyone ceased talking. The grant writer would not respond to me. Later in the conversation, the mentor reminded the peer advocates that there would be a scheduled deinstitutionalization rally on the steps of the Texas Capitol in March. In the next session that same day, I witnessed two severely disabled elderly women wheeled in. It was inappropriate, as they were unable to answer questions or play games. They were both suffered from severe cerebral palsy and IDD and had been forced to come to the meeting on that cold, wet February afternoon. Over the next few months, I witnessed this repeatedly. I complained to the Human Rights officer and never received a response. One young man, who came in later and stated that he did not want to leave the center was pressured by the group and the mentors. Guardians were openly criticized as being obstacles to success on a regular basis. Funding for this program comes from the TCDD.

The Arc has openly stated that Money Follows the Person funds would be used to assist in closing facilities. They testify and pressure legislators to close centers in Texas. Employees have been known to mock family members and coach their advocates to tell families that they are selfish for placing loved ones in a care facility rather than keeping them home (not always possible), or that they are taking funds from the community programs. Meanwhile, they do not assist desperate families, like my own, in placing their loved ones who could never thrive in a group home, into facilities. Last night I listened to a desperate single mother who is in her sixties, plead for help in placing her three hundred (300) pound 35 year old, violent, self injurious, severely autistic son into a facility. The Arc nor Disability Rights will assist her.

REQUEST

We respectfully request you consider report language in the fiscal year 2021 LHHS spending bill barring Federal funds from incentivizing states to close their specialized facilities for persons unable to care for themselves. Suggested Report Language for fiscal year 2021 Spending Bill, Attachment 2.

Respectfully submitted.

[This statement was submitted by Debra Wallace, Texas Families and Friends for Choice.]

PREPARED STATEMENT OF THE TOURETTE ASSOCIATION OF AMERICA

Dear Chairman Blunt, Ranking Member Murray and Members of the Subcommittee:

The Tourette Association of America (TAA) would like to take this opportunity to thank the members of the Subcommittee for the opportunity to submit written testimony and for considering our request for funding for fiscal year 2021. The Centers for Disease Control and Prevention (CDC) play a pivotal role in educating the public. To that end, the Tourette Syndrome Public Health Education and Research Program at the CDC is critically important to the TS and Tic Disorder community. We respectfully request that you continue funding the enacted level $2 million appropriation for the program in fiscal year 2021 Labor, Health and Human Services (LHHS), Education and Related Agencies Appropriations. The program on Tourette Syndrome is administered within the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the CDC, in partnership with the TAA. This program was established by Congress in the Children's Health Act of 2000 (Public Law 106–310 Title 23) and is the only such program that receives Federal funding for Tourette Syndrome (TS) public health education. With your support at the previously enacted level of $2 million, CDC can ensure critically necessary progress continues in the areas of public education, research and diagnosis for TS and Tic Disorders.

The TAA is the premier national non-profit organization working to make life better for all people affected by TS and Tic Disorders. We have served in this capacity for 46 years. Tics are involuntary, repetitive movements and vocalizations. They are the defining feature of a group of childhood-onset, neurodevelopmental conditions known collectively as Tic Disorders and individually as Tourette Syndrome, Chronic Tic Disorder (Motor or Vocal Type), and Provisional Tic Disorder. People with TS and Tic Disorders often have substantial healthcare costs across their lifespan for healthcare visits, special educational services, medication, and psychological and behavioral counseling. In a recent survey conducted by the TAA (2018 TAA Impact Survey: https://tourette.org/research-medical/impact-survey/), 63 percent of parents struggle to cover the high costs of services for their child such as counseling, appointments and tutoring; 34 percent of parents report they lost their job or they are not able to work as often due to the increased caregiver duties of having a child living with TS; and, 18 percent of parents are not able to afford medications and/or desired medical care for their child.

The CDC Tourette Syndrome Website (https://www.cdc.gov/ncbddd/tourette/data.html) on data and statistics states that data suggests roughly 50 percent of children and teens with TS are not diagnosed. Studies including children with both with diagnosed and undiagnosed TS have estimated that 1 out of every 162 children (0.6 percent) have TS. However, these numbers do not include children with Chronic or Provisional Tic Disorders. The estimated combined total of all school-aged children with TS or another related Tic Disorder is approximately 1-in-100. Factoring in lifelong prevalence, we estimate 1 million adults and children are living with Tourette Syndrome or another Tic Disorder in the United States today. Diagnosis is often complicated. Among children diagnosed with TS, 86 percent have been diagnosed with at least one additional mental, behavioral, or developmental condition according to the CDC website. These co-occurring conditions include Attention Deficit-Hyperactivity Disorder (ADHD), Obsessive Compulsive Disorder (OCD), Autism, Oppositional Defiance Disorder, anxiety, depression, learning difficulties among others and can significantly impact the lives of those affected by TS. In fact, in TAA's 2018 Impact Survey, 42 percent of children felt that dealing co-occurring conditions was one of the biggest challenges in managing TS. In addition, 32 percent of children and 51 percent of adults have considered suicide or participated in self-harming behaviors. This underscores the need to increase the diagnosis rate so physicians, teachers and parents can ensure that adequate support services are in place. The CDC TS Program works to ensure primary care, family doctors or pediatricians are equipped with the additional knowledge necessary either to diagnose or to refer a patient for optimal treatment.

Education professionals often do not receive detailed instruction on how to assess and accommodate students who may have TS and Tic Disorders. A study published in the Journal of Developmental & Behavioral Pediatrics and written in partnership between the CDC and the Tourette Association of America, "Impact of Tourette Syndrome on School Measures in a Nationally Representative Sample", found children with Tourette were more likely to have an individualized IEP, have a parent contacted about school problems and have incomplete homework as compared to children without Tourette or a Tic Disorder. Additionally, most children with Tourette Syndrome had other mental, behavioral, or emotional disorders or learning and language disorders. In TAA's 2018 Impact Survey, 83 percent of children felt that TS negatively impacted their school experience and education and 69 percent of parents noted their child having an individualized education plan (IEP) or 504 plan in place at their school. Educators spend a significant amount of time with their students providing more opportunities to assess symptoms and behavior over a longer period of time. By increasing their knowledge base and understanding of Tourette Syndrome, Tic Disorders and associated co-morbidities, educators can refer students for medical assessment and can also better serve the needs of this population whose challenges are unique to the disorder. Educators can then begin to work more closely with medical providers to develop effective, individualized education plans.

TS and Tic Disorders are greatly misunderstood and often suffer from misinformation and stigma. For example, coprolalia, the involuntary utterance of obscene and socially unacceptable words and phrases, is an extreme and rare symptom often sensationalized by the media. Less than 10 percent of those diagnosed have this symptom, it is not required for diagnosis, and does not persist in many cases. The CDC TS Public Health, Education and Research Program provides important information on symptoms/diagnostic criteria on their website and through the outreach program educating the public and parents on Tourette Syndrome and Tic Disorders to ensure a better understanding which can lead to better diagnosis, earlier treatment and a better understanding.

Delayed diagnosis or the lack of diagnosis can increase healthcare costs, increase education costs and delay important treatment and therapy for the patient. Comprehensive Behavior Intervention for Tics (CBIT) is a non-medicated treatment consisting of three important components: training the patient to be more aware of his or her tics and the urge to tic; training patients to do competing behavior when they feel the urge to tic; and, making changes to day-to-day activities in ways that can be helpful in reducing tics. CBIT is now recognized as a first line treatment by the American Academy of Neurology: https://www.aan.com/Guidelines/Home/GuidelineDetail/958. The CDC Tourette Syndrome Public Health, Education and Research Program strives to increase the understanding and awareness among these critically important medical and education professionals to increase the percentage of school aged children with TS who are diagnosed, improve the timeframe from symptoms to diagnosis and educate them about treatment options like CBIT.

We appreciate the opportunity to submit testimony and appreciate your thoughtful consideration of our request. TAA urges you to provide continued funding for fiscal year 2021 for the Tourette Syndrome Public Health Education and Research Program at CDC's National Center for Birth Defects and Developmental Disabilities at the previously enacted level of $2 million.

Prepared Statement of the Trauma Coalition

As you consider Labor Health and Human Services appropriations for fiscal year fiscal year (2021), the Trauma Coalition, a broad group of organizations representing the nations frontline trauma providers, writes to ask the Committee to provide $11.5 million in funding for the Military and Civilian Partnership for the Trauma Readiness Grant Program.

In 2016, the National Academies of Science, Engineering, and Medicine (NASEM) released a report titled, “A National Trauma Care System: Integrating Military and Civilian Trauma Systems to Achieve Zero Preventable Deaths After Injury.” This report finds that one of four military trauma deaths and one of five civilian trauma deaths could be prevented if advances in trauma care reach all injured patients. In the report, the National Academies recommended that the United States adopt an overall aim for trauma care of “zero preventable deaths after injury,” and sets forth elements of system redesign that would provide military personnel with real-world training and experience at civilian trauma centers. This training has the dual benefit of maintaining military surgical battle readiness between wars while at the same time improving civilian access to trauma care. The report concludes that military and civilian integration is critical to saving these lives both on the battlefield and at home, preserving the hard-won lessons of war, and maintaining the nation's readiness and homeland security.

Section 204, of S. 1379, the Pandemic and All-Hazards Preparedness and Advancing Innovation Act of 2019 (PAHPAI), known as the MISSION ZERO Act was signed into law June 24, 2019 (Public Law No: 116–22). MISSION ZERO takes the recommendations of the NASEM report to create a U.S. Department of Health and Human Services (HHS) grant program to cover the administrative costs of embedding military trauma professionals in civilian trauma centers. These partnerships will allow military trauma care teams and providers to gain experience treating critically injured patients and increase readiness for when these units are deployed. Similarly, best practices from the battlefield are brought home to further advance trauma care and provide greater civilian access.

When it comes to trauma care, a symbiotic military/civilian partnership of training, education, and memorializing this knowledge and skill has long existed. By facilitating the implementation of military-civilian trauma partnerships and growing and strengthening this collaboration, this program will preserve lessons learned from the battlefield, translate those lessons to civilian care, and ensure service members maintain their readiness to deploy in the future.

We ask you to fully fund these lifesaving grants and include $11.5 million for the Military and Civilian Partnership for the Trauma Readiness Grant Program. This funding will allow military and civilian trauma professionals and hospitals to harness the benefits of this unprecedented and innovative program.

Our organizations stand ready to work with you to support this critical effort. Thank you for your consideration.

American Academy of Orthopaedic Surgeons
American Association of Neurological Surgeons
American Burn Association
American College of Emergency Physicians
American College of Surgeons
American Society of Plastic Surgeons
American Trauma Society
Congress of Neurological Surgeons
Eastern Association for the Surgery of Trauma
Emergency Nurses Association
National Trauma Institute
The American Association for the Surgery of Trauma
Trauma Center Association of America
Society of Trauma Nurses

PREPARED STATEMENT OF THE TREATMENT ADVOCACY CENTER

The Treatment Advocacy Center appreciates the opportunity to provide written testimony on the National Institute of Health fiscal year 2021 budget appropriations.

The Treatment Advocacy Center is a national nonprofit dedicated exclusively to eliminating barriers to the timely and effective treatment of serious mental illnesses such as schizophrenia and bipolar disorder. Our organization promotes laws, policies and practices for the delivery of psychiatric care and supports the development of treatments for and research into factors of serious mental illness that have the potential for reducing suffering and improving lives of individuals living with these conditions.

The National Institute of Mental Health (NIMH) is the main Federal Government agency for research into mental illness. The NIMH was authorized through the passage of the National Mental Health Act in 1946 to better help individuals with mental health disorders through better diagnosis and treatments. With a budget of almost $2 billion in 2020, the NIMH conducts research and funds outside investigators to better understand mental illness and develop new treatments to reduce the burden these disorders have on individuals.

Unfortunately, the NIMH has a recent history of ignoring those with the most severe mental illnesses. As Treatment Advocacy Center Founder Dr. E. Fuller Torrey wrote in Psychiatric Times earlier this month:

Congress awarded the National Institute of Mental Health an additional $98 million as part of the National Institutes of Health budget resolution in December 2019, which brings the NIMH budget to just under $2 billion and represents a 35 percent increase since 2015, one of the largest increases in the history of the NIMH. Yet, during the 5 years from 2015 through 2019, NIMH funded a total of 2 new drug treatment trials for schizophrenia and bipolar disorder, according to clinicaltrials.gov. This contrasts with the 5-year period from 2006 through 2010 when NIMH funded 48 such trials. NIMH has thus almost entirely given up its role of evaluating drugs for the treatment of 2 disorders (emphasis added).

In December 2019, the NIMH released a draft of their five-year strategic plan for public comment. They reported receiving more than 6,000 responses over the winter holidays, including from our organization identifying concrete examples of research initiatives the NIMH could be pursuing today to help people with serious mental illness recover and live better lives. Despite this robust response, NIMH made no substantive changes to the research goals or objectives in the final version released to the public earlier this week.

The NIMH research goals for 2020–2025 heighten the existing imbalance in NIMH research. In doing so, they offer little hope for new or better treatments for individuals who are currently afflicted with a mental illness during their lifetime, especially a serious mental illness. This failure is inexcusable given the large increase in research funding given to NIMH in recent years.

Future NIMH funding must be used to correct the existing imbalance, not worsen it, especially now that the COVID–19 pandemic has upended the mental health treatment system and will likely result in an exacerbation of symptoms in people currently affected and an increase in serious mental illnesses among Americans. Those with the most severe forms of mental illness deserve to be prioritized.

Thank you for your consideration of this request.

Sincerely,

E. Fuller Torrey, MD, Founder of the Treatment Advocacy Center and Associate Director for Research, Stanley Medical Research Institute

Michael B. Knable, DO, Board President, Treatment Advocacy Center and Medical Director, Clearview Communities

John Snook, Executive Director, Treatment Advocacy Center, snookj@treatmentadvocacycenter.org

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PREPARED STATEMENT OF TRUST FOR AMERICA'S HEALTH

Trust for America's Health (TFAH) is pleased to submit this testimony on the fiscal year 2021 appropriations bill. TFAH is a non-profit, non-partisan organization that promotes optimal health for every person and community. Right now, communities across the country are overwhelmed with responding to the Coronavirus Disease 2019 (COVID–19) pandemic, while also responding to long-standing issues like chronic diseases, substance misuse and suicide epidemics, health disparities, and environmental threats after years of underfunding of the public health system. While the United States spends an estimated $3.6 trillion annually on health, less than 3 percent of that spending is directed toward public health and prevention.[1] By investing in the Centers for Disease Control and Prevention (CDC) and other public health programs, we can make critical investments for our public health system, which is facing unprecedented challenges. It is important to note that TFAH's recommendations are for modest increases to public health programs, given congressional budget caps. However, the COVID–19 pandemic is demonstrating the dire price we are paying for neglecting the public health infrastructure and prevention of disease.

TFAH believes bold action toward a significant funding increase is needed for CDC, state, territorial, tribal, and local public health programs. Health departments are responding to COVID–19 using archaic surveillance methods, such as paper and fax,[2,3] and with depleted workforce[4] that are the result of years of insufficient funding. TFAH's most recent report, The Impact of Chronic Underfunding on America's Public Health System, finds that health threats are increasing, while public health budgets remain stagnant.[5] Given the devastation of COVID–19 on communities' health, as well as state and local budgets, we urge Congress to work toward long-term, sustainable investments in health departments' infrastructure and workforce. Public health experts have estimated a $4.5 billion annual shortfall for state, terri-

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[1] The Impact of Chronic Underfunding on America's Public Health System: Trends, Risks, and Recommendations, 2020. Washington, DC: Trust for America's Health. February, 2020. https://www.tfah.org/report-details/publichealthfunding2020/.

[2] King, M. Black doctors blast 'woefully anemic' data on minority coronavirus cases. Politico. April 20, 2020. https://www.politico.com/news/2020/04/20/minority-cases-coronavirus-197203.

[3] Written Testimony of Sharon M. Watkins, PhD before House Committee on Science, Space and Technology: Hearing on Fighting Flu, Saving Lives: Vaccine Science and Innovation. November 20, 2019. https://science.house.gov/imo/media/doc/Watkins%20Testimony.pdf.

[4] New Workforce Survey: Public Health Turnover Could Pose Threat to Community Health. De Beaumont Foundation. January 14, 2019. https://www.debeaumont.org/news/2019/new-workforce-survey-public-health-turnover-could-pose-threat-to-community-health/.

[5] The Impact of Chronic Underfunding of America's Public Health System, Trust for America's Health 2020.

torial, tribal, and local public health infrastructure.[6] Such an investment would help ensure every community is served by a comprehensive public health system.

In addition, we support the proposal advanced in a letter led by former Senators Tom Daschle, Bill Frist and former CDC Director Tom Frieden to congressional leadership calling for creation of a Health Defense Operations (HDO) budget designation that would exempt certain health security budget lines from the Budget Control Act spending caps.[7] Such a designation is needed to get out of the cycle of disinvestment in public health, followed by emergency supplemental funding, followed again by erosion of funds. Health security is national security, so funding for protection of Americans against biosecurity threats is critical to our recovery and resilience.

For fiscal year 2021, TFAH also urges the Committee to support programs within CDC and the Public Health and Social Services Emergency Fund (PHSSEF):

Emergency Preparedness: The COVID–19 outbreak has demonstrated that it is not enough to deliver short-term, supplemental funding after a disaster occurs; a proper response requires training, plans and systems that can only be established with consistent, ongoing funds. The Public Health Emergency Preparedness (PHEP) cooperative agreement, the main Federal program that ensures health departments protect Americans from the effects of health emergencies, is a cornerstone of the nation's health security. PHEP grants support 62 state, territory, and local grantees to develop core public health capabilities, including in areas of public health laboratory testing, health surveillance and epidemiology, community resilience, countermeasures and mitigation, incident management, and information management. Unfortunately, funding for PHEP has been cut by a third since fiscal year 2003. TFAH recommends at least $824 million for the PHEP (CDC), the level authorized in 2006.

The pandemic is also demonstrating the impact of failing to invest in comprehensive readiness and surge capacity of the healthcare delivery system. Funding for the Hospital Preparedness Program (HPP), administered by the Assistant Secretary for Preparedness and Response, has been cut in half since fiscal year 2003. HPP provides critical funding and technical assistance to healthcare coalitions (HCCs) across the country to meet the disaster healthcare needs of communities. There are 360 HCCs, comprised of public health agencies, hospitals, emergency management and others, that develop and implement healthcare and medical readiness; healthcare and medical response coordination; continuity of healthcare services delivery; and medical surge. TFAH recommends at least $474 million for HPP (PHSSEF), the level authorized in 2006.

Environmental Health: To effectively and efficiently address public health challenges, data must incorporate environmental impacts on health. Since CDC's National Environmental Public Health Tracking Network began, grantees have taken over 400 data-driven actions to improve health. Data includes asthma, drinking water quality, lead poisoning, flood vulnerability, and community design. State and local health departments use this data to conduct targeted interventions in communities with environmental health concerns. Currently, 25 states and one city are funded to participate in the Tracking Network. With a $1.44 return in healthcare savings for every dollar invested, the Tracking Network is a cost-effective program that examines and combats harmful environmental factors.[8] TFAH recommends at least $40 million for National Environmental Public Health Tracking Network (CDC), which would enable at least three additional states to join the network.

Obesity and Chronic Disease Prevention: In 2017–2018, 42.4 percent of adults were obese.[9] Yet, funding for CDC's obesity prevention efforts only equal to about 31 cents per person, even though obesity accounts for nearly 21 percent of U.S. healthcare spending.[10] During the COVID–19 pandemic, obesity has been identified

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[6] Developing a Financing System to Support Public Health Infrastructure. Public Health Leadership Forum, 2019. https://www.resolve.ngo/docs/phlf__developingafinancingsystemtosupportpublichealth636869439688663025.pdf.

[7] Letter to congressional leadership on Health Defense Operations budget designation. May 5, 2020. In preventepidemics.org. https://preventepidemics.org/wp-content/uploads/2020/05/Health-Defense-Operations-Letter-to-Congress__05.05.20.pdf.

[8] Return on Investment of Nationwide Health Tracking, Washington, DC: Public Health Foundation, 2001.

[9] Hales CM et al. Prevalence of Obesity and Severe Obesity Among Adults: United States, 2017–2018. NCHS Data Brief No. 360, Feb 2020. https://www.cdc.gov/nchs/data/databriefs/db360-h.pdf.

[10] J. Cawley and C. Meyerhoefer, "The Medical Care Costs of Obesity: An Instrumental Variables Approach," Journal of Health Economics 31, no. 1 (2012): 219–30, doi: 10.1016/j.jhealeco.2011.10.003.

as one of the major risk factors for severe outcomes.[11] To adequately address obesity and chronic disease, we must invest in preventive and culturally appropriate strategies. CDC's Division of Nutrition, Physical Activity and Obesity (DNPAO) works to decrease obesity and chronic disease in communities across the U.S. DNPAO supports healthy eating, active living, and obesity prevention by creating healthy child care centers, hospitals, schools, and worksites; building capacity of state health departments and national organizations; and, conducting research, surveillance and evaluation studies. DNPAO's new initiative, Active People, Healthy Nation, aims to help 27 million Americans become more physically active by 2027. DNPAO only has enough money to implement its State Physical Activity and Nutrition Programs (SPAN) in 16 states. TFAH recommends at least $125 million for DNPAO (CDC) to fund every state for its SPAN work and continue implementing Active People, Healthy Nation strategies.

Additionally, the Racial and Ethnic Approaches to Community Health (REACH) program, within DNPAO, works in 31 communities across the country. It supports innovative, community-based approaches to develop and implement evidence-based practices, empower communities, and reduce racial and ethnic health disparities. As we are seeing the affect that underlying health disparities are having on COVID–19 patients, we urge renewed investment in programs such as REACH that promote health equity. TFAH recommends at least $76.95 million for REACH (CDC) to restore funds historically diverted from core REACH programs.

Healthy Outcomes in Schools: CDC's Division of Adolescent and School Health (DASH) provides evidence-based health promotion and disease prevention education for less than $10 per student. Through school-based surveillance, data collection, and skills development, DASH collaborates with state and local education agencies to increase health surveillance and services, promote protective factors, and reduce risky behaviors. DASH programs reach approximately 2 million of the 26 million middle and high school students. TFAH recommends at least $100 million for DASH (CDC) to expand its work to 20 percent of all middle and high school students.

Substance Use Epidemic: Substance misuse is a public health epidemic experienced by too many communities across the country. From 2009–2018, 530,893 Americans have died from drug- related causes.[12] Increased funding and flexibility for the Opioid Overdose Prevention and Surveillance program at CDC would expand prescription drug monitoring programs and surveillance; strengthen evidence-based prevention efforts; and strengthen CDC's surveillance systems to translate data into action by educating consumers and equipping health departments with resources to promote prevention. We urge you to prioritize primary prevention of substance misuse and to allow flexibility to broadly prevent substance misuse, not solely opioid misuse. TFAH recommends at least $650 million for Opioid Overdose Prevention and Surveillance (CDC) to expand and support innovative prevention activities in states.

New Initiative: Age-Friendly Public Health: Every day 10,000 Americans turn 65 years of age, yet there have been limited collaborations between the public health and aging sectors. The COVID–19 outbreak shows how vital this collaboration could be. Public health interventions play a valuable role in optimizing the health and well-being of older adults by prolonging their independence, reducing their use of expensive healthcare services, coordinating existing multi-sector efforts and identifying gap areas, as well as disseminating and implementing evidence-based policies. We recommend the Committee fund a program to administer and evaluate a healthy aging grant program to support state and local health departments to promote and address the public health needs of older adults, and collaborate with partners in the aging sector. TFAH recommends at least $50 million to develop Age-Friendly Public Health at CDC and support grants to states and localities.

New Initiative: Social Determinants of Health: Social and economic conditions such as housing, employment, food security, and education have a major influence on individual and community health.[13] These Social Determinants of Health (SDOH) are receiving increased attention. Public health departments are uniquely situated to build these collaborations across sectors, identify SDOH priorities in communities, and help identify strategies that promote health. Currently most public health departments lack funding and tools to support such cross-sector efforts

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[11] Coronavirus Disease 2019 (COVID–19): Groups at Higher Risk for Severe Illness. CDC, 2020. https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/groups-at-higher-risk.html.

[12] WONDER Data, CDC. https://wonder.cdc.gov/.

[13] Taylor, L et.al, "Leveraging the Social Determinants of Health: What Works?" Yale Global Health Leadership Institute and the Blue Cross and Blue Shield Foundation of Massachusetts, June 2015.

and are limited by disease-specific Federal funding. We recommend the Committee fund CDC to support local and state public health agencies to convene across sectors, gather data, identify priorities, establish plans, and take steps to address unmet non-medical social needs. Recently, Rep. Nanette Diaz Barragán introduced a bill, the Improving Social Determinants of Health Act (H.R. 6561) that would authorize such a program, with endorsements from nearly 160 organizations.[14] TFAH recommends at least $50 million to develop a Social Determinants of Health Program (CDC) and enable grants to states and localities.

Conclusion: TFAH appreciates the opportunity to present this testimony to the Committee. By restoring previous budget cuts and expanding prevention activities, we will reinforce our ability to protect and improve the lives of communities nationwide. Thank you.

[This statement was submitted by John Auerbach, President & CEO, Trust for America's Health.]

PREPARED STATEMENT OF THE U.S. HEREDITARY ANGIOEDEMA ASSOCIATION

SUMMARY OF FISCAL YEAR 2021 RECOMMENDATIONS

—Provide the National Institutes of Health (NIH) with at least a $3 billion increase in discretionary funding for fiscal year 2021 to bring overall agency funding up to a minimum of $44.7 billion annually.
  —Continue to encourage advancement and expansion of the hereditary angioedema research portfolio at NIH (including advancing treatment options and diagnostic tools for HAE with normal C1–Inhibitor), as well as research efforts focused on rare conditions more broadly, through timely committee recommendations.
  —Please provide proportional funding increases for NIH's various Institutes and Centers, most notably; the National Institute of Allergy and Infectious Diseases (NIAID), the National Centers for Advancing Translational Sciences (NCATS), and the National Heart, Lung, and Blood Institute (NHLBI)
—Provide the Centers for Disease Control and Prevention (CDC) with at least a $600 million increase in discretionary funding for fiscal year 2021 to bring overall agency funding up to a minimum of $8.3 billion annually.
—Encourage the Centers for Medicare and Medicaid Services (CMS) to prevent discrimination in health coverage by ensuring rare disease patients do not face arbitrary restrictions when seeking charitable assistance to maintain access to life-sustaining care and therapy and to prevent from being steered into Federal need-based and illness-based programs that they would not otherwise qualify for while properly managing their illness (building on committee recommendations included in the Committee Report accompanying the fiscal year 2020 House LHHS Appropriations Bill).

Chairman Blunt, Ranking Member Murray, and distinguished members of the subcommittee, thank you for the opportunity to present the views of the U.S. Hereditary Angioedema Association (U.S. HAEA) on funding and related policy items for NIH, CDC, and CMS during consideration of appropriations for fiscal year 2021. First and foremost, thank you for supporting these programs in fiscal year 2020. It is our hope that this invest will continue for fiscal year 2021 to ensure that meaningful progress can continue in specific, promising areas.

ABOUT U.S. HAEA

U.S. HAEA is a patient-driven organization comprised of affected individuals and their families. In this regard, we would primarily like to recognize this Subcommittee for its leadership and commitment to providing medical research and public health programs with notable funding increases for fiscal year 2020. This investment will have a tangible positive impact for patients by significantly improving scientific inquiry and public health activities.

U.S. HAEA is a non-profit patient advocacy organization dedicated to serving the estimated 6,000 HAE sufferers in the U.S. We provide a support network and a wide range of personalized services for patients and their families. We are also com-

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[14] The Improving Social Determinants of Health Act of 2020 (H.R. 6561) Background. In Trust for America's Health. https://www.tfah.org/wp-content/uploads/2020/05/SDOH-bill-fact-sheet.pdf.

mitted to advancing clinical research designed to improve the lives of HAE patients and ultimately find a cure.

ABOUT HEREDITARY ANGIOEDEMA

Hereditary angioedema (HAE) is a painful, disfiguring, debilitating, and potentially fatal genetic disease that occurs in about 1 in 30,000 people. Symptoms include episodes of swelling in various body parts including the hands, feet, face and airway. Patients often have bouts of excruciating abdominal pain, nausea and vomiting that is caused by swelling in the intestinal wall. The majority of HAE patients experience their first attack during childhood or adolescence. Approximately one-third of undiagnosed HAE patients are subject to unnecessary exploratory abdominal surgery. About 50 percent of patients with HAE will experience laryngeal edema at some point in their life. This swelling is exceedingly dangerous because it can lead to death by asphyxiation. The historical mortality rate due to laryngeal swelling is 30 percent.

A RESEARCH SUCCESS STORY

There was a time not long ago that HAE was a debilitating, and often life-ending, chronic disease. In addition to the serious health impacts, affected individuals suffered with trauma, anxiety, and PTSD stemming from torturous attacks (and the uncertainty of when the next attack might occur). Due to advancements in medical research, HAE patients now have access to life-altering and life-sustaining medications. Properly medically managing the disease now allows many the freedom to work productively, live independently, and thrive.

While we are appreciative of the scientific progress, much more can be done. There is no cure of HAE and treatment is highly individualized. More needs to be learned about the underlying disease mechanisms and successful treatment often involves personalized care and a customized treatment regimen prepared (using trial and error) by a leading physician expert.

NIH has a modest, but meaningful HAE research portfolio. Recent annual investments will facilitate growth in this portfolio and have led to important new scientific projects. The ongoing research at NIH (and complimentary research through the Department of Defense Peer-Reviewed Medical Research Program) will lead to a time when HAE patients can move beyond their disease. However, a key question that remains is how much of this investment is going to rare and ultra-rare disease research programs, particularly in-light of the “big ticket” items that are often now the focus of annual research appropriations.

THE IMPORTANCE OF PROPER HEALTH COVERAGE AND ACCESS

The HAE community first became aware of the fact that the Centers for Medicare and Medicaid Services (CMS) had allowed private insurers offering marketplace plans to deny coverage to individuals receiving charitable assistance in 2015 when more than a dozen HAE patients in Louisiana received notices that their coverage was being cancelled due to the fact someone else had helped them pay their premiums. Since that time, the practice has become pervasive and HAE patients are regularly informed that they will lose coverage if they receive any charitable assistance, that they may be committing fraud, and that they may face legal action if they accept assistance. This dynamic has effectively become a back door to pre-existing condition discrimination that is implemented to steer HAE patients into tax-payer funded healthcare. Moreover, the threat now stretches beyond just marketplace plans (to Medigap plans and COBRA) due to the inability to address this issue when it first began jeopardizing health for patients with no alternatives.

Many HAE patients properly manage their illness when they have proper access to healthcare and treatment. HAE patients would typically not qualify for need-based or health-based government programs due to the life-sustaining nature of their treatment. If, however, proper coverage is lost, an HAE patient may have to endure a life-threatening experience of waiting while they spend down to qualify for Medicaid or become sick enough to apply for disability.

US HAEA has joined with other patient-driven organizations experiencing the harm of current pre-existing condition discrimination facilitated by barriers to charitable assistance and the related practice of a restrictive co-pay accumulator to form the ad hoc group, United for Charitable Assistance (UCA). We join with UCA and all stakeholders in asking this subcommittee to once again highlight these rare-disease challenges for CMS and request the current barriers are resolved to protect patients that have no other reasonable options to maintain coverage.

We thank the Subcommittee for including meaningful language through the fiscal year 2020 appropriations process asking CMS to show leadership in addressing these barriers. We hope Congress will continue to work with patient stakeholders to end coverage scrutiny and payment discrimination moving forward.

[This statement was submitted by Anthony J. Castaldo, President and CEO, U.S. Hereditary Angioedema Association.]

PREPARED STATEMENT OF THE UNITED STATES WORKFORCE ASSOCIATIONS

Dear Chairman Blunt and Ranking Member Murray:

The undersigned organizations make up the United States Workforce Association (USWA), a collaborative effort of local workforce boards, businesses, educational institutions, and organizations involved in workforce and economic development activities across the country. These organizations are directly involved in the implementation of the bipartisan Workforce Innovation and Opportunity Act (WIOA) of 2014, specifically promoting the successful execution by local workforce boards of the law to serve businesses, employers, and job—and career-seekers. With the country facing unprecedented demand for unemployment insurance and possible economic recession within the COVID–19 outbreak, the employer-led, local workforce development system must have the Federal resources necessary to provide businesses with talent to begin the recovery. Adequate Federal funding would ensure the system is poised to address these community needs.

As the Senate Appropriations Committee considers the fiscal year 2021 Labor-HHS Appropriations Bill, we urge you to support further Federal investment into WIOA and fully fund the law beyond its fiscal year 2020 authorized levels. Appropriated levels have fallen short of authorized levels specifically in Title I accounts at the Department of Labor (Adult Employment and Training Services, Youth Workforce Investment Activities, and Dislocated Worker Employment and Training Services). An expanded Federal investment across WIOA programs leads to more job training, education, skills development and innovative, proven practices like industry-based sector partnerships, career pathways, and apprenticeships. These strategies will need to be implemented seamlessly following the COVID–19 outbreak.

As our country grapples with the response to COVID–19, local leaders are engaged directly with businesses to help keep individuals employed. We are also working with the mass waves of unemployed individuals to help them stay connected to the workforce and evaluate other opportunities if they have been laid off. Emergency appropriations are greatly needed to address this unprecedented health, economic, and social destabilization but an increased Federal investment will also address these funding concerns.

The fiscal year 2021 Labor, Health and Human Services, Education, and Related Agencies Appropriations bill must fully fund all Titles I, II, III, and IV at a minimum to the level authorized by the Workforce Innovation and Opportunity Act (WIOA).

The funding levels we are requesting in the fiscal year 2021 Labor, HHS, Education Appropriations Bill are listed below:

Title I—Department of Labor

—At least $899.987 million for Adult Employment and Training Services,
—At least $963.837 million for Youth Workforce Investment Activities, and
—At least $1.436 billion for Dislocated Worker Employment and Training Services

Title II—Department of Education

—$678.640 million for Adult Education

Title III—Department of Labor

—$667,000,000 for Wagner-Peyser (fiscal year 2020 Enacted)

Title IV—Department of Education

—$3,610,040,000 for Vocational Rehabilitation Services (fiscal year 2020 Enacted)

FISCAL YEAR 2021 ADMINISTRATION BUDGET PROPOSAL LANGUAGE

We also wanted to highlight concerning language contained in the fiscal year 2021 Department of Labor Budget Proposal that would give Governors more authority to re-designate and consolidate local workforce boards. The budget proposal language would waive protections given to local control by circumventing Section 106 of the Workforce Innovation and Opportunity Act (WIOA). Congress recognized that local economic conditions are best addressed at the local level when WIOA was passed in 2014. That local control is critical when dealing with employers and other stakeholders as we can address economic issues with flexible resources and innovative solutions. We oppose the language included in the budget and encourage you to further support local control within the Federal workforce system.

This training, support and business partnership is vital to our country's economic prosperity. For further information, please contact Chris Andresen.

Sincerely.

Bob Lanter
Executive Director
California Workforce Association

Luann Dunsford, CEO
Michigan Works! Association

John Trott
President
Ohio Workforce Association

Kelly Folks, President
Rocky Mountain Workforce
Development Association

Melinda Mulawka Mack
Executive Director
New York Association of Training and
Employment Professionals

Greg Vaughn
Executive Director
Texas Association of Workforce Boards

Michelle Cerutti, President
Illinois Workforce Partnership

Jeff Frederick
President
North Carolina Association of
Workforce Development Boards

Tonja Mettlach, Executive Director
Massachusetts Workforce Association

Mari Kay-Nabozny
Chief Executive Officer
Northwest Wisconsin Workforce
Investment Board, Inc.

Michelle Day, President
Maryland Workforce Association

Kevin Perkey, President
Washington Workforce Association

Heather Ficht, Chair
Oregon Workforce Partnership

Robin King, President
Florida Workforce Development Association

Teri Drew, Chairman
Arizona Workforce Association

Jeanna Fortney, Director
Minnesota Association of Workforce Boards

Angela Carr Klitzsch, Chair
Indiana Workforce Board Alliance

Carrie Amann, Executive Director
Pennsylvania Workforce Development Association

PREPARED STATEMENT OF VOR

Thank you for the opportunity to provide outside witness testimony for the record to the Senate Appropriations, Subcommittee on Labor, HHS, Education, and Related Agencies regarding the fiscal year 2021 Budget for the Department of Health and Human Services (DHHS). This testimony does not include any funding request.

VOR submits this testimony as a request for language in the fiscal year 2021 Labor, HHS, Education and Related Agencies appropriations bill[1] that:

—Expressly prohibits the use of appropriations by a Protection and Advocacy (P&A) System to bring a lawsuit against a Medicaid licensed and certified intermediate care facility for individuals with intellectual disabilities (ICF/IID), un-

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[1] Submitted in March 26, 2020 email from Caroline Lahrmann to Senator Blunt's staff, Dan Burgess and Caitlin Wilson.

less the affected individuals and their legal guardians have been provided reasonable notice of the lawsuit.

—Expressly prohibits states from using Money Follows the Person (MFP) funds or the resulting Federal Matching Assistance Percentages (FMAP) to override beneficiary choice and be used by a state to finance and abet the closure of an ICF/IID home and the resulting transfer of its residents, or to incentivize private providers to close or reduce the number of beds in their ICF/IID facilities.

INTRODUCTION

VOR is a national nonprofit organization advocating for high quality care in a full continuum of residential options and human rights for all people with intellectual and developmental disabilities (I/DD).

It has been twenty years since the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) was last reauthorized. During that time, the Administration for Community Living (ACL) through its agency, the Administration on Intellectual and Developmental Disabilities (AIDD), and their state-based DD Act programs, especially Protection & Advocacy (P&A) Systems for Individuals with Developmental Disabilities, have engaged in activities designed to close intermediate care facilities for individuals with intellectual disabilities (ICFs/IID). This activity has occurred against the wishes of the vast majority of legal guardians of the residents, disregarding the plain language of the Americans with Disabilities Act (ADA) and the Supreme Court's *Olmstead* decision. Too often the consequences have been disastrous for the residents, resulting in abuse, neglect and even death. Since the last DD Act reauthorization expired 13 years ago, these programs have been able to continue to ignore the DD Act and the Supreme Court only through the appropriations process. To remedy this problem VOR makes the above referenced language requests for the Labor, HHS Appropriations Bill and Report.

THE *OLMSTEAD* DECISION, MEDICAID LAW, AND THE DD ACT PROTECT CHOICE BASED ON NEED

HHS-funded P&A Systems cite the landmark U.S. Supreme Court decision, *Olmstead v L.C.* (1999)[2] as justification for their position to close HHS-funded ICF/IID homes. These Federal agencies misrepresent and misapply the *Olmstead* decision's requirements. The Supreme Court is clear in its holding that the ADA requires individual choice before community placement can be imposed and recognizes the need for specialized care:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings... Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it." [*Olmstead v. L.C.* 527 U.S. 581, 601–602 (1999)]

> "As already observed (by the majority), the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk... 'Each disabled person is entitled to treatment in the most integrated setting possible for that person—recognizing on a case-by-case basis, that setting may be an institution.'" [*Olmstead, 605*] (quoting VOR's *Amici Curiae brief*)[3]

Likewise, Medicaid law and regulations require that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." [42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C.§ 1396n(c)(2)(C)]

The DD Act,[4] which authorizes funding for P&A Systems, supports residential choice and recognizes that individuals and their families are in the best position to make care decisions:

"Individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive, including regarding choosing where the individuals live from available options, and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families." [DD Act, 42 U.S.C. 15001(c)(3)(2000)]

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[2] The full Supreme Court Ruling in Olmstead is available for download at: https://supreme.justia.com/cases/Federal/us/527/581/.

[3] https://www.vor.net/legislative-voice/legislator-toolkit/dd-act-reauthorization/item/vor-olmstead-amicus-brief.

[4] The DD Act is available for download at: https://acl.gov/sites/default/files/about-acl/2016-12/dd__act__2000.pdf.

PROTECTION & ADVOCACY CLASS ACTION LAWSUITS

Protection & Advocacy (P&A) Systems are a DD Act program charged to protect and advocate the rights of individuals with developmental disabilities. [42 U.S.C. § 10543] Lawsuits have been a favorite tool of P&As. P&As have filed more than 15 class action lawsuits seeking closure (not relating to conditions of care) over the objections of residents and their families.

In 2014, for example, Disability Rights Ohio (DRO), the State's P&A, cited *Olmstead* when it threatened[5] and later filed a class action against Ohio's ICF/IID program over the widespread objections of ICF/IID families. Families filed over 21,000 hardcopy petition signatures with the Ohio General Assembly objecting to DRO's threats and policy proposals, including closing and downsizing ICF/IID facilities. The threat of litigation alone led to the closing of two state-run ICFs/IID and hundreds of private ICF/IID beds. Despite state concessions, DRO still filed a class action on March 31, 2016 against the state without notifying families of individuals who DRO sought to include as class members. Eventually, ICF/IID families who learned of the suit intervened in the action. The Court ordered ICF/IID families' intervention and eventually dramatically narrowed the class to protect the interests of ICF/IID residents and those individuals who may want an ICF/IID placement in the future. In its Order on intervention, the Court noted that the rights of ICF/IID residents in the litigation "were not protected until the Guardians filed their Motion to Intervene." (*Ball v. Kasich* 2:16-cv-282, Opinion and Order, July 25, 2017, Doc #261, pp 17–18.) The Court's statement highlights the importance of VOR's language request, to provide notice to families of P&A litigation so that they can act to protect the rights of their severely disabled loved ones.

MONEY FOLLOWS THE PERSON

MFP was passed in 2005 as part of the Deficit Reduction Act, the primary goal being to rebalance state service systems toward home and community-based services (HCBS), rather than institutional care.[6] For the I/DD population, this goal has been accomplished. Today, Home & Community Based Services (HCBS) represent approximately 54 percent of the total Federal Medicaid I/DD budget; ICFs/IID represent only 17 percent.[7] As the goal of the program has been realized, MFP has now become hijacked by ideological extremists as a means to close all institutional care for individuals with I/DD. In December 2019, the CEO of the ARC stated, "We applaud elected officials who understand the value of MFP, core to our mission to advance community living and close all institutions."[8] (Emphasis added.) P&As play a key role in this effort, creating the environment for litigation-wary states to close ICFs/IID. Then, MFP furthers states' ability to implement the resulting closings. As such, a program that expressly honored choice[9] consistent with *Olmstead*, has lost its way and is being misused to override the choice of I/DD beneficiaries to their life-sustaining ICF/IID homes. VOR families have experienced states' misuse of MFP in two ways: (1) Using MFP and its enhanced FMAP to help finance whole closures of state-run ICFs/IID and the resulting transfers of residents; (2) Using MFP's enhanced FMAP to incentivize private providers to close their ICFs/IID and transfer residents with MFP funds. Here are a few examples:

Ohio: MFP was used to help finance closings of two state-run ICFs/IID in 2015 affecting about 200 persons; families passionately opposed the closures in the state legislature. MFP's enhanced FMAP was used to financially incentivize private providers to close ICFs/IID and transfer residents.

Pennsylvania: In 2017, MFP was used to help finance the closing of Hamburg, a state-run ICF/IID, affecting 74 residents. Closures of two more state centers were announced in 2019. Families of the centers have filed a Federal lawsuit to halt these closures.

Virginia: Deaths increased by 70%[10] when the state closed several of its Training Centers (state run ICFs/IID) in response to DOJ litigation. Four of five centers closed, affecting approximately 1,000 residents. Families opposed the closures by in-

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[5] July 1, 2014 DRO letter to state of Ohio: https://www.vor.net/images/stories/pdf/DROLetterGovernorKasich.pdf.

[6] Public Law 109–171 § 6071(a)(1).

[7] https://stateofthestates.org/wp-content/uploads/documents/UnitedStates.pdf.

[8] https://thearc.org/huge-victory-for-community-living-for-people-with-disabilities-agreement-in-congress-to-commit-to-money-follows-the-person-program/.

[9] Public Law 109–171 § 6071 (a)(2).

[10] Robert Anthony, PhD. Study of Mortality Rates Connected to Virginia Training Centers Closures: https://www.vor.net/get-help/more-resources/item/mortality-studies.

tervening in the litigation to protect their loved ones' interests. MFP was used to help transfer displaced residents to community settings.

Illinois: Moved to close two state run ICFs/IID, Jacksonville and Murray, in 2012. The Chicago Tribune reported[11] that an "auction" was held to find new homes for residents of Jacksonville. "A state official read aloud medical histories of residents...prompting group home officials to raise their hands for desired picks." Beneficiary choice was not considered when making the decision to close the centers. In fact, families of Murray filed a Federal lawsuit to halt the closing of Murray and were successful in keeping Murray open. The Tribune reported that state officials promised an independent and safe life for residents in community settings, "but those promises obscured evidence found in the state's own investigative files that revealed many group homes were underfunded, understaffed and dangerously unprepared for the new arrivals with complex needs."

DEINSTITUTIONALIZATION EFFORTS PERSIST DESPITE WIDESPREAD ABUSE, NEGLECT, & DEATHS

ACL/AIDD and their state-based programs persist in their ideological devotion to community placement despite reports:

—of an extraordinary death rate of nearly 16 percent in Georgia[12]
—deaths increased by 70 percent for individuals moved from ICFs/IID to the community in Virginia[13]
—1,200 "unnatural and unknown" deaths in New York[14]
—a risk of mortality in community settings of up to 88 percent in California[15]
—more than 100 deaths in Connecticut[16]
—hundreds of deaths in the District of Columbia[17]
—a Chicago Tribune series on widespread abuse and neglect in Illinois' community system[18]

plus many more reports of abuse, neglect and death across the majority of all states.[19] Sadly, such results, when beneficiary choice and need are overridden, are not surprising.

CONCLUSION AND SOLUTION

Reauthorization of the DD Act is the appropriate place for a comprehensive review of HHS activities to determine if the programs they fund, such as P&A Systems, are operating within the letter and spirit of relevant law. As the DD Act programs continue to be funded through the appropriations process, VOR believes it is necessary and proper to require the programs to take actions to protect beneficiaries' rights.

VOR's requests build on previous actions by this Committee. In fiscal year 2016, 2018, and 2019, the Omnibus Appropriations Act required that P&As provide affected individuals and their families with notice of any class action that a P&A would initiate on their behalf. We request that the Committee continue this requirement. The fiscal year 2016 appropriations also included language that "strongly urged [HHS] to continue to factor the needs and desire of patients, their families, caregivers, and other stakeholders, as well as the need to provide proper settings for care, into its enforcement of the Developmental Disabilities Act." Nearly identical language was also included in the fiscal year 2017 Commerce, Justice Appropriations. VOR is unaware that HHS followed the laws and requests the Committee

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[11] https://www.chicagotribune.com/investigations/ct-group-home-investigations-cila-met-20161229-htmlstory.html.

[12] Augusta Chronicle, August 26, 2019 https://www.augustachronicle.com/news/20190826/report-deaths-lack-of-housing-plague-georgia-system-for-disabled-mentally-ill.

[13] Robert Anthony, PhD. Op Cit.

[14] New York Times series, Abused and Used, 2011–2012 http://archive.nytimes.com/www.nytimes.com/interactive/nyregion/abused-and-used-series-page.html.

[15] Mortality of Persons With Developmental Disabilities After Transfer Into Community Care: A 1996 Update, Robert Shavell and David Strauss https://www.ncbi.nlm.nih.gov/pubmed/10207577.

[16] Abuse, Neglect Cited As Factors In Deaths Of Dozens of Developmentally Disabled In State Care https://www.courant.com/news/connecticut/group-home-deaths/hc-dds-deaths-0303-20130302-story.html.

[17] "Invisible Lives: Residents Languish; Profiteers Flourish," March 15, 1999, https://www.washingtonpost.com/wp-srv/local/daily/march99/grouphome15__full.htm; and "Invisible Deaths," December 5, 1999, https://www.washingtonpost.com/wp-srv/local/invisible/deaths5.htm.

[18] Chicago Tribune, "Suffering in Secret," three-part series beginning November 2016 https://www.chicagotribune.com/investigations/ct-group-home-investigations-cila-met-20161117-htmlstory.html.

[19] VOR Abuse and Neglect Document https://www.vor.net/get-help/more-resources.

to require HHS to submit reports to Congress with respect to each of these areas so the Congress can start the process of determining whether and/or how HHS is meeting its obligations to respect the right of choice and make sure proper care is provided for those who leave ICFs/IID.

[This statement was submitted by Hugo Dwyer, Executive Director, VOR.]

Prepared Statement of the Western Governors' Association

Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee, the Western Governors' Association (WGA) appreciates the opportunity to provide written testimony on the appropriations and activities of the Federal agencies under the Subcommittee's jurisdiction, including the Departments of Labor (DOL), Health and Human Services (HHS), and Education (ED). WGA is an independent organization representing the Governors of the 22 westernmost states and territories. The Association is an instrument of the Governors for bipartisan policy development, information-sharing and collective action on issues of critical importance to the western United States.

Western states are aligning education to workforce needs in an effort to create economic opportunities for westerners and support growing economies. DOL and ED programs have a significant effect on how states address challenges related to skills gaps, unemployment and educational attainment. Western Governors understand the importance of working closely with the Federal Government to ensure that Federal and state investments in education and employment training support shared goals.

Career and technical education (CTE) provides students with opportunities to explore careers and participate in programs of study designed around specific professions. CTE programs are funded through the Carl D. Perkins Career and Technical Education Act (Perkins Act). States distribute Perkins Act funds to school districts, community or technical colleges, and other local recipients. Western Governors encourage Congress to recognize that Governors and states are in the best position to determine how to use Federal CTE funding to meet the needs of their economies. Adequate funding of Perkins State Grants is essential to ensure that CTE programs align with statewide visions for education and workforce development.

Western Governors understand the importance of work-based learning programs to help jobseekers obtain experience and training for in-demand occupations while earning money. Western Governors support the expansion of work-based learning programs, including federally registered apprenticeship programs. These are important tools to address skills gaps in specific sectors in western states. While apprenticeships have been traditionally used in the building trades, western states are leading the way in expanding registered apprenticeship opportunities to new sectors, including healthcare and information technology. Western Governors encourage Congress to support and incentivize state-, local-, and industry-led partnerships to create and scale apprenticeship programs through increased appropriations. New Federal investments in apprenticeships should align with existing efforts to foster a coherent system with minimal duplication at the Federal, state and local levels.

DOL funding for workforce development through the Workforce Innovation and Opportunity Act (WIOA) supports economic growth and job creation in the states. Western Governors request that the 15 percent reserve for statewide activities be maintained in appropriations under WIOA. This funding allows Governors to be flexible and innovative in addressing state needs.

Expanding education and training programs for cybersecurity is especially important to Western Governors. A skilled cyber workforce is imperative to protect critical infrastructure, which includes a vast array of potential targets. These include: the nation's electric grid; energy resource supply and delivery chains; finance, communications, and election systems; and a panoply of public, private, military and industrial systems.

Despite efforts by Western Governors to address the shortage of qualified healthcare workers in our states, significant challenges remain. Governors urge the Federal Government to examine and implement programs to ensure states have an adequate healthcare workforce—including positions in primary care, behavioral and oral health as well as other in-demand specialties—prepared to serve diverse populations in urban, suburban and rural communities. Understanding that significant disparities remain in access and treatment for many populations, Governors support efforts to increase the diversity of the healthcare workforce to improve health outcomes for all.

Western Governors also support efforts to improve the quality and quantity of behavioral health services, as these are essential to reducing suicide rates and treating a range of behavioral health conditions, including substance use disorder. The ten states with the highest suicide rates in the nation are all in the West. Western states are also among those with the highest overall rates of substance use disorder, especially for youth between the ages of 12–17. Western Governors recognize and support efforts at the Federal, state and local levels to promote the integration of physical and behavioral health services. The Governors encourage Congress and the Administration to support states' integration efforts and encourage healthcare providers to better incorporate behavioral and physical medicine into their practice of care.

Western Governors recognize that it is an enormous challenge to judiciously balance competing funding needs throughout the Federal Government, and appreciate the difficulty of the decisions this Subcommittee must make. The foregoing recommendations are offered in a spirit of cooperation and respect. WGA is prepared to assist you as the Subcommittee discharges its critical and challenging responsibilities.

[This statement was submitted by James D. Ogsbury, Executive Director, Western Governors' Association.]

PREPARED STATEMENT OF THE WOMEN FIRST RESEARCH COALITION

The members of the Women First Research Coalition (WFRC) thank the Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies for the opportunity to submit the following outside witness testimony for the fiscal year 2021 appropriations in support of increasing the amount of women's health research conducted by the National Institutes of Health (NIH). To support and facilitate research in women's health at the NIH, we ask that you consider our report language on "Women's Health Research Priorities." Additionally, we ask that you consider adding emergency provisions to fund research at NIH related to COVID–19, including projects that examine the virus as it relates to conditions only or predominantly occurring in women.

WFRC is a coalition comprised of the nation's leading professional medical and research organizations specializing in women's health. Our coalition was formed to address pressing challenges in women's health research and we are dedicated to raising awareness among Federal policymakers, Executive Branch officials and the public about the need for sustained and strengthened investment in women's health research, the prioritization of research in conditions that are specific to women or those conditions that may present differently in women than men, advance an equitable and appropriate investment in women's health research that improves the health outcomes of women, and ensure an adequate women's research workforce.

Prioritize Women's Health Research at the NIH

The NIH has made significant advances in understanding how sex and gender differences influence certain diseases and conditions as women now account for roughly half of all participants in NIH-sponsored clinical trials.[1] However, there remain significant gaps in our understanding of women's unique health conditions despite women accounting for over half of the United States population. Unfortunately, the implications of these gaps are clear: our country is currently in the midst of a maternal mortality crisis; cervical cancer survival rates have stagnated since the mid-1970s; vaginal mesh procedures that were not studied in clinical trials require regulatory action from the FDA;[2] and there are significant gaps in our understanding of women's fertility and hormonal functions.[3,4]

There are a number of examples of areas in women's health research where additional study is urgently needed. Those provided here are illustrative of the gaps in our understanding of common women's health conditions. The benefits of cervical cancer prevention are well known, and yet new discovery in this area as well as widespread implementation of known approaches to prevention, such as the HPV vaccine, is not optimal. Research to help understand barriers to screening programs, discover new approaches to screening, and wider implementation of known strategies is needed. There also remain large disparities in genetic testing, access to care,

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[1] https://orwh.od.nih.gov/sex-gender/nih-policy-sex-biological-variable.

[2] https://www.fda.gov/medical-devices/implants-and-prosthetics/urogynecologic-surgical-mesh-implants.

[3] MacDorman MF, Declercq E, Cabral H, Morton C. Recent Increases in the U.S. Maternal Mortality Rate: Disentangling Trends From Measurement Issues. Obstet Gynecol. 2016;128(3):447–55.

[4] Jemal A, Ward EM, Johnson CJ, et al. Annual report to the nation on the status of cancer, 284 1975–2014, featuring survival. J Natl Cancer Inst. 2017;109.

and other aspects of providing care for women with cervical, endometrial, and other gynecologic cancers. Enhancing our understanding of these at a much deeper level would help facilitate strategies for overcoming disparities.

Another example—one in three women who have given birth suffer from pelvic organ prolapse, a condition that occurs when the pelvic floor muscles and connective tissue supporting the pelvic organs (bladder, uterus and cervix, vagina, and rectum) weaken or tear and can no longer support these organs. Over 50 percent of women aged 65 and older suffer from urinary incontinence. More research is needed to improve prevention and treatment strategies for these and other urogynecologic conditions that affect millions of American women.

These significant health concerns are increasing at a time when NIH funding for women's health research remains disproportionately low, particularly for research in obstetrics and gynecology, in comparison to other areas of research. It is critical that Federal policymakers prioritize funding to support research related to the full range of women's health issues. An increased investment in women's health research will improve the health outcomes of women and ensure a sufficient workforce of physician-scientists to improve their health through research and clinical care.

NIH Offices, Institutes, and Centers, including but not limited to the Office of Research on Women's Health (ORWH), the Eunice Kennedy Shriver National Institute of Child Health and Human Development, the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Cancer Institute (NCI), are responsible for important research in women's health that has transformed medicine and improved the health outcomes of women today. To continue its promising multicenter research, the NIH should develop a plan to prioritize research in conditions specific to women and those that may present differently in women than men. An equitable investment in women's health research is critical to improving the health outcomes of women and ensuring the future of research and discovery in this critical field.

FISCAL YEAR 2021 REPORT LANGUAGE REQUEST

National Institutes of Health Office of the Director

Women's Health Research Priorities.—The Committee is concerned that funding for women's health research specifically related to obstetrics and gynecology remains disproportionately lower than other areas of research at the NIH. We believe more focus on this research is required to address the rising maternal morbidity and mortality rates; rising rates of chronic debilitating conditions in women; and stagnant cervical cancer survival rates. The Committee encourages the NIH to convene a consensus conference to include representatives from the Office of Research on Women's Health (ORWH), the Eunice Kennedy Shriver National Institute of Child Health and Human Development, and the National Cancer Institute, as well as any other relevant NIH Institutes and Centers and public stakeholders, to evaluate research currently underway related to women's health. As part of the consensus conference, NIH shall submit a report in the fiscal year 2022 Congressional Justification that identifies priority areas for additional study to advance women's health research, including reproductive sciences.

Funding to Support Research Related to COVID–19

WFRC recognizes and appreciates the actions already taken by Congress to address the COVID–19 public health emergency, including providing funding to NIH. Early data show that the virus manifests itself differently in women than in men, and has serious effects beyond those on the respiratory system. The NIH must prioritize research to gain a better understanding of how and why this is happening. In recent years, the NIH has done significant work to gain an understanding of sex as a biological variable and of the role of sex must be examined as it relates to COVID–19 infection, disease progression, and the development of effective therapeutics. All COVID–19 related studies must enroll participants that are balanced by gender.

It is critical that we also study the effects of COVID–19 on conditions that are unique to or predominantly occur in women, such as pregnancy. While limited data suggest that the outcome of COVID–19 during pregnancy is not worse than that of non-pregnant women, the clinical experience of influenza, SARS and MERS infections indicates that severe respiratory infections may worsen during pregnancy, which could exacerbate morbidity and mortality during gestation. Poorly justified concerns about the safety of medications and vaccines during pregnancy have already led to the exclusion of pregnant women from almost all pertinent COVID–19 clinical trial, including vaccine trials. While the emerging reports do not find a significant effect of COVID–19 infection on the newborn, it remains to be determined whether the child is affected in the long-term. Every attempt should be made, based on sound scientific and clinical data, to include pregnant women in clinical trials designed to prevent COVID–19, mitigate its severity, and gain a better understanding of the virus. While most medical fields have the ability to continue caring for their patients by telehealth or to postpone elective procedures, pregnant women still require in-person care in the clinics or hospitals in certain circumstances.

The COVID–19 pandemic has also drastically disrupted care for women seeking fertility and contractive services and those with chronic disease like cancer and benign gynecological disease. Moreover, we may see an increase in gynecologic cancers, such as cervical and endometrial cancers due to patients postponing or forgoing screenings out of fear of exposure to the virus. These disruptions in care are expected to continue for a significant period of time, and therefore it is important to understand and mitigate the effect of COVID–19. We need evidence as to how best to provide care for conditions specific to women during the COVID–19 pandemic and future pandemics.

FISCAL YEAR 2021 FUNDING REQUEST

To address the COVID–19 pandemic, we must devote research to prevent, treat, and understand the deadly virus. We ask that the Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies consider emergency funding for research (and all related costs) dedicated to COVID–19 at the NIH, and prioritize research on its effect on conditions that affect only women, such as pregnancy, breast and ovarian cancer, benign gynecologic disease, and delays in fertility and contraceptive services.

PREPARED STATEMENT OF YMCA OF THE USA

Thank you, Chairman Blunt and Ranking Member Murray, for the opportunity to provide testimony on behalf of our nation's 2,700 YMCAs and the 22 million individuals—including eight million youth—we serve annually. Every day, Ys work to address critical social issues that affect our nation, nurturing the potential of every child and making our communities healthier by preventing chronic disease and decreasing disparities among minority populations.

As President and CEO of YMCA of the USA (Y–USA), I believe that our country has never needed the YMCA more than it does now. With the impact of COVID–19 changing nearly every aspect of daily life, I submit this testimony in support of the attached programs, which the Y leverages to ensure our communities are strong, safe and secure in a time of great need.

The Y has been serving communities across the country for nearly 170 years—through both prosperous and challenging times. We have weathered world wars, other pandemics, economic recessions and great social and geopolitical upheaval. So, we know the Y will survive this crisis. But we cannot thrive without partnerships and support.

Even with facilities closed, Ys are continuing to find ways to help those in need by providing emergency child care for essential workers, feeding programs for children without access to school meals, emergency shelter for those experiencing homelessness, check-ins for seniors facing isolation, blood drives, and holistic health and wellness support for all ages. Many of these programs are supported by Federal appropriations under your committee's jurisdiction.

As the nation's largest nonprofit provider of child care, we know that child care is a backbone of the nation's economic recovery efforts and essential to our health and public health infrastructure; parents need safe, reliable child care to return to work. The Y is an experienced community provider of quality care, with more than 1,400 early learning sites, 7,300 before- and after-school program sites, and 2,000 summer enrichment and learning programs, prior to COVID–19. Many of these programs serve vulnerable children and families and leverage Head Start, Child Care and Development Block Grant (CCDBG) and 21st Century Community Learning Centers (21st CCLC) funding to ensure that kids are safe, healthy, engaged and on a path to lifelong success.

With school and child care closures, out-of-school time—traditionally thought of as the before- and after-school hours and summer months—is now all the time. This crisis has underlined how critical child care is for working families and how child care programs help prepare young children for school and complement what children learn in school. I am proud of the Y's ability to respond to community needs during this crisis by transitioning from traditional child care programs to operating more than 1,100 emergency child care sites for essential personnel, more than 1,100 emergency feeding sites and offering virtual youth development programming. Continuing to invest in child care will help the Y ensure that young children and school-aged children alike thrive.

We also know that COVID–19 has put stress on families who are attempting to navigate new safety protocols, school closures, uncertain child care, job losses, social isolation and barriers to support services, which, unfortunately, lead to an increased risk of child abuse and neglect. This impact is magnified since teachers, child care providers and other adults trained in identifying and reporting abuse, like those at the Y, have not been able to offer in-person services. Strengthening the system to face these challenges will require increased efforts across the entire child welfare continuum, which depends on increased Federal funding. This includes increasing funds for Child Abuse Prevention and Treatment Act (CAPTA) Titles I and II, which enable states and community-service organizations, like our YMCAs, to increase abuse prevention through locally driven services that are essential to building healthy and thriving communities.

As the pandemic continues to adversely affect the physical health of millions, the Y also continues to be a leading voice on health and well-being. Over the past decade, the Y has driven innovation in prevention and control of chronic disease in partnership with the CDC to save lives and reduce healthcare spending. During this pandemic, our nation is seeing that investing in chronic disease prevention programs and evidence-based health interventions has never been more critical to help mitigate the impacts of other diseases, especially among certain racial and ethnic populations that have been disproportionately affected by COVID–19. The CDC has supported the Y to scale evidence-based initiatives such as the National Diabetes Prevention Program; hypertension and blood pressure monitoring programs; comprehensive cancer programs; and arthritis control, falls prevention and weight management programs, among others, to save lives.

According to the CDC, older adults and individuals with serious underlying medical conditions are likely to be at higher risk of severe illness from COVID–19. Six out of ten adults in the United States have at least one chronic disease and four out of ten have more than one. This means people living with diabetes, hypertension, obesity, lung disease and cancer are at a higher risk of becoming critically ill if they contract COVID–19. Our evidence-based health intervention programs, supported through the CDC's Center for Chronic Disease Prevention and Health Promotion, prevent and help people better manage these conditions. During the COVID–19 pandemic, most of our YMCAs have moved their in-person evidence-based programs to virtual platforms and have seen incredible uptake and retention rates. Ys have also placed tens of thousands of check-in calls with seniors and other at-risk populations to provide support, wellness and connection during this time of isolation.

We are also acutely aware of growing unforeseen challenges arising from the nation's aggressive, though necessary, COVID–19 response. Recent data from Florida has shown that childhood drowning deaths in the state have increased more than 100 percent during the months when stay-at-home orders have been in place, with anecdotal data pointing to drownings resulting from at-home working parents being overly tasked and unable to monitor their children full-time. With summer approaching, and stay-at-home orders remaining in place, funding for drowning prevention programs and data collection at CDC's Injury Center has never been more critical.

While no one is certain what the future holds, we do know that the path forward for many of our Ys and the communities they serve will be extremely challenging. The Y is ready to meet that challenge head-on. We hope that you will take into consideration the accompanying fiscal year 2021 Labor, Health and Human Services, Education and Related Agencies appropriations requests for programs that fund many of these vital services our communities rely on.

Thank you for your consideration of these requests; they will be critical in ensuring the Y can help communities across the nation survive and thrive during and beyond this trying time. We hope you will be able to visit some of our Ys, when the time is appropriate, and see firsthand the powerful impact these programs have on the lives of individuals, children and families in our communities.

[This statement was submitted by Kevin Washington, President and CEO, YMCA of the USA.]