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DEPARTMENT OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 2022

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 AMERICA'S PUBLIC TELEVISION STATIONS AND THE PUBLIC BROADCASTING SERVICE

On behalf of America's 158 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 (Public Broadcasting Service). We urge the Subcommittee to support $565 million in two-year advance funding for the Corporation for Public Broadcasting (CPB) in FY 2024, $20 million for the Public Broadcasting Interconnection System in FY 2022 and $30 million for the Ready To Learn program at the Department of Education in FY 2022.

CORPORATION FOR PUBLIC BROADCASTING: $565 MILLION (FY 2024) TWO-YEAR ADVANCE FUNDED

Public television plays a key role in educating our children; providing job training; preserving our diverse, dynamic culture and democracy; and keeping Americans informed, safe and healthy. Public television's essential services have never been more critical than during the COVID–19 pandemic, when local public television stations in all 50 states provided enhanced educational services and content to help support students, families, teachers, and schools with the sudden challenge of virtual learning.

Federal funding for CPB is essential to making 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 a decade—resulting in an approximate $100 million in lost purchasing power.

Recognizing this loss, we appreciate that Congress increased the forward funded CPB appropriation by $20 million for FY 2022 and an additional $10 million for FY 2023.

While public broadcasting is grateful for these increases, The public broadcasting system is still about $75 million, in inflation-adjusted dollars, behind where the system was 10 years ago, at a time when it is bearing the costly expense of providing access to content on ever emerging platforms and stations continue to offer more and more essential services to their communities.

Public broadcasting respectfully requests that Congress take another substantial step toward securing our current and future public service goals in the FY 2022 appropriations process.

The $565 million that public broadcasting is requesting in FY 2022 for FY 2024 will help restore lost purchasing power and enable local stations to leverage ad-

vancements in technology and make investments in the future that will educate more children and adults, provide additional critical resources and capabilities to teachers and schools, 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

Public media is committed to education and service for all Americans. Public broadcasting allows people at all income levels and from all parts of the country-rural and urban-to have access to consistent, high-quality, diverse content for free. This educational programming is readily available to children, parents, teachers, senior citizens, those pursuing their high school equivalency degrees, and many others.

Since last spring, as schools across the country shifted to remote learning in the face of the COVID–19 pandemic, local public television stations rolled out new education initiatives, including curated At-Home Learning broadcasts, airing instructional lessons created by teachers, and educational datacasting pilots to serve students without internet connectivity. These resources provided critical support to schools, teachers, and parents and helped bridge the digital gap for rural and underserved students. This extraordinary response by public television stations, many of which partnered with state and local education agencies, has provided much needed educational resources and support in communities across the country.

Public television's educational broadcast content has helped more than 90 million pre-school age children get ready to learn and succeed in school. 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 LearningMedia—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. PBS LearningMedia provided teachers and students with critical resources and digital content and the number of users grew by 240% during the pandemic.

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 and instructional content created by teachers. Last year, 60% of kids ages 2–8 watched PBS KIDS content. Parents also looked to public television for educational resources, with PBS Parents users increasing by 80% during the pandemic.

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 retraining American veterans, by providing digital learning opportunities for training, licensing, continuing education credits, soft skills 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, PBS WARN uses the public television interconnection system and local stations' broadcast infrastructure to support 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 use 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 (APTS) to maximize and promote datacasting technology and the opportunity to partner with local public television stations in communities nationwide.

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. Through the pandemic, public television has been providing essential front-line coverage to ensure Americans have the facts they need to stay healthy and local information on where they can turn for help if they need it.

For the 18th year in a row, PBS was ranked the most trusted among national institutions. That trust is more important than ever. Over the last year, when inaccurate information could endanger people's lives, Americans could 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. As some of the last locally controlled media, public television 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 two years ago, 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.

The $565 million that public broadcasting is requesting in FY 2024 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, Henry Louis Gates, Jr. and Stanley Nelson, spend years developing programs like The Vietnam War, Country Music, The Black Church, Tell Them We Are Rising: The Story of Black Colleges and Universities and a documentary on Muhammed Ali airing this fall. 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 BROADCASTING 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 FY 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 FY 2022.

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 who 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: Elinor Wonders Why, Peg + Cat, SuperWhy!, Martha Speaks, Odd Squad and Molly of Denali—a curious and resourceful 10-year-old Alaska Native girl who lives in the fictional village of Qyah, Alaska—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:

—Children from low-income households who were provided with RTL-funded Molly of Denali videos, digital games, and activities were better able to solve problems using informational text, -oral, written, or visual text designed to inform—a fundamental part of literacy that paves the way for future learning, particularly in social studies and the sciences. After only nine weeks of access, this impact is equivalent to the difference in reading skills a first-grader typically develops over three months.[1]

—Ready To Learn-funded resources from the PBS KIDS series *The Cat in the Hat Knows a Lot About That!* increased science learning in children from low-income households and had a positive impact on children's understanding of core physical science concepts of matter and forces-equivalent to the difference in science knowledge an early elementary student develops over five months.[2]

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 FY 2022 to support current grantees and further enhance the discoverability and 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 five years and supported through annual appropriations. Funding in FY 2022 would provide the third year of funding in the latest grant round. Providing $30 million for Ready To Learn in FY 2022 will ensure that CPB, PBS and stations can continue to create the highest quality, proven-effective kids educational media, meeting kids, caregivers and teachers where they are on a variety of platforms, while expanding local, on-the-ground outreach through 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 or streaming subscriptions 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% 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 $565 million in FY 2024 for CPB in addition to $20 million in FY 2022 for public broadcasting's interconnection system and $30 million in FY 2022 for the Ready To Learn Program.

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[1] Kennedy, J. L., Christensen, C., Maxon, T., Gerard, S., Garcia, E., Hupert, N., Vahey, P., & Pasnik, S. (2021).

[2] (Grindal, T., Silander, M., Gerard, S., Maxon, T., Garcia, E., Hupert, N., Vahey, P., Pasnik, S. (2019). Early Science and Engineering: The Impact of The Cat in the Hat Knows a Lot About That! on Learning. New York, NY, & Menlo Park, CA: Education Development Center, Inc., & SRI International.)

PREPARED STATEMENT OF THE NATIONAL PUBLIC RADIO

Chairwoman Murray, Ranking Member Blunt and Members of the Subcommittee,

Thank you for this opportunity to urge the Subcommittee's support for a robust annual federal investment of $565 million in FY 2024 in public broadcasting through the Corporation for Public Broadcasting (CPB) and $20 million in FY 2022 to continue upgrading the public broadcasting interconnection system and other technologies and services that create system efficiencies.

As the President and CEO of National Public Radio (NPR), I offer this statement on behalf of the public radio system, a nonprofit public service media enterprise that includes NPR, more than 1,000 public radio stations, other producers and distributors of public radio programming, and many stations, large and small, that create and distribute content through the Public Radio Satellite System(r) (PRSS(r)). Every day, public radio connects with millions of Americans on the air, online, through smart speakers and mobile devices, and in person to explore current news, music, enduring ideas, and what it means to be human. About 98.5% of the U.S. population is within the broadcast listening area of one or more public radio stations.

Federal funding provided by Congress to the CPB enables local, noncommercial radio stations to provide news, information, and cultural programming to meet the needs of local communities and offer diverse perspectives. This funding is the bedrock of the public broadcasting system. On average, for every $1 in federal grant money that a public radio station receives, it raises $10 locally from audiences and local sponsors. Public radio stations are locally owned and managed, and thereby accountable to the local leaders and listeners they serve.

Many newspapers have lost circulation and advertisers, and are closing their doors, eliminating sources of local news. More than 3,100 journalists at local public radio stations help to fill this need—bringing trusted, reliable, independent news and information of the highest editorial standards to keep communities connected. On May 6, 2021, the Radio Television Digital News Association recognized this quality journalism by awarding public radio 277 Regional Edward R. Murrow Awards—80 percent of the 343 awards in U.S. radio categories.

Continued investments in newsgathering capacities at public radio stations will help ensure that public media can continue to fill the gap for news and information in America's communities with expanded local and regional coverage and digital services. CPB is helping to fund public radio collaboration across key regions. In 2019, NPR and public radio stations in Texas joined together to launch the first regional reporting hub. In 2020, NPR and local stations launched a Gulf states hub covering Mississippi, Alabama, and Louisiana—one of the most news deprived regions in the country—as well as hubs in California and the Midwest. Another NPR collaboration funded by CPB—the Stations Investigations Team-supports local stations' investigative journalism, helping with technical skills such as data collection and analysis, as well as training. These collaborative arrangements allow stations to utilize resources more efficiently, increase the scope of regional coverage, and promote journalistic skills and mentoring.

Public radio stations play an important role in civics—supporting state house coverage, reporting on local elections, and fostering dialogue among communities. On a broader scale, public radio seeks to connect Americans, including students, through coverage of national civics issues and questions. For example, with CPB support, New Hampshire Public Radio produces Civics 101: A Podcast, exploring topics such as types of civic action, electoral processes, fundamental rights, landmark Supreme Court cases, and key documents, such as the Magna Carta. NHPR also provides resources for educators, including teacher created lesson plans, to use these audio resources in the classroom. By inspiring audiences of all ages to engage with foundational civics topics, public radio can support the search for common ground across the political spectrum.

Throughout the COVID–19 pandemic, public radio stations have provided life-saving information and documented stories of how the pandemic affected communities across the nation. In May 2020, a collaborative reporting project from NPR and The Texas Newsroom found that COVID–19 testing sites in four major cities in Texas were located in predominately white neighborhoods, and through the examination of available testing data, revealed that it was harder for people of color to find test sites near where they lived. Following this exclusive report, Dallas County opened two walk-up testing sites in Southern Dallas, and Governor Greg Abbot announced that the state would bring more testing to underserved communities. In 2021, NPR and reporters from The Texas Newsroom and The Gulf States Newsroom teamed up to examine the availability of COVID–19 vaccination sites, again identifying disparities in the location of vaccination sites in major cities in the Southern United States.

At the beginning of the pandemic, as listeners transitioned to working and living in quarantine, public radio's digital audiences grew 250 percent. Audiences sought insight into the nation's response to the coronavirus and how their local communities were affected. Public radio stations provided live blogs on the coronavirus, explanations of public health orders, and information on the development and distribution of vaccines. By the end of 2020, public radio station websites demonstrated continued audience growth, showing a 31 percent year-over-year growth in average monthly users and a 67 percent increase in monthly newsletter traffic.

Madam Chairwoman, Ranking Member, and members of the subcommittee, I would be remiss if I did not thank you for the support you provided to public radio, and the entire public broadcasting system, through the Coronavirus Aid, Relief, and Economic Security ("CARES") Act in 2020 and the American Rescue Plan Act earlier this year. Your support during this crisis ensured that local public radio stations received needed resources to maintain essential programming and services for the communities that depended upon them.

We have seen that the COVID–19 pandemic further demonstrated the value of public radio embracing the challenges of a multi-platform media marketplace, while continuing to hold a dominant position in traditional radio broadcasting. Public radio stations offer original content through a variety of platforms and channels to reach new audiences, including terrestrial radio, satellite radio, the web (desktop and mobile), smart speakers, and podcasts—and application-driven mobile services on iOS and Android (both phone and tablet) and via aggregators such as Apple Music, Facebook News, Stitcher, and TuneIn. The strength of this multi-platform approach is that public radio can reach listeners wherever they are and attract new and diverse listeners. For example, Southern California Public Radio—with CPB support—is reaching out to younger, Latino audiences by producing innovative, on-demand content and increasing the diversity of its on-air hosts, producers and production staff. NPR has also partnered with classrooms across the country in the annual Student Podcast Challenge, which invites middle school and high school students to work with their teachers to develop and produce a podcast for the opportunity to be featured on NPR; a similar challenge is available for college students. Thousands of students and teachers have participated across all 50 states, utilizing resources designed to support the process in the classroom, develop journalism and broadcast skills, and connect public radio to youth audiences.

Public radio is more than journalism. Stations offer communities access to innovative music, arts, entertainment, and other cultural programming. Public radio music-format stations play a key role in supporting noncommercial music in the United States, playing a broad collection of sounds and styles including jazz, blues, classical, folk, alternative, bluegrass, zydeco, roots, and other eclectic genres. Public radio stations make this wide variety of music accessible to listeners through traditional broadcasts, streaming, live performances, and music journalism. This programming supports discovery and creativity, and connects local and national audiences to a broader cultural conversation thus enriching both hearts and minds. Funding for CPB plays a key role in enabling stations and program producers to provide these cultural opportunities.

Public radio would not be possible without the federal funding provided for the PRSS—the satellite content distribution system on which the public radio system—including almost all stations, networks, and producers—generally depends. The federal appropriation would allow the current satellite-and-internet delivery system to continue to be modernized and maintained with next-generation equipment and software.

The PRSS is open to all public telecommunications entities, including independent producers; program syndicators and distributors; national, state, and local organizations; and public radio stations. Stations that receive programming distributed by the PRSS range from those located in remote villages in northern Alaska and on Native American reservations in the Southwest, to major market stations such as WNYC in New York City and KUSC in Los Angeles. Through almost 400 downlinks, PRSS transmits programs distributed from NPR, other major content producers, and more than 100 independent radio producers and organizations with a variety of formats that include news, public affairs, documentaries, classical music, and jazz.

CPB's support of interconnection for the PRSS facilitates the cost-effective and efficient distribution of high-quality, educational programming to this country's increasingly diverse population. As part of that mission, the PRSS provides free, or "in kind," satellite transmission services to distribute programming to un-served or under-served audiences. Currently, full-time support is given to three program service groups: Native Voice One serving Native American listeners; Satelite Radio

Bilingüe, a Spanish-language service; and the African American Public Radio Consortium.

The PRSS also plays a vital role in the nation's emergency alert system by receiving Presidential alerts (also called Emergency Action Notification (EAN) alerts) fed directly from FEMA, which it can transmit to public radio stations in the event of a nationwide crisis. In addition, the PRSS MetaPub service enables local public radio stations equipped with this technology to issue emergency text and graphic alerts—such as tornado and hurricane warnings, evacuation routes, and COVID–19 information—that are visible on screens and synched with over-the-air broadcasts to mobile phones, HD radios, "connected car" smart dashboards, Radio Data System displays, and via online audio streaming. To date, about 10 percent of interconnected public radio stations have the capability to issue live text alerts using the MetaPub system in the event of a natural or humanmade disaster, such as a chemical spill.

In closing, public radio provides an essential public service for local communities across the nation—embracing their diversity, telling their stories, and keeping them informed with trustworthy, independent news, information, and public safety alerts upon which they rely. Your support for the CPB appropriation will ensure that public media can continue to provide these critical services and be positioned to embrace the future of the media landscape. Thank you for your support of the public broadcasting system.

[This statement was submitted by John F. Lansing, President and CEO, National Public Radio.]

NONDEPARTMENTAL WITNESSES

PREPARED STATEMENT OF THE ACADEMY FOR RADIOLOGY & BIOMEDICAL IMAGING RESEARCH

Madam Chair and members of the Subcommittee, I am Mitchell Schnall, President of the Academy for Radiology & Biomedical Imaging Research (Academy), and the Eugene P. Pendergrass Professor of Radiology and Chair of the Radiology Department at the Perelman School of Medicine at the University of Pennsylvania. The Academy is more than 200 academic research departments, patient advocacy groups, industry partners, and imaging societies that represents thousands of radiologists and researchers in all 50 states. The Academy is the only advocacy organization representing the broad spectrum of the imaging research community by collectively advocating for robust and consistent federal research funding.[1] It is my pleasure to submit this testimony on behalf of the Academy. We strongly support the President's request of $52 billion for the National Institutes of Health and ask that no less than $46.111 billion of that be for the NIH's base program budget for FY2022. Investigator-initiated research continues to be the foundation of basic science and discovery. The latter figure represents an increase of $3.177 billion over the FY2021 enacted levels. Moreover, the Academy supports a proportional increase to the National Institute of Biomedical Imaging and Bioengineering (NIBIB), resulting in at least $441.1 million for FY2022—a $30.4 million increase over FY2021. These base increases reflect approximately 5% above the biomedical research and development price index (BRDPI). Through consistent, strong funding for NIH and our national research infrastructure we can continue to make advancements that will improve the lives of patients with a wide spectrum of diseases and disorders. The Academy is grateful for the Subcommittee's past support of NIH and encourages you to continue advancing biomedical research and radiology and imaging science.

Imaging is not limited to any one disease or condition. Instead, it serves as a necessary diagnostic tool that researchers and clinicians of all types use to help advance our understanding of biological systems and how best to develop and deliver treatments benefitting patients. By improving our imaging tools and techniques, we broaden the resources available to address many challenging conditions. In my own work as a clinician-scientist, I use state-of-the-art technologies like specialized magnetic resonance imaging (MRI) and 3-dimensional mammography (digital breast tomosynthesis) to improve the diagnosis and treatment of cancer types, including breast, prostate, and pancreatic, while also researching rare and orphan diseases.

Imaging Innovation to Help Patients

Imaging tools can apply to a wide range of diseases and disorders and can have very real impacts on patient outcomes. This results from Congress's sustained federal investment in biomedical research at NIH over the last several years. Over time, basic science advancements translate into a variety of clinical settings, ultimately benefitting patients. This Subcommittee's continued support of NIH, and specifically NIBIB and the other Institutes and Centers that support imaging research, will help generate future breakthroughs across many biomedical challenges. Moreover, these innovations can be translated into the commercial products, supporting the biotechnology industry and jobs. Below are examples of the community's response to the COVID–19 pandemic, advances in detecting and treating cancer, and the role of imaging in detecting and treating neurodegenerative diseases.

Medical Imaging and Data Resource Center: Merging Diagnostics and Machine Learning

In the first of a two-year effort launched in 2020, the goal of the Medical Imaging and Data Resource Center (MIDRC) is "to foster machine learning innovation through data sharing for rapid and flexible collection, analysis, and dissemination of imaging and associated clinical data...in the fight against COVID–19."[2] MIDRC is an NIBIB-funded collaboration between the American College of Radiology (ACR), the Radiological Society of North America (RSNA), the American Association of Physicists in Medicine (AAPM), and the University of Chicago. These partners are building an accessible and shareable database that can be used to accelerate clinical diagnosis, monitoring, and treatment of COVID–19. Datasets are now being released for public use. Moreover, MIDRC is developing machine learning tools for evaluating medical images to determine the likelihood and future severity of infection, as well

[1] https://www.acadrad.org/about-the-academy/.
[2] https://www.midrc.org/.

as the prognosis for recovery. While currently focused on Covid–19, the methods can be applied to any large set of biomedical images to analyze and identify the likelihood of disease or disorder. Leveraging these innovations and computational tools augments human evaluation. This technology, using nationwide data, also improves predictive tools for identifying serious conditions and recovery prognoses while serving as an "early warning" system for future outbreaks.

Combining Diagnostics and Therapy to Treat Cancer

Recent technological advances in imaging have transformed the landscape for detecting and treating many types of cancer. Today, diagnostics and therapeutics can be combined into one action. The evolving field of theranostics—therapy-diagnostics—uses imaging agents, called radiotracers, to simultaneously diagnose and deliver therapy to affected cells. These targeted molecules are engineered to seek out specific types of cancer cells, which may be part of primary tumors or circulating throughout the body as metastases. Imaging for prostate cancer is now 100 times more effective than it was only 15 years ago. And now, these same agents can be loaded with radioisotopes designed to kill cells, becoming "smart bombs" aimed at cancer. Extensive work is underway to develop smart radiotherapy agents for numerous cancers including prostate cancer. Other targeted agents recently approved by the FDA can simultaneously seek out and destroy neuroendocrine cancer cells, a form of pancreatic cancer. These advances are helping physicians become much more effective in diagnosing and treating these and many other types of cancer, including lymphoma and thyroid cancer. Consequently, the patient receives very real benefits—the ability to find and treat cancer in a single action rather than requiring repeated visits, evaluations, and more invasive procedures. Theranostics, built on research funded by multiple institutes at NIH, has the potential to further advance society's goal of making cancer a treatable disease across a broad array of tumor types.

Detecting Neurodegeneration to Manage Treatments

Every American knows at least one family with a member afflicted by a neurodegenerative condition such as Alzheimer's disease or another form of dementia. The inexact and sometimes subtle symptoms of these conditions in their early stages, combined with the challenges of studying a living human brain, can make effective diagnoses challenging. Recent breakthroughs in imaging provide alternative, more precise tools physicians can use to diagnose and manage the care of affected patients. New imaging agents allow investigators to detect and quantify amyloid plaques and Tau proteins in the brains of patients—two leading indicators for Alzheimer's disease. This ability informs and accelerates the search for new treatments and methods to predict which patients may benefit from such therapies. In fact, a recent clinical trial investigated a new treatment for the removal of amyloid plaque from patients, an approach enabled by an approved imaging agent supported by an NIH grant.

Treatment of another neurological condition, Parkinson's disease, has also advanced because of emerging imaging research. Patients suffering from essential tremor symptoms, including those with Parkinson's, can now benefit from therapies in which magnetic resonance imaging (MRI) images are used to direct sound waves—High-intensity Focused Ultrasound—in a non-invasive way to alter neuronal connections and activities. This intervention often leads to instantaneous improvement in patient symptoms. While not a cure, alleviation of tremor symptoms allows patients to continue managing their condition by caring for themselves through actions such as dressing, eating, and other activities that require fine motor skills.

SUMMARY AND CONCLUSION

Sustained and robust NIH funding is crucial to advancing our efforts to understand and ultimately treat a myriad of diseases and disorders across human systems. NIH investments are also a key economic driver at local research institutions, and NIH funds flow to every state in the nation.[3] If we are to remain a global leader in biomedical research and innovation, continued, strong support for NIH is essential. Funding NIH's base program with at least $46.111 billion will provide the robust support needed to sustain growth for biomedical research.

Thank you for your strong, continued support of NIH, NIBIB, and all the Institutes and Centers working to advance our biomedical research efforts and to improve the lives of patients worldwide. On behalf of the Academy, I urge you to continue your strong support of our nation's research and innovation enterprise.

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[3] https://www.unitedformedicalresearch.org/wp-content/uploads/2021/03/NIHs-Role-in-Sustaining-the-U.S.-Economy-FINAL-3.23.21.pdf.

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

PREPARED STATEMENT OF THE ACADEMY OF NUTRITION AND DIETETICS

Dear Chair Murray and Ranking Member Blunt,

The Academy of Nutrition and Dietetics appreciates the opportunity to submit testimony to the subcommittee for FY22 appropriations. Representing more than 112,000 credentialed nutrition and dietetics practitioners, 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.

For FY22, we strongly urge you to provide funding for the promotion of the 2020–2025 Dietary Guidelines for Americans by the HHS Office of Disease Prevention and Health Promotion; the CDC Division of Nutrition, Physical Activity, and Obesity; and for Americans Older Americans Act senior nutrition programs. In the Department of Education, we support the Health Professionals of the Future program proposed in the President's budget.

Funding: DGA Promotion by the HHS Office of Disease Prevention and Health Promotion—FY2022 Request: $3 million

The 2020–2025 Dietary Guidelines for Americans were released in December 2020 and featured new nutrition recommendations for children from birth through 24 months and pregnant and lactating women. For the Dietary Guidelines for Americans to achieve their intended reach and impact, it is essential that the federal government invest in educating consumers and health care professionals on these new guidelines.

The HHS Office of Disease Prevention and Health Promotion (ODPHP) and the USDA Center for Nutrition Policy and Promotion (CNPP) and they should jointly work to develop materials for comprehensive education campaigns aimed at: (1) educating consumers on how to use the new Dietary Guidelines to inform their dietary choices; and (2) health care professionals to align their dietary guidance with the new Guidelines.

The campaign should be informed by scientific research on health behavior change, as well as input from key stakeholder groups, including nutrition assistance program participants and administrators, health care providers, community leaders, and health and nutrition advocates. The campaign should incorporate educational materials representing wide diversity of cultural food preferences and should be available in languages that meet the needs of populations at risk for diet-related disease.

Funding: Older Americans Act Nutrition Programs (HHS ACL)

The Older Americans Act authorizes a wide array of service programs that are overseen by the HHS Administration for Community Living and delivered through a national network of state agencies, area agencies on aging, and nearly 20,000 service providers.[1] Most program participants have household incomes below 100% of the federal poverty level.[2] In addition to directly combatting senior hunger during this time of uncertainty, senior meals programs have also reduced the need for seniors to leave their homes to get food, helping to limit their exposure to COVID–19. A significant increase in funding for these programs would not only allow more seniors to be served but would free up money for the nutrition assessment and educational components of these programs that are often sacrificed in order to reduce wait lists for meals.

Congregate Nutrition Services

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 issues. For the duration of the COVID–19 public health emergency, service agencies have been given the flexibility to convert their congregate meals programs into drive-up or grab-and-go programs and to use any surplus funds from their congregate nutrition services budget to provide home-delivered meals.

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[1] https://acl.gov/about-acl/authorizing-statutes/older-americans-act.
[2] https://fas.org/sgp/crs/misc/IF10633.pdf.

Home-Delivered Nutrition Services

Home-Delivered Nutrition Services provides more than 145 million meals per year to 867,000 participants, with more than half of program participants categorized as being at high nutrition risk.[3] The program also serves as a welfare check for isolated seniors and as a primary access point for other home- and community-based services. The demand for this crucial nutrition security program has been unprecedented during the COVID–19 pandemic.

Funding: CDC Division of Nutrition, Physical Activity, and Obesity—Division of Nutrition, Physical Activity and Obesity—FY2022 Request: $125 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.[3] Adult obesity prevalence is at over 42% in 2017–2018.[4] 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. Having obesity is a top risk factor for severe disease, hospitalization and death from COVID–19. Minority and low-income communities often lack access to healthful foods and safe places to be active, and these inequities contribute to obesity and other chronic disease disparities that are contributing to disproportionate COVID–19 morbidity and mortality.

State Physical Activity and Nutrition Program—FY2022 Request: $60 million

The State Physical Activity and Nutrition (SPAN) grant program at DNPAO awards competitive grants to states to implement multi-component, evidence-based strategies at the state and local level to improve nutrition and physical activity.[5] With its current funding level, SPAN is only able to fund 16 states, which is does via five-year grants (currently FY18–22). DNPAO estimates that it would cost an additional $1.2 million per state to expand the program, so we are requesting $60 million of the $125 million for DNPAO to go to SPAN to allow every state to receive SPAN grant funding.

Funding: Health Professionals of the Future (ED)—FY2022 Request: $200 million

COVID–19's disproportionate impact on communities of color has made the need for health professional workforce diversity and culturally competent care more urgent than ever. Historically Black Colleges and Universities (HBCUs), Tribal Colleges and Universities (TCUs), and other Minority Serving Institutions (MSIs) have long been leaders in addressing health equity in America. Specifically, HBCUs graduate 43% of all African Americans with postsecondary degrees in STEM fields and roughly 15% of all African American physicians. Despite these successes, gaps remain, particularly among registered dietitian nutritionists.

The Health Professionals of the Future proposal[6] put forth in the FY22 President's budget would help close these gaps by creating and funding a competitive grant program that provides funding to MSIs to create or expand graduate programs that prepare students for high-skilled jobs in the health care sector and help diversify the healthcare sector pipeline. Authorized activities would include the development of a career and educational pathways exploratory system to assist undergraduate and graduate students in learning about career opportunities in these fields and connecting students to internships and jobs; support services to help students complete graduate programs; scholarships or fellowships for tuition or to support on-the-job training.

Contact

Please feel free to contact me at hmartin@eatright.org with any questions on these important issues. Thank you for the opportunity to submit our recommendations to the subcommittee.

Sincerely.

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

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[3] https://www.cdc.gov/nccdphp/dnpao/state-local-programs/funding.html.
[4] https://www.cdc.gov/obesity/data/adult.html.
[5] https://www.cdc.gov/nccdphp/dnpao/state-local-programs/span-1807/index.html.
[6] https://www2.ed.gov/about/overview/budget/budget22/justifications/t-highered.pdf#page=147.

PREPARED STATEMENT OF THE AD HOC GROUP FOR MEDICAL RESEARCH

The Ad Hoc Group for Medical Research is a coalition of nearly 400 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 at least $46.1 billion for NIH's base program level budget in FY 2022.

As a result of the strong, bipartisan vision of the House and Senate Labor-HHS-Education Subcommittees over the last six years, Congress has helped the agency regain some of the ground lost after years of effectively flat budgets. That 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. 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 long-term robust increases in the NIH budget.

In FY 2022, the Ad Hoc Group for Medical Research supports at least $46.1 billion for the NIH base program level budget, including funds provided through the 21st Century Cures Act Innovation Fund for targeted initiatives, a $3.2 billion increase over the NIH's program level funding in FY 2021. This funding level, supported by nearly 400 stakeholder organizations, would provide 5% growth in the base budget above inflation, expanding NIH's capacity to support promising science in all disciplines. We are grateful for President Biden's enthusiasm for medical research investments and welcome opportunities to engage with the Congress and the Administration regarding the proposed Advanced Research Projects Agency for Health (ARPA–H). Robust growth in the foundational research that NIH supports will be key to this vision, and we urge lawmakers to ensure no less than $46.1 billion for the NIH's base and that any additional funds for ARPA–H or other targeted initiatives supplement, rather than supplant, this core investment.

We further recommend a funding allocation for the Labor-HHS-Education Subcommittee in FY 2022 that allows for the necessary investment in NIH and other agencies that promote the health of our nation. We believe that science and innovation are essential if we are to continue to meet current and emerging health challenges, improve our nation's physical and fiscal health, and sustain our leadership in medical research.

In addition, we remain concerned about the lingering $16 billion impact of the coronavirus pandemic on medical research progress in all disease areas, and especially on the research workforce, as highlighted by NIH Director Dr. Francis Collins' recent testimony before this Subcommittee. The supplemental funding Congress has provided over the last year has been instrumental in advancing research on COVID–19, with tremendous success in the form of multiple safe and effective vaccines to combat SARS–CoV–2 and other advances. But the pandemic has threatened progress across numerous other areas, with particular challenges for women, minorities, and early career investigators in the research workforce. We continue to urge support for emergency resources, as outlined in the RISE Act (H.R. 869/S. 289), that will allow the NIH to rebuild the nation's strong and diverse research workforce infrastructure and continue to invest in broad and new research areas that will provide better health for patients in the future.

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. For patients and their families, NIH is the "National Institutes of Hope." The following are a few of the many examples of how NIH research has contributed to improvements in the nation's health.

—NIH-funded basic research laid the groundwork for the novel mRNA vaccine technology used in the first two FDA approved SARS–CoV–2 vaccines. Vaccines continue to be one of our most cost-effective public health tools with every $1 spent on routine childhood vaccinations estimated to save $5 in direct costs, and $11 in broader costs to society.
—Following nearly three decades of NIH-funded research into novel mechanisms of drug action, breakthroughs in the treatment of depression came in 2019 with two new FDA-approved drugs—one for treatment-resistant depression and the first ever treatment for postpartum depression.
—In 2007, induced pluripotent stem cells (iPSC) were discovered when adult cells were re-engineered into early non-differentiated versions of themselves. In 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 most common form of Age-related Macular Degeneration, 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.
—The death rate for all cancers combined has declined in adults since the early 1990s and since the 1970s for children. Overall cancer death rates have dropped by 29% including a 2.2% drop from 2016 to 2017, the largest single-year drop in cancer mortality ever reported.

Sustaining Scientific Momentum Requires Sustained Funding Growth. 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 six years have allowed NIH to more than 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. In FY 2020, NIH was able to fund more than 1,400 grants for ESIs, reinvigorating the spirits of researchers in the biomedical workforce. Sustained increases are needed to allow NIH to continue support of new talent and innovation in medical research.

Even with recent investments 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 eight years. A $1 increase in public clinical research stimulates an additional $2.35 in private sector investments after three years. According to a United for Medical Research report, in FY 2020, NIH-funded research supported more than 536,000 jobs across the U.S. and generated more than $91 billion in 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. Robust funding of the NIH, and strengthening our commitment

to medical research, is a critical element in ensuring the health and well-being of the American people and our economy. Therefore, for FY 2022, the Ad Hoc Group for Medical Research recommends that NIH receive at least $46.1 billion in base funding to advance the foundational research NIH supports and continue the momentum in our nation's investment in medical research.

PREPARED STATEMENT OF THE AIDS INSTITUTE

Dear Chairwoman Murray 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 FY2022 Labor, Health and Human Services, Education, and Related Agencies (L–HHS) appropriation measure. This year's L–HHS bill is more important than ever, as it will set up critical funding streams to help rebuild and reinvest in our nation's public health infrastructure, which has been decimated by COVID–19. As you craft the FY2022 L–HHS appropriations bill, we urge you to significantly increase funding for the Ending the HIV Epidemic Initiative, as well as appropriate additional funds for core public health programs that work to treat and prevent HIV and viral hepatitis in the United States. These programs, many of which are a part of the safety net health system, will be key tools in recovering from COVID–19, and ensuring those most impacted by the COVID pandemic's economic fallout can still access critical care.

HIV IN THE UNITED STATES

Approximately 1.2 million people are living with HIV in the U.S. 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) being the newest tool that couples with traditional prevention techniques like condoms and syringe service programs. Despite these advancements, new cases of HIV have been stagnant at around 38,000 cases a year since 2013. Over the last year, COVID–19 has severely impacted HIV prevention and treatment programs, many of which have had to reduce services, suspend in-person testing, transition to telehealth, and detail staff to COVID response. These programs have been forced to innovate during COVID, and we hope some of the lessons learned can be sustained after the pandemic has ended, such as expansion of at-home HIV testing and increased utilization of telemedicine for HIV treatment and PrEP expansion. It is extremely important that additional funding goes to these programs this year so that we can again start reducing new HIV infections while allowing programs to refocus on core HIV prevention and treatment programs that are vital to making progress against this epidemic.

Additionally, we believe that ending HIV is a racial justice issue. Three quarters of new HIV infections are among people of color because of racism and structural barriers in the healthcare system. To end HIV, these barriers must be broken down, and we believe people living with HIV and the communities they live in must be the drivers behind eliminating racism in healthcare.

ENDING THE HIV EPIDEMIC INITIATIVE

The Ending the HIV Epidemic Initiative (EHE), which began in 2019, is focused on reducing new HIV infections by 90 percent over ten years. In the last two years, your Committee provided $260 million and $404 million respectively for the EHE Initiative, which is run by the CDC, the Health Resources and Services Administration (HRSA), and the National Institutes of Health (NIH). The resources were focused on 57 jurisdictions with the greatest share of HIV incidence, enabling these jurisdictions to craft and implement community-specific plans to reduce the spread of HIV. HRSA's EHE funding for Community Health Centers has already shown promising results, with more than 10,000 new clients being treated for HIV, nearly 865,000 HIV tests administered, and 63,000 new PrEP prescriptions for people at risk for HIV. With greater funding and continued commitment from the Biden Administration to grow the EHE Initiative, The AIDS Institute believes this nation can make significant progress toward the goal of ending the HIV epidemic.

We urge you to fund year three of the EHE Initiative at the following levels: $371 million for the CDC Division of HIV/AIDS Prevention to conduct targeted testing, connection to treatment, and robust surveillance; $212 million for the Ryan White HIV/AIDS Program to increase access to high-quality HIV care and treatment; $152

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. In order for jurisdictions to better plan for years four through ten of the Initiative, we urge the Committee to work with HHS, OMB and the White House Office of HIV/AIDS Policy to make public out-year funding projections for appropriations needed to accomplish the goals of the Initiative by 2030.

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, so it is critical that HIV testing and prevention programs are in place to help connect people to care. 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. The Ryan White Program successfully engages individuals in care and treatment, increases access to HIV medications, and helps over 88 percent of clients achieve viral suppression (which is critical for HIV prevention, because people who have achieved viral suppression cannot transmit HIV to others). Increased funding is required in FY2022 because COVID–19 has strained and will continue to strain Ryan White programs, which have had to respond to increased demand from people living with HIV who lost their jobs and their health insurance because of the pandemic.

The AIDS Institute requests that the Subcommittee fund the Ryan White HIV/AIDS Program at a total of $2.776 billion in FY2022, distributed in the following manner: Part A at $686.7 million; Part B (Care) at $444.7 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 $212 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

There has been significant increase in the number of new cases of hepatitis A (HAV), hepatitis B (HBV), and hepatitis C (HCV) in the U.S. over the past decade, despite medical advances that make preventing and treating viral hepatitis more effective. There are highly effective vaccines for both HAV and HBV, yet cases of HAV have increased 1,300 percent since 2015 and the number of new cases of HBV have remained stable for the past decade. There are several curative treatments for HCV, yet the number of new HCV cases has increased by 484 percent over the past decade with no signs of slowing. The increased incidence of viral hepatitis is largely due to increased injection drug use related to the opioid epidemic. Moreover, the CDC estimates that as many as half of the people who are living with chronic HBV and HCV (400,000 and 1.2 million people respectively) may be unaware that they have contracted the conditions. Left untreated, viral hepatitis causes liver damage, liver disease, cancer, and death. It also contributes to or exacerbates other serious and chronic conditions, increasing health care costs. We also expect to see even greater increases in viral hepatitis cases when data become available for 2020, as we know that many state public health systems were unable to maintain outreach, testing, and treatment services for viral hepatitis while also battling COVID–19, and many harm reduction programs were also unable to operate at full capacity during the pandemic. We can eliminate viral hepatitis, but doing so will require

substantially increased investment in the public health infrastructure for prevention, screening, and treatment.

INFECTIOUS DISEASE IMPACT OF THE OPIOID CRISIS

The recent explosion of opioid use has created tremendous risk for viral hepatitis and HIV outbreaks and increasing infection rates among new groups and undoing progress toward curbing transmissions. The COVID–19 pandemic has caused another surge in injection drug use, with 2020 poised to have the highest overdose death total on record. The systems built to respond to HIV and viral hepatitis are well poised to conduct outreach, engagement, and early intervention services with individuals who use drugs. A comprehensive response to the opioid epidemic must include infectious disease prevention efforts to reduce the infectious disease consequences of the epidemic.

Starting in FY19, Congress allocated new funding to surveil, prevent and treat infectious diseases commonly associated with injection drug use, including viral hepatitis and HIV. We urge the Subcommittee to appropriate $120 million for the CDC's infectious diseases and opioid epidemic efforts.

CDC VIRAL HEPATITIS PREVENTION

The CDC's Viral Hepatitis program funding level is only $39.5 million, which is not nearly sufficient to address the increasing scope of the epidemic. In 2016, the agency suggested it would need 10 times that amount annually to establish a comprehensive national program to effectively combat the spread of viral hepatitis. This year, we request that the Subcommittee appropriate $134 million to the CDC to address the rise in viral hepatitis and combat the impact of the opioid crisis.

SYRINGE SERVICE PROGRAMS

Syringe service programs (SSPs) are a critical tool in the fight to end the opioid epidemic and eliminate viral hepatitis. These important public safety programs reduce the spread of infectious disease, prevent overdose deaths, and connect clients to treatment. The presence of SSPs has been associated with a 50 percent decline in new HIV and viral hepatitis incidence, and when combined with medication-assisted treatment, there is a two-thirds reduction in HIV and HCV transmission. Extensive research shows that these programs save money and that they do not increase drug use. But there are not enough SSPs to meet the growing need, and appropriations language prohibiting them from using federal funds to purchase sterile syringes makes it difficult for many programs to meet their biggest expense. We urge your Subcommittee to increase funding for SSPs and to remove all restrictions on federal funding for syringe service programs, including for the purchase of sterile syringes. The President's FY22 Budget Request and the House's FY21 appropriations bill both removed the restrictions for the purchase of sterile syringes.

PUBLIC HEALTH INFRASTRUCTURE

Decades of chronic underfunding of public health infrastructure programs have left the United States extremely vulnerable to public health disasters, as evidenced by the untold physical and economic harm COVID–19 has wrought on our nation, with more than 33 million Americans sickened and over 600,000 deaths to date. Pandemics are a threat to our nation's safety and health, and we urge the Committee to fund public health programs with the same priority as traditional defense programs. Billions in increased funding is needed annually to ensure that public health programs are modernized, fully staffed, and prepared for public health emergencies. Yearly appropriations have fallen far short of what is needed to protect America's health, which has allowed emerging threats like COVID–19 to wreak havoc.

The AIDS Institute thanks Chairwoman Murray for reintroducing the Public Health Infrastructure Saves Lives Act (S.674), which would create the Core Public Health Infrastructure Program withing the CDC. We believe that this program, if fully funded, will start to rebuild and bolster critical infrastructure needed to prepare for the next public health threat. We thank the Committee and your colleagues for significant increases in emergency funding approved during COVID–19, but we also urge you to ensure that this funding is sustained to forestall future emergencies. We urge the Committee Members and your colleagues to support S. 674, and once signed into law, ensure that the authorized programs are fully funded by your Committee.

Thank you for your consideration of this written testimony. If you have questions or would like to discuss these issues further, please do not hesitate to contact Nick Armstrong at narmstrong@taimail.org or Frank Hood at fhood@taimail.org.

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

PREPARED STATEMENT OF AIDS UNITED

Dear Chairman Leahy, and Vice Chairman Shelby:

As the committee continues its important deliberations on the Fiscal Year (FY) 2022 Labor, Health and Human Services, Education, and Related Agencies (Labor-HHS) appropriation bill, we thank you for your commitment to ending the HIV/AIDS epidemic in the United States and request that you increase the federal government's financial commitment to meet the goals of the federal ending the epidemic initiative and support safety net programs that protect the public health.

Our scientific knowledge of HIV treatment, prevention and epidemiology has never been stronger, but progress, until recently, has stalled. Over the past three years, a concerted effort to target resources where they can be most effective has occurred through the Ending the HIV Epidemic Initiative (EHE Initiative), which has the goal of reducing new HIV infections by 90% by 2030. Additionally, the HIV National Strategic Plan: A Roadmap to End the Epidemic has been developed. We urge Congress to capitalize on the expertise developed by communities as part of the EHE Initiative so that we can improve and expand the Initiative. Ending HIV by 2030 is possible, but resources are needed to achieve this goal.

The COVID–19 pandemic has shown a light on the impact of decades of underfunding our Nation's public health infrastructure, resulting in an inadequate response to an incredibly destructive pandemic. Below are detailed domestic HIV funding requests that we join our coalition partners in the Federal AIDS Policy Partnership in urging committee to include in the FY2022 appropriations bills. A chart detailing each request as well as previous fiscal year funding levels for each program is available here: http://federalaidspolicy.org/fy-abac-chart/.

ENDING THE HIV EPIDEMIC INITIATIVE

Over the last two years, on a bipartisan basis, Congress has appropriated additional funding for the Ending the HIV Epidemic Initiative, which sets the goal of reducing new HIV infections by 50% by 2025, and 90% by 2030. We ask Congress to increase funding in FY2022 for the Ending the HIV Epidemic Initiative by at least the amounts listed below in the following operating divisions:

—CDC Division of HIV/AIDS Prevention for testing, linkage to care, and prevention services, including pre-exposure prophylaxis (PrEP) (+$196 m);
—HRSA Ryan White HIV/AIDS Program to expand comprehensive treatment for people living with HIV (+$107 m);
—HRSA Community Health Centers to increase clinical access to prevention services, particularly PrEP (+$34.7 m);
—The Indian Health Service (IHS) to address the combat the disparate impact of HIV on American Indian/Alaska Native populations (+$22 m); and
—NIH Centers for AIDS Research to expand research on implementation science and best practices in HIV prevention and treatment.

THE RYAN WHITE HIV/AIDS PROGRAM

The Ryan White Program provides comprehensive care to populations disproportionately impacted by the HIV epidemic. Over three quarters of Ryan White clients are racial and ethnic minorities, and nearly two thirds are under the federal poverty level. With 88% of Ryan White clients achieving viral suppression, the program has a proven track record of success.

The Ryan White Program provides services critical to managing HIV, often inadequately covered by insurance, including case management; mental health and substance use services; adult dental services; and transportation, legal, and nutritional support services. Many Ryan White Program clients live in states that have not expanded Medicaid and must rely on the Ryan White Program as their only source of HIV/AIDS care and treatment. While increasingly clients have access to insurance, patients still experience cost barriers, such as high premiums, deductibles, and other patient cost sharing. The Ryan White Program, particularly the AIDS Drug Assistance Program (ADAP), assists with these costs so that clients can access comprehensive treatment.

Currently ADAPs are experiencing increased demand, particularly as people have lost health coverage and incomes due to the economic impact of COVID–19 and state and local budgets have been increasingly stressed. We urge Congress to fund the Ryan White HIV/AIDS Program at a total of $2.768 billion in FY2022, an increase of $345 million over FY2021, distributed in the following manner:

—Part A: $731.1 million
—Part B (Care): $437 million
—Part B (ADAP): $968.3 million
—Part C: $225.1 million
—Part D: $85 million
—Part F/AETC: $58 million
—Part F/Dental: $18 million
—Part F/SPNS: $34 million
—EHE Initiative: $212 million

CDC PREVENTION PROGRAMS

CDC HIV Prevention and Surveillance

Increasing funding for high-impact, community focused HIV prevention services has proven to result in a strong return on investment. Not only are these prevention tools effective at halting new HIV infections, but in the long term they result in decreased lifetime medical costs that are associated with HIV treatment. HIV prevention tools that meet the special prevention needs of these populations must be expanded. HIV will not be eliminated unless we focus resources on those most impacted.

The CDC's Division of HIV Prevention is the federal leader in creating new and innovative strategies for HIV prevention. Through partnerships with state and local public health departments and community-based organizations, the CDC has expanded targeted, high-impact prevention programs that work to address racial and geographic health disparities. We urge you to fund the CDC Division of HIV Prevention at $822.7 million in FY2022, an increase of $67 million over FY2021. This is in addition to the $371 million for EHE Initiative work within the Division.

CDC STD Prevention

Our nation faces a compounded public health crisis. STI rates are at an all-time high for the sixth year in a row. STI data from 2018 shows that combined cases of chlamydia, gonorrhea, and syphilis infections are nearing 2.4 million cases a year—up 30%. STIs have life-changing and life-threatening consequences that include infertility, cancer, ectopic pregnancy, pelvic inflammatory disease, and transmission of HIV. More than 17 years of level funding for STI programs has resulted in a more than 40% reduction in buying power. The STI health infrastructure is part of the public health infrastructure and the need to rebuild is higher than ever. While STI rates peak, the same people who work to prevent the spread of sexually transmitted diseases—contact tracers and disease intervention specialists—have been redeployed to address the current COVID–19 pandemic. Consequently, 80% of sexual health screening clinics being forced to reduce hours or shut down because of understaffing. We urge you to fund the CDC Division of STD Prevention at $252.9 million to rebuild its infrastructure and respond to the dramatic rise in STIs across the country.

Congenital Syphilis is a fully preventable disease if women are provided early, accessible prenatal care that includes STI testing. Despite this, the transmission of congenital syphilis from mother to child during birth increased by 185% between 2014–2018 with an increase more than 40% between 2017 and 2018 alone. The result: a 22% increase in newborn deaths. Twenty million dollars should be allocated to activate a new congenital syphilis elimination initiative at the CDC Division of STD Prevention (DSTDP)—with funds distributed to all STI-funded health departments—to increase prenatal outreach and screenings for congenital syphilis and postnatal follow up for both mothers and babies to ensure that congenital syphilis is detected at the earliest possible stage. We urge you to fund the CDC Division of STD Prevention at $272.9 million in FY2022, an increase of $91.1 million over FY2021.

CDC Viral Hepatitis Prevention

The ongoing opioid crisis and increased injection drug has drastically increased the number of new viral hepatitis cases in the U.S. The CDC estimates that between 2010 and 2017 the country experienced a 374% increase in new hepatitis C (HCV) infections, with an estimated 44,600 new cases in 2017. The number of new cases of hepatitis B (HBV) has also increased over the past several years, with 22,200 new cases in 2017, ending years of declining rates. Of the more than 3.2 mil-

lion people now living with HBV and/or HCV in the U.S., as many as 65% are not aware of their infection.

The CDC's Division of Viral Hepatitis (DVH) remains the lead agency combating viral hepatitis at the national level by providing important information and funding to the states. The division is currently funded at only $39.5 million. This is nowhere near the nearly $393 million CDC estimates is needed for a national viral hepatitis program focused on decreasing mortality and reducing the spread of the disease. We have the tools to prevent this growing epidemic and the Viral Hepatitis National Strategic Plan for the United States: A Roadmap to Elimination (2021—2025). However, only with significantly increased funding can there be an adequate level of testing, education, screening, treatment, surveillance, and on-the-ground syringe service programs needed to reduce new infections and put the U.S. on the path to eliminate hepatitis as a public health threat. We urge you to fund the CDC's Division of Viral Hepatitis at $134 million in FY2022, an increase of $94.5 million over FY2021.

CDC Infectious Diseases and Opioid Epidemic Funding

The FY2019 budget included new funding for the CDC to combat infectious diseases commonly associated with injection drug use in areas most impacted by the opioid crisis. The United States is experiencing an ongoing overdose crisis and some experts have estimated that the U.S. surpassed 100,000 deaths from opioid overdose in 2020, a more than 40% increase from 2019 itself a record year. Outbreaks or significant spikes in infections of viral hepatitis, as well as HIV, in a short period of time among people who inject drugs continue to occur throughout the country. Syringe Services Providers (SSPs) are first responders to the opioid and infectious diseases crisis effectively help prevent drug overdoses and new HIV and hepatitis infections. They have the knowledge, contacts, and ability to reach people who use drugs; they provide naloxone and other overdose prevention resources; and they connect people to medical care and support, including Substance Use Disorder treatment. This program, which is only funded at $13 million, increases prevention, testing, and linkage to care efforts to combat increasing new infections and is strongly needed to provide a strong on the ground response to this crisis. These services are urgently needed, and adequate funding would provide a critical down payment for services needed to help stop the spread of opioid-related infectious diseases. We urge you to fund the CDC's Infectious Diseases and Opioid Epidemic program in FY2022 at the $120 million requested in the president's FY2021 budget, an increase of $107 million over FY2021.

Syringe Services Programs

The Department of Health and Human Services has said that syringe service programs (SSPs) are a proven, evidence-based, and effective tool in HIV and hepatitis prevention. Beyond providing access to sterile syringes, SSPs connect people to substance use treatment, HIV and hepatitis testing, and other supportive services. These cost-effective programs must be expanded, especially in areas hardest hit by the opioid epidemic. SSPs have also been providing COVID–19 related services to vulnerable populations during the pandemic. The FY2021 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. We urge you to remove all restrictions on federal funding for syringe service programs in those jurisdictions that are experiencing or at risk for a significant increase in HIV or hepatitis infections due to injection drug use.

Minority HIV/AIDS Initiative (MAI)

Racial and ethnic minorities in the U.S. are disproportionately impacted by HIV/AIDS. African Americans, more than any other racial/ethnic group, continue to bear the greatest burden of HIV in the U.S. Three out of four new HIV infections occur among people of color. While there have been consistent decreases in new HIV infections among certain populations, HIV infections are not decreasing among Black and Latinx gay and bisexual men.

The Minority HIV/AIDS Fund supports cross-agency demonstration initiatives to support HIV prevention, care and treatment, and outreach and education activities across the federal government. MAI programs at the Substance Abuse and Mental Health Administration target specific populations and provide prevention, treatment, and recovery support services, along with HIV testing and linkage service when appropriate, for people at risk of mental illness and/or substance abuse. We urge you fund the Minority HIV/AIDS Fund at $105 million, and SAMHSA's MAI program at $160 million in FY2022, an increase of $49.6 million and $44 million

over FY2021 levels, respectively. We also urge you to fund Minority AIDS Initiative programs across HHS agencies at $610 million in FY2022.

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.

Please do not hesitate to be in touch for more information regarding HIV appropriations with our Vice President and Chief Advocacy Officer, Carl Baloney, Jr., at cbaloney@aidsunited.org.

Sincerely.

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

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 outside witness testimony on the Fiscal Year (FY) 2022 appropriations for Alzheimer's and other dementia research and public health activities at the U.S. Department of Health and Human Services. Specifically, we respectfully request a $289 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 (P.L. 115–406) at the Centers for Disease Control and Prevention (CDC).

The Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support, and research. It 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. AIM is the advocacy affiliate 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

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, Alzheimer's is also creating an enormous strain on the health care system, families, and federal and state budgets. The annual cost for all individuals with Alzheimer's or other dementia will total $355 billion for health care, long-term care, and hospice care in 2021. This does not include the over $250 billion in unpaid caregiver costs. The U.S. taxpayer-funded federal health care programs Medicare and Medicaid are expected to cover about $239 billion, or 67 percent, of these costs this year. While an estimated 6.2 million Americans age 65 and older are currently living with Alzheimer's, nearly 13 million Americans will have Alzheimer's by 2050 and costs will exceed $1.1 trillion (in 2021 dollars). Alzheimer's and other dementia threaten to bankrupt families, businesses, and our health care system.

INVESTING IN ALZHEIMER'S TREATMENTS

The Food and Drug Administration (FDA) recently approved the first treatment for Alzheimer's disease since 2003 and the first to address the underlying biology of Alzheimer's disease. The FDA determined there is substantial evidence that aducanumab (marketed as Aduhelm) reduces amyloid plaques in the brain and that the reduction in these plaques is reasonably likely to predict important benefits to patients.

This approval represents an important step forward in Alzheimer's research. This new treatment is pivotal, while not a cure. This is the first of a number of new treatments to come. We recognize the drug may work differently for everyone who takes it, and may not work for some individuals. Importantly, aducanumab was studied in and appropriate for people living with early Alzheimer's dementia and mild cognitive impairment (MCI) due to Alzheimer's who showed evidence of a buildup of amyloid plaques in the brain. The therapy has not yet been tested on people with more advanced cases of dementia or Alzheimer's disease.

The recent years of increased investment provided by Congress to NIH have been integral to this and other promising therapeutic approaches to treating Alzheimer's disease. For example, NIH supported basic science investigations behind the discovery of immunotherapies like aducanumab, as well as translational research for next-generation immunotherapies. Additionally, the selection of participants for aducanumab clinical trials hinged on amyloid PET imaging, a technology that would not exist today without the publicly-funded research supported by NIH. The federal commitment, combined with unprecedented philanthropic support, provides the foundation for an optimistic view of the future, which is needed because there is much work to be done.

This is just the beginning of meaningful treatment advances. History has shown us that approvals of the first drug in a new category invigorates the field, increases investments in new treatments, and encourages greater innovation. We are hopeful that this drug is just the beginning for better treatments to come. Looking at the big picture of science, there is a crucial need for effective treatment options for diverse populations living in all stages of Alzheimer's. Alzheimer's must be addressed through multiple different pathways—more than just amyloid—with an eye toward effective combination therapies, pharmacological and nonpharmacological, that work at different stages of the disease.

While recent NIH funding increases have laid the foundation for breakthroughs in diagnosis, treatment, and prevention, and enabled significant advances in understanding the complexities of Alzheimer's, there is still much left to be done. We cannot leave any stone unturned. Investment in Alzheimer's research is only a fraction of what's been applied over time, with great success, 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 build upon promising research advances. An increase of $289 million in Alzheimer's research at NIH in FY2022 would enable scientists to conduct more inclusive, efficient, and practical clinical trials; increase knowledge of risk and protective factors in individuals and across diverse populations; discover better biomarkers to detect disease and monitor treatment response; pursue a precision medicine approach to detect the disease earlier and tailor treatment plans to an individual's unique symptoms and risk profile; and leverage emerging digital technologies and big data to speed discoveries. We need to continue to increase investment in Alzheimer's and dementia research to maximize every opportunity for success.

ADDRESSING ALZHEIMER'S AS A PUBLIC HEALTH CRISIS

As scientists continue to search for ways to cure, treat, or slow the progression of Alzheimer's through medical research, public health plays a critical role in promoting cognitive function and reducing the risk of cognitive decline. Now more than ever it is apparent how crucial it is to have an established infrastructure in place to respond to public health threats.

In 2018, Congress acted decisively to address Alzheimer's as an urgent and growing public health threat through the passage of the bipartisan BOLD Act. This law authorizes $100 million over five years for CDC to build a robust Alzheimer's public health infrastructure across the country focused on public health actions that can allow individuals with Alzheimer's to live in their homes longer and delay costly long-term nursing home care. Congress appropriated $10 million for the first year of BOLD's implementation in FY20, which allowed CDC to award funding to three Public Health Centers of Excellence (PHCOE), focused on risk reduction, caregiving, and early detection, and 16 public health departments across the country. These state, local, and tribal public health department recipients are creating statewide dementia coalitions, hiring dementia coordinators, and developing or updating Alzheimer's and other dementia strategic plans. The $15 million Congress appropriated for the second year of BOLD's implementation in FY21 will help fund additional public health departments and expand the impact of this crucial work into more communities across the country.

The Alzheimer's Association is grateful to be leading the Dementia Risk Reduction PHCOE, focusing on community-level actions to reduce the risk of developing Alzheimer's and other dementia. Researchers are increasingly studying the impact that lifestyle behaviors may have on the risk of developing Alzheimer's and other dementia. The future of reducing Alzheimer's could be in treating the whole person with a combination of drugs and modifiable risk factor interventions, as we do now with heart disease. The Center will work with public health agencies on addressing social determinants of health with respect to dementia risk; capacity building to enable

smaller public health agencies to engage in dementia risk reduction activities; and partnering with health systems in their communities to advance risk reduction.

Over 65 percent of American adults have at least one risk factor for dementia. Although risk factors like age, genetics, and family history cannot be changed, other risk factors can be modified to reduce the risk of cognitive decline and dementia. Examples of modifiable risk factors are physical activity, smoking, education, staying socially and mentally active, blood pressure, and diet. In fact, the 2020 recommendations of The Lancet Commission on dementia prevention, intervention, and care suggest that addressing modifiable risk factors might prevent or delay up to 40 percent of dementia cases.

The Alzheimer's Association is leading a five-year clinical trial to evaluate a two-year intervention to see whether lifestyle interventions that simultaneously target multiple risk factors can protect cognitive function in older adults at increased risk for cognitive decline. The U.S. Study to Protect Brain Health Through Lifestyle Intervention to Reduce Risk (U.S. POINTER) will evaluate the effects of lifestyle interventions, like physical exercise, a healthier diet, cognitive and social stimulation, and self-management of heart and vascular health, on changes in cognitive function. It is crucial that forthcoming findings from studies like U.S. POINTER are translated into public health interventions across the country. Investing now in a robust public health infrastructure ensures cutting edge research can be effectively and efficiently disseminated into local communities.

While these BOLD implementation efforts are important steps forward, and we are grateful to this Subcommittee and Congress for the initial funding, CDC must receive the full $20 million authorized in the law for FY2022 to ensure the meaningful impact that Congress intended. The Alzheimer's Association and AIM urge Congress to include the full $20 million for the third year of BOLD's implementation at CDC in FY2022. Activities supported by the requested $20 million in FY22 would enable CDC to award additional PHCOEs, focused on important priorities such as Tribal Health and avoiding preventable hospitalizations, and expand the number of state, local, and tribal public health departments across the country that receive funding for Alzheimer's public health activities. Finally, as Alzheimer's is one of the most prevalent chronic diseases facing our nation, we look forward to the day that the Subcommittee and CDC elevate Alzheimer's and other dementia to the Division level as with other major chronic diseases.

CONCLUSION

The Alzheimer's Association and AIM appreciate the steadfast support of the Subcommittee and its priority setting activities. We urge the Subcommittee and Congress to provide an additional $289 million for Alzheimer's research activities at NIH and $20 million for full implementation of the BOLD Infrastructure for Alzheimer's Act at CDC in FY 2022.

PREPARED STATEMENT OF THE ALZHEIMER'S FOUNDATION OF AMERICA

On behalf of the Alzheimer's Foundation of America (AFA), a national nonprofit that unites more than 2,000 member organizations in the goal of providing support, services and education to individuals, families and caregivers affected by Alzheimer's disease and related dementias nationwide, I am submitting the following budget requests for your consideration as you prepare fiscal year (FY) 2022 appropriations levels for the federal budget.

For federal programs that impact those living with dementia and their family caregivers, AFA recommends the following budget allocations for FY '22:

—an additional $289 million for a total $3.4 billion for Alzheimer's disease clinical research at the National Institutes of Health/National Institute on Aging (NIH/NIA);

—$560 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;

—$46.1 billion (a $3.2 billion increase over FY '21) for total spending at the NIH;

—support for President Biden's call for $6.5 billion to launch the Advanced Research Projects Agency for Health (ARPA–H) at NIH;

—an additional $50 million to fund caregiver supports and services provided by Older Americans' Act (OAA) programs administered by the Administration for Community Living (ACL), including a $7.5 million increase for the Alzheimer's Disease Program for a total expenditure of $35 million in FY '22; and

—$20.5 million to support BOLD Act initiatives, including a $500,000 increase for the Healthy Brain Initiative and $4 million for fall prevention at the Centers for Disease Control and Prevention (CDC).

National Institutes of Health/National Institute on Aging (NIH/NIA):

NIA sponsors and conducts the lion's share of federal aging-related research, including research into Alzheimer's disease and related dementias, and this pioneering science contributes significantly to the improved care and quality of life of older adults. A key NIA priority is translating research into better and more efficient care through the development of effective interventions that are disseminated to health care 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 lower cost of care.

AFA is extremely grateful to the Subcommittee for recent increases in federal funding for Alzheimer's disease research at NIH/NIA. Additional resources for fighting Alzheimer's disease and related dementias at NIH have greatly increased 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 $289 million, for a total of approximately $3.4 billion for Alzheimer's disease clinical research at NIH in FY '22.

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 $560 million be allocated to conduct BRAIN Initiative research for FY '22.

AFA also urges the Subcommittee to budget at least $46.1 billion for total NIH spending in FY '22, a $3.2 billion increase over the NIH's program level funding in FY '21, 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.

AFA also supports the President's call for an additional $6.5 billion to launch the Advanced ARPA–H at NIH. ARPA–H would leverage existing public sector basic science research programs along with private sector efforts to accelerate development of new capabilities for disease prevention, detection, and treatment and overcome bottlenecks that have limited progress in areas such as Alzheimer's disease. Any funding for ARPA–H, however, should not come from the existing programming budget for NIH and should be considered an additional appropriation to AFA's $46.1 billion request for all of NIH.

Centers for Disease Control and Prevention (CDC):

The Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act requires 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 as 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 funding for FY '22.

For older adults—especially for those living with dementia—falls are common, costly, and often preventable. They represent the leading cause of injury-related death among adults age 65 years of age and older. CDC's National Center for Injury Prevention and Control developed tools for clinicians and other health care partners to identify and address falls and fall risk. AFA urges a continued investment of $4 million to continue funding fall prevention programs at CDC.

Administration for Community Living (ACL):

AFA is requesting a $50 million increase for vital ACL programming impacting those living with dementia, including a $7.5 million increase to the Alzheimer's Disease Program for a total funding of $35 million in FY '22. In addition, AFA is re-

questing that the following amounts be allocated to the following Older Americans' Act (OAA) programs administered by ACL:

—*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 $24.5 million (for a total of $213.6 million) be allocated in FY '22 to support this important program.

—*Lifespan Respite Care Program (LRCP):* AFA urges the Subcommittee to allocate a minimum of $10 million—a $2.9 million increase—to LRCP in FY '22. 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.

—*Falls Prevention:* In response to COVID, several community-based fall prevention interventions, supported with ACL investments, have transitioned to a digital environment in cases where they can safely be implemented in the home. AFA, therefore, urges $10 million, a $5 million increase over FY '21 funding, be allocated so ACL can continue vital fall prevention activities at ACL.

—*Home Delivered Nutrition Program:* This vital program provides grants to states for nutrition services for older people, including many living with dementia. In addition to healthy meals, the programs provide a range of services including being an important link to in-home and community-based supports such as homemaker and home-health aide services, transportation, home repair and modification, and falls prevention programs. AFA calls for a $10.1 million increase, or $286.3 million, for home delivered nutrition programs in FY '22.

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 work 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 like Alzheimer's disease—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.

AFA thanks the Subcommittee for the opportunity to present our recommendations and looks forward to working with you and your staff 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.

Sincerely.

[This statement was submitted by Charles J. Fuschillo, Jr., President and CEO, Alzheimer's Foundation of America.]

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

Chairwoman Murray, Ranking Member Blunt, 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 (FY) 2022 appropriations bill. AAAAI respectfully requests the subcommittee to include $12.2 million in funding for the Consortium on Food Allergy Research (CoFAR) 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. Also, the AAAAI supports funding of $100 million for the National Healthcare Safety Network which enables the Centers for Disease Control and Prevention (CDC) to target prevention of healthcare acquired and antimicrobial resistant infections and improve antibiotic prescribing.

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 16 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 FY22 Labor/HHS appropriation reflects the importance of trans-NIH research on food allergies. AAAAI strongly supports the following NIAID report language submitted by Senator Blumenthal 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 eight percent of children and ten percent of adults in the U.S. 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 the 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.

ANTIMICROBIAL RESISTANCE (AMR) AND PENICILLIN ALLERGY

The growing threat of antimicrobial resistance, combined with the dwindling pipeline of novel antibiotic research, requires policies that prevent inappropriate use of antibiotics. One of the primary ways to combat this threat begins with penicillin—the most commonly reported drug allergy. According to the CDC, approximately 10 percent of the U.S. population report being allergic to penicillin, yet 9 out of 10 patients reporting a penicillin allergy are not truly allergic when formally evaluated, such that fewer than one percent of the population is truly allergic to penicillin. More recently, the CDC cited the importance of correctly identifying if patients are penicillin-allergic in decreasing the unnecessary use of broad-spectrum antibiotics in its 2018 update of Antibiotic Use in the United States: Progress and Opportunities. The AAAAI strongly supports more widespread and routine use of penicillin allergy evaluation for patients with a self-reported history of allergy to penicillin. Evaluation can accurately identify patients who, despite reporting a history of penicillin allergy, can safely receive penicillin.

The AAAAI supports funding of $100 million for the National Healthcare Safety Network which enables CDC to target prevention of healthcare acquired and antimicrobial resistant infections and improve antibiotic prescribing. The Antibiotic Resistance Solutions Initiative will benefit from significant new resources to achieve the goals outlined in the National Action Plan for Combating Antibiotic-Resistant Bacteria, including strengthening antibiotic stewardship to promote best practices for prescribing antibiotics such as penicillin.

AAAAI also wishes to express its appreciation to the subcommittee for the inclusion of language regarding the importance of penicillin allergy testing in the FY20 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 penicillin allergy evaluation for patients with a history of allergy to penicillin or another beta-lactam drug (e.g., ampicillin or amoxicillin). Penicillin allergy evaluation can accurately identify 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 FY22 appropriations 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 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 (FY) 2022 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 Pediatric Subspecialty Loan Repayment (HRSA), $50 million for Firearm Injury and Mortality Prevention Research (CDC/NIH), $10 million for Pediatric Mental Health Care Access Grants (HRSA), $12 million for implementation of Scarlett's Sunshine Act (CDC/HRSA), $22.334 million for Emergency Medical Services for Children (HRSA), $280 million for the National Center for Birth Defects and Developmental Disabilities (CDC), $271.2 million for Global Immunizations (CDC), and $15 million and report language for the Vaccine Awareness Campaign to Champion Immunization Nationally and Enhance Safety (VACCINES) Act (CDC).

Pediatric Subspecialty Loan Repayment Program (HRSA):

FY 22 Request: $50 Million; FY 21 Level: Never Funded.—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 health care needs by offering loan repayment to pediatric subspecialists and child mental health providers who agree to serve in an underserved area. 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. Spotlighting the needs of children with autism spectrum disorder (ASD), as an example, there are approximately 1.5 million children with ASD but there are only about 700 practicing board-certified developmental-behavioral pediatricians. The national wait time for a pediatric developmental evaluation is 5.4 months. In terms of equity, ASD prevalence among Hispanic children is about 16% lower than among white and black children, which suggests that more Hispanic children with autism are not being identified. In addition, black children with ASD are significantly less likely than white children to have a first evaluation by the age of three.

Firearm Injury and Mortality Prevention Research (CDC/NIH):

FY 22 Request: $50 Million Total; FY 21 Level: $25 Million Total.—The AAP is tremendously appreciative of and applauds Congress for continuing to provide $25 million total, split evenly between CDC and NIH, for firearm injury and mortality prevention research in FY 21. In the midst of the COVID–19 pandemic, communities across the U.S. continue to suffer from the public health crisis of firearm-related injuries and deaths with early data showing 2020 being a record-breaking year for gun violence, injuries, and deaths. A public health approach to firearm violence prevention is urgently needed to promote health equity and address the disproportionate burden of this epidemic on communities of color. The foundation of this 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. The initial investments in FY20 and FY21 are important, but increased funding is still needed to overcome the decades-long lack of federal funding that set back our nation's response to the public health issue of firearm-related morbidity and mortality. Over time, additional funding can generate research into important issues such as the best ways to prevent unintended firearm injuries and fatalities among women and children; the most effective methods to prevent firearm-related suicides; the measures that can best prevent the next shooting at a school or public place;

and numerous other vital public health questions. Continued and expanded investments are essential to the success of this important work.

Pediatric Mental Health Care Access Grants (HRSA):

FY 22 Request: $10 Million; FY 21 Level: $10 Million.—The AAP appreciates the additional funds included in the American Rescue Plan for the Pediatric Mental Health Care Access Grants, in recognition of the impact of COVID–19 on child and adolescent mental health, and urges Congress to continue providing $10 million for FY 22 appropriations. This program supports the development of new statewide or regional pediatric mental health care 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 health care, improve health and functional outcomes, increase satisfaction with care, and achieve costs savings.

Activities Authorized under Scarlett's Sunshine Act (CDC/HRSA):

FY 22 Request: $12 Million; FY 21: Level: N/A.—The AAP urges Congress to provide first-time appropriations of $12 million to implement the Scarlett's Sunshine Act. Little is known about the tragic, sudden and unexpected deaths of young children because of variations in investigations and death certifications. Enacted in December 2020, this law will help states better understand sudden unexpected infant death and sudden unexpected death in childhood, facilitate data collection and analysis to improve prevention, and support grieving families. Funds should support work at both CDC and HRSA's Maternal Child Health Bureau given their complementary efforts on this issue.

Emergency Medical Services for Children (HRSA):

FY 2022 Request: $22.334 Million; FY 21 Level: $22.334 Million.—The AAP urges the committee to maintain $22.334 million in funding for the Emergency Medical Services for Children (EMSC) Program in FY 22. 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.

National Center for Birth Defects and Developmental Disabilities (CDC):

FY 22 Request: $280 Million; FY 21 Level: $167.8 Million.—The AAP requests $280 million for FY 22 for the National Center for Birth Defects and Developmental Disabilities (NCBDDD), including $100 million for Surveillance for Emerging Threats to Mothers and Babies (SET–NET). This would allow the program to scale nationally and serve as the nationwide preparedness and response network the United States needs to protect pregnant individuals and infants from emerging public health threats. 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, as well as COVID–19.

Global Immunization—Polio and Measles/Other (CDC):

FY 22 Request: $271.2 Million ($176 Million for Polio and $50 Million for Measles/Other); FY 21 Level: $226 Million ($176 Million for Polio and $50 million for Measles/Other).—Vaccines are one of the most cost-effective and successful public health solutions available. 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 declined by 79% between 2000 and 2015 thanks to expanded immunization, saving an estimated 20.3 million lives. Unfortunately, the gains from global immunization are in jeopardy. During the COVID–19 pandemic, many countries diverted resources set aside for polio and routine immunizations to fight the pandemic. To finance immunization gaps in countries and recover from pandemic-related disruptions requires an additional $255 million over the next three years. Failing to close these gaps will leave millions of children at risk and will compromise U.S. global health security due to increased possibility of importing highly infectious diseases like measles into the U.S.

Activities Authorized under the VACCINES Act (CDC):

FY 22 Request: $15 Million; FY 21 Level: N/A.—The AAP is very appreciative that Congress specifically included the Vaccine Awareness Campaign to Champion Immunization Nationally and Enhance Safety (VACCINES) Act as part of Section 2302 of the American Rescue Plan that provided $1 billion to improve vaccine confidence for both COVID–19 and routine immunizations. We urge Congress to include $15 million authorized by the VACCINES Act for CDC to research vaccine hesitancy and establish an evidence-based public awareness campaign to help improve vaccination rates across the lifespan. We also urge Congress to request a report on the progress of these activities at the CDC.

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 FY 2022 and beyond. If we may be of further assistance, please contact the AAP Department of Federal Affairs at pjohnson@aap.org. Thank you for your consideration.

[This statement was submitted by Lee Savio Beers, MD, FAAP, President, American Academy of Pediatrics.]

PREPARED STATEMENT OF THE AMERICAN ALLIANCE OF MUSEUMS

Chairwoman Murray, Ranking Member Blunt, 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 $80 million for fiscal year (FY) 2022, an increase of $39.5 million. We request that $2.5 million of this increase be directed to explore establishing, and to fund projects related to, a roadmap to strengthen the structural support for a museum Grants to States program administered by OMS, as authorized by the Museum and Library Services Act, in addition to the agency's current critical direct grants to museums.

AAM—representing more than 35,000 individual museum professionals and volunteers, museums of all types, and corporate partners serving the museum field—stands for the broad scope of the museum community.

I want to express the museum field's gratitude for the $40.5 million in funding for OMS in FY 2021, and we applaud the bipartisan group of 41 Senators who recently wrote to you in support of FY 2022 OMS funding. We also applaud the President's budget proposal for additional funding for OMS for the grants program authorized by the African American History and Culture Act and the grants program authorized by the National Museum of the American Latino Act as steps in the right direction. OMS is a vital investment in protecting our nation's cultural treasures, educating students and lifelong learners alike, and bolstering local economies. During the COVID–19 pandemic, OMS has provided critical leadership to the museum community through its CARES Act grants. For example, the agency has been providing science-based information and recommended practices to reduce the risk of transmission of COVID–19 to staff and visitors engaging in the delivery of museum services.

Through the IMLS CARES Act Grants to Museums and Libraries, IMLS awarded $13.8 million to 68 museums and libraries to support their response to the coronavirus pandemic. IMLS received 1088 applications from museums but was only able to fund 39 awards, fewer than 4 percent of the applications, for a total of $8.28 million—far below the $261.5 million requested. Unfortunately, none or very little of the $200 million allocated to IMLS in the American Rescue Plan is expected to be awarded to museums.

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,* pre-pandemic U.S. museums supported more than 726,000 jobs and contributed $50 billion to the U.S. economy per year, including significant impact on individual states. For example, the total financial impact that museums have on the economy in the state of Washington is $1.01 billion, supporting 14,145 jobs. For Missouri it is a $852 million impact, including 13,653 jobs.

Nationally, museums spend more than $2 billion yearly on education activities and the typical museum devotes 75% of its education budget to K–12 students.

IMLS is the primary federal agency responsible for helping museums connect people to information and ideas. OMS supports all types of museums—from art museums to zoos—by awarding grants that help them better serve their communities. 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, with wide bipartisan support. OMS grants to museums are highly competitive and decided 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.

There is high demand for funding from OMS. In FY 2020 OMS received 784 applications requesting nearly $146 million, but current funding has allowed the agency to fund only a small fraction of the highly rated grant applications it receives. $80 million would allow OMS to double its grant capacity for museums, funds that museums will need to help recover from the pandemic and continue to serve their communities. This substantial funding increase would still be greatly shy of the high demand of $146 million in highly rated grant applications. A Grants to States program administered by OMS, in addition to the agency's current direct grants to museums, would merge federal priorities with state-defined needs, expand the reach of museums, and increase their ability to serve their communities, address underserved populations, and meet the needs of the current and future museum workforce.

Museums are 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. PPP 1 and PPP 2, and Shuttered Venue Operators Grants (limited to museums with theatres with fixed seating) have and will provide a critical lifeline for many museums. But the museum field will need robust ongoing support from IMLS, especially as not all museums were eligible for pandemic relief funds. According to a report by McKinsey and Company, the arts, entertainment, and recreation sectors will not fully recover from this public health crisis and muted economy until 2025.

Recent survey data confirmed that the dire economic harm to museums caused by the COVID–19 pandemic will result in a long road to recovery for the field. Three-quarters of museums (76 percent) report that their operating income fell an average of 40 percent in 2020 while their doors were closed to the public for an average of 28 weeks due to the pandemic. Museums have largely been unable to offset losses by cutting expenditures. Fifteen percent (the equivalent of more than 5,000 US museums) confirmed there was a "significant risk of permanent closure" or they "didn't know" if they would survive the next six months absent additional financial relief. Nearly half (46 percent) of museums surveyed report that their total staff size has decreased by an average of 29 percent compared with pre-pandemic levels. Only 44 percent of all respondents plan to rehire or increase their staff size in the coming year. Pre-pandemic museums supported 726,000 jobs. Fifty-nine percent of responding museums were forced to cut back on education, programming, and other public services due to budget shortfalls and/or staff reductions during the pandemic. Thirty-nine percent of responding museums require investments in their building, HVAC equipment, and other infrastructure to improve energy efficiency and reduce the environmental impact of their operations. The average anticipated cost of these improvements is $668,000 per museum.

Despite economic distress, museums have been filling critical gaps in our communities. During the pandemic, museum professionals—severely impacted by the pandemic themselves-stepped up by serving the needs of their communities. They are addressing education gaps and 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. Museums 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 have donated their PPE and scientific equipment to fight COVID–19, and provided access to child care and meals to families of health care workers and first responders. In the midst of financial distress, they are even raising funds for community relief and providing reliable information on COVID–19 and vaccinations, some even serving as vaccination sites themselves. Museums are pivotal to our nation's ability to manage through the pandemic and recover from it as our nation opens back up.

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

In 2021, the Suquamish Indian Tribe of the Port Madison Reservation in Washington was awarded a $85,400 Native American/Native Hawaiian Museum Services grant to update an oral history project conducted from 1981–83 that has guided the development of the Suquamish Museum for over 30 years. The project will engage the 78 Suquamish elders who are 70 years of age and older to document their biographical, cultural, and personal knowledge for use in more contemporary programming and museum exhibits. Although the tribe recognized the need to gather oral histories during a retreat in 2018, the COVID–19 pandemic not only increased the sense of urgency but provided time to consider a plan for the project. Collecting oral histories of experiences in the more recent past will guide long range planning and help the museum focus its collections acquisitions for the next foreseeable decades.

In 2020, the Seattle Art Museum in Washington was awarded a $216,970 Museums for America grant to expand its early learner initiative known as Artful Beginnings to create increased opportunities for hands-on arts learning and engagement for children ages 2 through 6, their caregivers, and educators. The focus is on three core Artful Beginnings programs: Tiny Tots Workshops and Family Fun Storytime, Art Adventures, and an art-based outdoor preschool curriculum with Tiny Trees. The museum's three locations—as well as community partner facilities in South Seattle and South King County—will host the programs. Programming will focus on engaging traditionally underserved and lower-income audiences. The project underscores the museum's commitment to equity and inclusion and will work to engage all audiences more deeply.

In 2020, Port Townsend Marine Science Society in Washington was awarded a $49,613 Program Inspire! Grants for Small Museums grant to complete an exhibition master plan as part of a larger facility improvement project. The expanded and renovated facility will create an accessible, unified, cohesive exhibition experience with strong content linkages and seamless indoor-outdoor integration that gives the feeling of a journey into the Salish Sea. The process of developing the exhibition master plan will involve formative evaluation, including site visits, surveys, focus groups, and consultations with professionals. Representatives of key stakeholder groups, including educators and students, volunteers, marine conservation professionals, and other Salish Sea environmental organizations will provide input on the plan concept and exhibition content. The center intends to inspire responsible stewardship of global oceans through the development of immersive, informative content.

In 2020, the Walt Disney Hometown Museum in Marceline, Missouri, was awarded a $38,240 Program Inspire! Grants for Small Museums grant to expand its education and professional development programs for rural educators. The initiative is the result of a collaborative partnership that includes museum staff, K–16 educators, and others from the local community. Educators will have the opportunity to participate in an immersive learning workshop program where they will experience and explore place-based learning opportunities alongside guided instructional planning. The initiative will solidify bonds between the museum and the community, as educators and museum personnel collaborate to strengthen their understanding of how local culture connects to learning.

In 2020, the Missouri Botanical Garden in Saint Louis, Missouri, was awarded a $202,220 Museums for America grant to create a Butterfly House Entomology Lab to serve as a functional space for staff and volunteers to properly care for their invertebrate animal collection while providing guests an interactive experience. This exhibition will promote learning experiences focused on the butterfly life cycle, invertebrate animal conservation, and the field of entomology. The project also will include the addition of digital components such as monitors that highlight the characteristics of each display species and their region of origin. The addition of technology also will allow virtual field trips to the Butterfly House Entomology Lab.

In closing, I highlight recent national public opinion polling that shows that 95% of voters would approve of lawmakers who acted to support museums and 96% 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 by Laura L. Lott, President/CEO, American Alliance of Museums.]

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION FOR CANCER RESEARCH

Chair Murray, Ranking Member Blunt, and members of the subcommittee and staff, thank you for the opportunity to submit testimony. I am Dr. David Tuveson, Director of the Cold Spring Harbor Laboratory Cancer Center and Chief Scientist for the Lustgarten Foundation, the largest pancreatic cancer research philanthropic organization. I am submitting testimony as President of the American Association for Cancer Research (AACR). On behalf of the AACR's 48,000 members, I ask for your support for at least $46.1 billion in FY 2022 funding for the National Institutes of Health (NIH), and $7.6 billion for the National Cancer Institute (NCI).

We are in an era of unprecedented progress against cancer, including advances in immunotherapies and targeted anti-cancer therapies that led to spectacular decreases in cancer mortality. Thanks to investments at the NCI, we have new tools at our disposal that could only be dreamed of decades ago to maximize advances in early diagnosis of many types of cancer and offer highly effective treatments that improve health outcomes and reduce health disparities. Additionally, the funding that NCI provides to the NCI-designated cancer centers that are located all throughout the country is supporting pioneering new research, serving patients in their communities, and training the next generation of cancer scientists.

There are so many breakthroughs within our grasp, but to achieve them, we need federal investments to keep up with demand on basic research for cancer.

Since FY 2015, thanks to your leadership, NIH funding has increased by nearly 42%. But due to other funding needs at NIH, including worthy initiatives that take away from the top line, and a nearly 50% increase in applications at NCI since 2013, the funding increases have not kept up with demand.

Even with the significant funding you have provided, the percent of NCI grant applications that are funded, referred to as the success rate, is among the lowest of all institutes at NIH. In FY 2020, the NIH-wide success rate for competing research project grants, or RPGs, was nearly 21%. For NCI, it was only 12.8%, and that's the highest NCI's success rate has been in six years.

NCI has been stretching dollars to fund more grants. NCI Director, Dr. Sharpless, released his 15-by-25 milestone, an effort to increase the number of R01 grants funded until it reaches the 15th percentile in 2025. The AACR strongly supports this important mission, but to achieve the goal of funding more meritorious research, more funding will be needed.

While the success rate of an RPG at NHLBI is 22.2%, and NIDDK is 23%, NIAID is 23.9%, and the National Institute on Aging is 25.8%, NCI's rate of 12.8% is not sustainable to meet our pledge to apply new cancer science and medicine towards improving patient outcomes. With the low success rate, I worry the best and the brightest, in particular early-stage researchers, will choose other career paths. The United States cannot lead the world in cancer discoveries if the NCI success rate is so low that researchers choose another field.

Thanks to your leadership, language was included in the last two explanatory statements to prioritize competing grants and sustain commitments to continuing grants. I humbly ask you to continue these efforts in FY 2022 and provide funding to meet Dr. Sharpless' goal so the cancer research community can accelerate the path to discoveries and save lives.

I know cancer is personal for you, as it is for me. Thank you for this opportunity and for your commitment to bringing us closer to our mutual goal of conquering cancer.

[This statement was submitted by David A. Tuveson, MD, PhD, FAACR, President, American Association for Cancer Research.]

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION FOR CLINICAL CHEMISTRY

The American Association for Clinical Chemistry (AACC) welcomes the opportunity to provide testimony to the Senate Appropriations Subcommittee on Labor, Health & Human Services, and Education regarding our nation's fiscal year (FY) 2022 budget priorities. AACC and its partners are urging the subcommittee to support two initiatives vital to improving the quality and efficacy of healthcare in the United States:

—Improving Pediatric Reference Intervals—$10 million for the Centers for Disease Control and Prevention, Division of Laboratory Services, Environmental Health Laboratory to improve the quality of pediatric reference intervals used by health practitioners to diagnose, monitor, and treat children.

—Harmonizing Clinical Laboratory Test Results—an additional $7.2 million ($9.2 million in total) for the Centers for Disease Control and Prevention, Division

of Laboratory Services, Environmental Health Laboratory to continue its ongoing efforts to harmonize the reporting of clinical laboratory test results, which is the vital to providing better, more consistent healthcare in the United States.

IMPROVING PEDIATRIC REFERENCE INTERVALS

AACC, the American Academy of Pediatrics, the Children's Hospitals Association, and 30 other organizations have written to the subcommittee urging additional funding for the Centers for Disease Control and Prevention (CDC) to improve the quality of pediatric reference intervals (PRIs)—the range of numeric values expected in a healthy child—available to health practitioners to care for their young patients.

When making a diagnosis, the healthcare professional considers a laboratory test value within the context of a reference interval. If the test result falls outside of the defined reference interval for a healthy child—either higher or lower—the practitioner may order a medical intervention to address a health condition or change an ongoing treatment protocol. If the diagnosis or treatment change is incorrect for any reason, including an inaccurate reference interval, it could result in patient harm. Therefore, it is critical that the range of values used by practitioners to interpret test results are accurate.

Whereas the reference intervals for adults are generally reliable, there is considerable inconsistency and large gaps in the ranges available for children. Healthcare practitioners need reference intervals reflective of healthy children at each unique stage of physical development from birth through adolescence to adulthood. In addition, the intervals must also take into consideration any variations due to biological factors, such as ethnicity and gender.

Accurate and actionable PRIs are particularly important for our youngest patients, who are often unable to verbally communicate their symptoms. Unfortunately, most laboratories are unable to obtain enough samples from a diverse, healthy population of children to develop their own reference intervals.

Congress recognized the importance of this issue when in the accompanying report language to the Further Consolidated Appropriations Act of 2020 it requested CDC to develop and submit a plan for improving PRIs. The agency outlined its plan in the Department of Health and Human Services fiscal year 2021 congressional justification to Congress. The plan calls for the CDC to employ its existing infrastructure to initiate and advance this vital work. According to CDC, it can:

—collect clinical samples through its National Health and Nutrition Examination Survey (NHANES), which has the organization and expertise to collect specimens from healthy children; and

—utilize its Environmental Health Laboratory (EHL) to generate the reference intervals for children and disseminate the information to clinical laboratories. EHL has developed reference intervals in the past.

AACC and its partners support providing CDC with an additional $10 million to improve the quality of PRIs critical to caring for our nation's children.

HARMONIZING CLINICAL LABORATORY TEST RESULTS

Another issue that AACC and its allies request your assistance with is the harmonization of clinical laboratory test results. Laboratory test methods provide accurate test results, but different methods generate different numeric values. With different methods in use across the healthcare system, lack of harmonization makes it difficult to develop widely applicable clinical guidelines or performance measures. It also complicates data aggregation, which limits the development of tools to better inform health decision-making.

Tests that are harmonized (or standardized) provide the same numeric value for a condition regardless of the method or instrument used or the setting where the tests are performed. An early example of harmonization is cholesterol, which is widely utilized by the medical community to diagnose heart disease. A 2011 study published in Preventing Chronic Disease reports that early drug intervention based on cholesterol levels saved the health system $338 million to $7.6 billion annually between 1980—2000.[1] Harmonization can improve patient care while also saving money.

In recent years, Congress has supported the expansion of CDC's harmonization efforts, resulting in new activities to improve the detection and management of hormone disorders, kidney disease, cancer, and heart disease. With additional funding, the agency will be able to expand its harmonization activities to develop materials for non-traditional biomarkers, such as apolipoproteins, and the assessment of point

[1] Hoerger TJ, Wittenborn JS, Young W. A cost-benefit analysis of lipid standardization in the United States. Preventing Chronic Disease 2011; 8: A136.

of care testing devices that are increasingly being used by healthcare providers and patients.

AACC and its partners respectfully request that the subcommittee provide an additional $7.2 million ($9.2 million in total) for the CDC to continue and advance its harmonization activities. Congress has provided $2 million annually for this program since FY18.

AACC is a global scientific and medical professional organization dedicated to clinical laboratory science and its application to healthcare. We look forward to working with the subcommittee on these most important issues as it goes through the FY22 budget process. If you have any questions, please email Vince Stine, PhD, AACC's Senior Director of Government and Global Affairs, at vstine@aacc.org.

[This statement was submitted by David Grenache, PhD, D(ABCC), President, American Association for Clinical Chemistry.]

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 (FY) 2022. I currently serve as the chair of the Board of Directors and president of the Association. I am a professor in the Department of Diagnostic and Biological Sciences at the University of Minnesota School of Dentistry, where I also serve as the director emeritus of the Minnesota Craniofacial Research Training Program (MinnCResT).

For FY 2022, the American Association for Dental Research—along with our colleagues in the oral health community—is seeking at least $520 million for the National Institute of Dental and Craniofacial Research (NIDCR) and at least $46.111 billion for all of the Institutes and Centers at the National Institutes of Health (NIH). Funding at these recommended levels will allow for the entities' base budgets to keep pace with the biomedical research and development price index (BRDPI) and provide meaningful growth of 5%.

As our nation continues to respond to the global COVID–19 pandemic, we are reminded of the importance of the federal investment in science, and in particular, biomedical research. AADR is grateful to Congress for consistently prioritizing this research at NIH by providing steady and meaningful funding increases, which will be more important than ever to carry forward in the wake of the pandemic. While we recognize there will be funding challenges in FY 2022 given the tremendous resources allocated to COVID–19 relief, we cannot afford to underfund our nation's research agencies now. Underfunding will leave us ill-equipped to complete our exit from the current pandemic, deal with future pandemics, and risk losing the progress that has been made by congressional investment in biomedical research.

The requested 5% growth above BRDPI would provide critical support for these research agencies, which have been among the many enterprises negatively impacted by this public health crisis. The ongoing pandemic caused closures of university campuses and forced laboratories to scale back or halt research projects. It also required research agencies to shift existing resources and funding to coronavirus-related research at the expense of other important scientific inquiries about health and disease.

NIDCR—the largest institution dedicated exclusively to research to improve dental, oral and craniofacial (skull and face) health—is one the NIH Institutes and Centers that has prioritized COVID–19 research. To date, NIDCR has funded approximately $3.9 million of immediate and high impact research to protect and ensure the safety of personnel and patients in dental practices during the COVID–19 pandemic. The Institute will soon release a second round of funding related to COVID–19.[1] Funding for NIDCR COVID–19 research is critical to the nation's public health, supporting work that includes the use of personal protective equipment (PPE) in dental settings, aerosol and droplet transmission in dental settings, the infection of salivary glands and oral tissues by SARS–CoV–,[2] and the use of biosensors to detect SARS–CoV–2 in saliva.

This important research agenda with broad public health impact notwithstanding, NIDCR was not included among the NIH Institutes and Centers to receive targeted

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[1] National Advisory Dental and Craniofacial Research Council—January 2021. National Institutes of Health, 2021. https://videocast.nih.gov/watch=38984.

[2] Scientists Find Evidence that Novel Coronavirus Infects the Mouth's Cells. Press Release, NIDCR. https://www.nidcr.nih.gov/news-events/nidcr-news/2021/scientists-find-evidence-novel-coronavirus-infects-mouths-cells; Huang, N., Pérez, P., Kato, T. et al. SARS–CoV–2 infection of the oral cavity and saliva. Nat Med 27, 892–903 (2021). https://doi.org/10.1038/s41591-021-01296-8.

supplemental funding in COVID–19 relief legislation—nor has the annual investment in NIDCR kept pace with the overall funding increases provided to NIH over the past several years. Funding of at least $520 million in FY 2022 would help bring NIDCR funding into alignment with the overall NIH request and allow NIDCR to build on its myriad successes in 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. Oral health can affect activities that may be taken for granted: the ability to eat, drink, swallow, smile, speak, and maintain proper nutrition. The oral cavity also serves as a window into potential health issues, including but not limited to systemic diseases, such as diabetes, HIV/AIDS and Sjögren's, an autoimmune disease that causes one's immune system to attack parts of its own body.

Coronavirus research shows that the virus can infect more than the upper airways and lungs, but also cells in other parts of the body. In fact, recent NIDCR-supported research has also shown that the novel coronavirus can infect cells in the mouth. As the study's authors explain.[2] :

"The potential of the virus to infect multiple areas of the body might help explain the wide-ranging symptoms experienced by COVID–19 patients, including oral symptoms such as taste loss, dry mouth and blistering. Moreover, the findings point to the possibility that the mouth plays a role in transmitting SARS–CoV–2 to the lungs or digestive system via saliva laden with virus from infected oral cells."

According to NIDCR's press release on the study, this research is contributing to our understanding of COVID–19, including oral transmission, and could inform interventions to help combat the virus and alleviate the associated oral symptoms. Indeed, this seminal research may have important implications to explain why super-spreader events occur in places where people sing, speak loudly, or party.

Dental, oral and craniofacial research presents vast research opportunities, and we know NIDCR will continue to be the key player in advancing our understanding of the role of the mouth and oral tissues in many scientific frontiers going forward. One path to highlighting the Institute's work and the future of this research in the United States is through the U.S. Surgeon General's Report on Oral Health, a critical update to the seminal "Oral Health in America" report from July 2000. The report—originally set to be released in the fall of 2020—will document the progress in the improvement of oral health since 2000, provide insight into issues currently affecting oral health, and identify opportunities and challenges that have emerged over the past 20 years. 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 will also have a significant impact, and we have encouraged the administration to swiftly review and release the report. The long-awaited report is a critical public health document and is essential to moving our nation's health forward.

In addition to the important work of NIDCR, AADR recognizes that federal research and public health efforts work in concert and that success in one area can benefit another. Therefore, we encourage Congress—in addition to supporting NIH and NIDCR in FY 2022, to support the full breadth of federal agencies supporting oral health. Complementing our NIDCR and NIH requests, we urge you to provide $30 million for the CDC's Division of Oral Health, $46 million for the Title VII Health Resources and Services Administration (HRSA) programs that train the dental health workforce, at least $500 million for the Agency for Healthcare Research and Quality (AHRQ), and at least $200 million for the National Center for Health Statistics (NCHS).

The COVID–19 crisis shook our nation and reminded us of the critical role biomedical and public health research play in our society. Over the course of 2020 and 2021, we saw how the research enterprise can safeguard public health, national security and economic growth. We urge Congress to continue to prioritize biomedical research, including dental, oral and craniofacial research in FY 2022 so our nation's citizens can continue to enjoy the benefits of state-of-the-art, world-leading health care.

We appreciate the opportunity to submit this testimony and thank the Subcommittee for considering our request of at least $520 million in funding for NICDR and at least $46.111 billion for the Institutes and Centers at NIH. AADR stands ready to assist the Congress in any way we can and to answer any questions you may have.

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[1] National Advisory Dental and Craniofacial Research Council—January 2021. National Institutes of Health, 2021. https://videocast.nih.gov/watch=38984.

[This statement was submitted by Mark C. Herzberg, D.D.S., Ph.D., President, 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 want to thank the Subcommittee for its leadership and continued support of nursing education, the nursing profession, and nursing research, especially during this unprecedented time. As the national voice for academic nursing, AACN represents nearly 840 schools of nursing at private and public universities, who educate more than 580,000 students and employ more than 52,000 faculty.[1] Collectively, these institutions play a critical role in protecting the health of our nation by graduating registered nurses (RN), advanced practice registered nurses (APRN), educators, researchers, and other frontline providers. As we work to combat current public health challenges, such as COVID–19, and prepare for the future, ensuring a robust supply of nursing professionals requires a strong and sustained federal investment. For Fiscal Year (FY) 2022, AACN respectfully requests that you provide bold support of at least $530 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 and at least $199.755 million for the National Institute of Nursing Research (NINR), which was included in the President's FY 2022 Budget.

THE GROWING NURSING WORKFORCE DEMAND

Nurses comprise the largest sector of the healthcare workforce with more than four million RNs and APRNs, which include Nurse Practitioners (NPs), Certified Registered Nurse Anesthetists (CRNAs), Certified Nurse-Midwives (CNMs), and Clinical Nurse Specialists (CNSs).[2] Nurse educators, students, and practitioners are leaders within their institutions and communities; many of whom are also serving on the frontlines of the COVID–19 public health emergency. Even prior to COVID–19, our nation was in need of additional nurses. This demand is only expected to grow as we continue to combat the pandemic and address the healthcare needs of all patients, including those in rural and underserved areas. In fact, the Bureau of Labor Statistics' outlook for RN workforce demand projected an increase of 7% by 2029, representing the need for an additional 221,900 jobs.[3] Additionally, the need for most APRNs is expected to grow by 45%.[4] This increasing demand in the nursing workforce can be attributed to several factors such as an aging population, nursing retirements, and an increase in workplace stress.[5] Bold investments in Title VIII Nursing Workforce Development Programs and NINR would help prepare a highly educated nursing workforce and strengthen the foundation of nursing science, not only as we confront existing health challenges, but as we provide tomorrow's equitable and innovative healthcare solutions.

NURSING WORKFORCE INVESTMENTS: SUSTAINING EDUCATION TO SECURE A STRONG NURSING WORKFORCE

Our ongoing efforts to combat COVID–19 have made it abundantly clear that a well-educated nursing workforce is essential. For over fifty years, Title VIII Nursing Workforce Development Programs have been a catalyst for strengthening nursing education at all levels, from entry-level preparation through graduate study. Through grants, scholarships, and loan repayment programs, Title VIII federal investments positively impact the profession's ability to serve America's patients in all areas, bolster diversity within the workforce, and increase the number of nurses, in-

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[2] Scientists Find Evidence that Novel Coronavirus Infects the Mouth's Cells. Press Release, NIDCR. https://www.nidcr.nih.gov/news-events/nidcr-news/2021/scientists-find-evidence-novel-coronavirus-infects-mouths-cells; Huang, N., Pérez, P., Kato, T. et al. SARS–CoV–2 infection of the oral cavity and saliva. Nat Med 27, 892–903 (2021). https://doi.org/10.1038/s41591-021-01296-8.

[1] American Association of Colleges of Nursing. (2021) Who We Are. Retrieved from: https://www.aacnnursing.org/About-AACN/Who-We-Are.

[2] National Council of State Boards of Nursing. (2021). Active RN Licenses: A profile of nursing licensure in the U.S. as of April 23, 2021. Retrieved from: https://www.ncsbn.org/6161.htm.

[3] U.S. Bureau of Labor Statistics. (2021). Occupational Outlook Handbook-Registered Nurses. Retrieved from: https://www.bls.gov/ooh/healthcare/registered-nurses.htm.

[4] U.S. Bureau of Labor Statistics. (2021). 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.

cluding those at the forefront of public health emergencies and caring for our aging population.

Each Title VIII Nursing Workforce Development Program provides a unique and crucial mission to support nursing education and the profession. For example, the Advanced Nursing Education (ANE) programs help increase the number of APRNs in the primary care workforce and supported more than 8,200 students in Academic Year 2019–2020 alone.[6] In addition, the Nurse Faculty Loan Program (NFLP) awarded 45 grants to schools that supported 2,270 graduate nursing students in Academic Year 2019–2020.[7] According to AACN's Annual Survey, student enrollment in entry-level baccalaureate nursing programs increased by 5.6% in 2020.[8] While this heightened interest in nursing education is promising news, we need to ensure these students have ample nursing faculty to guide them through their clinical and didactic education and prepare them to respond to our nation's ever-changing healthcare environment.

As we address social determinants of health and work to build an equitable healthcare system for all patients, it is imperative that we recruit individuals from diverse backgrounds to the nursing profession. Increasing diversity in the profession will not only create lifelong career pathways, but will also improve care quality and access to population-centered care. The Nursing Workforce Diversity (NWD) program serves as a glowing example of a successful Title VIII initiative that accomplishes this goal. In fact, in Academic Year 2019–2020, the NWD program awarded grants supporting 11,620 nursing students from disadvantaged backgrounds.[9] The recruitment of underrepresented racial and ethnic individuals and those from economically diverse backgrounds to nursing positively impacts the classroom, professional practice environments, and ultimately patients.

As such, to ensure the stability of our nursing workforce now and in the future, we request at least $530 million for Title VIII Nursing Workforce Programs.

FROM RESEARCH TO REALITY: NURSING SCIENCE PROTECTS AMERICANS' HEALTH

AACN recognizes how scientific research and discovery is the foundation on which nursing practice is built and is essential to advancing evidence-based interventions, informing policy, and sustaining the health of the nation. As one of the 27 Institutes and Centers at NIH, NINR plays a fundamental role in improving care and is on the cutting edge of new innovations impacting how nurses are educated and how they practice. In fact, 80% of research-focused educational training grants at nursing schools are funded by NINR.[10] Through these grants and others, nurse scientists, often working collaboratively with other health professionals, are generating and translating impactful new research in areas such as big data and data science, precision health, and genomics.[11] Despite the critical research these grants support, NINR was only able to fund 8.9% of grant applications in 2017, due to insufficient funding.[12] This is the lowest research project grant (RPG) success rate among all NIH institutes and centers, and is significantly lower than the overall NIH RPG

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[6] Department of Health and Human Services Fiscal Year 2022 Health Resources and Services Administration Justification of Estimates for Appropriations Committees. Pages 153–155. Retrieved from: https://www.hrsa.gov/sites/default/files/hrsa/about/budget/budget-justification-fy2022.pdf.

[7] Department of Health and Human Services Fiscal Year 2022 Health Resources and Services Administration Justification of Estimates for Appropriations Committees. Page 167. Retrieved from: https://www.hrsa.gov/sites/default/files/hrsa/about/budget/budget-justification-fy2022.pdf.

[8] American Association of Colleges of Nursing. (2021). Student Enrollment Surged in U.S. Schools of Nursing in 2020 Despite Challenges Presented by the Pandemic. Retrieved from https://www.aacnnursing.org/News-Information/Press-Releases/View/ArticleId/24802/2020-survey-data-student-enrollment%20%20%20%20%20.

[9] Department of Health and Human Services Fiscal Year 2022 Health Resources and Services Administration Justification of Estimates for Appropriations Committees. Page 159. Retrieved from: https://www.hrsa.gov/sites/default/files/hrsa/about/budget/budget-justification-fy2022.pdf.

[10] Schnall, R. (2020) National Institute of Health (NIH) funding patterns in Schools of Nursing: Who is funding nursing science research and who is conducting research at Schools of Nursing? Journal of Professional Nursing, 36(1), 34–41. Retrieved from https://www.sciencedirect.com/science/article/pii/S8755722319301164?via=ihub#.

[11] National Institutes of Health, National Institute of Nursing Research. The NINR Strategic Plan: Advancing Science, Improving Lives. Retrieved from: https://www.ninr.nih.gov/sites/www.ninr.nih.gov/files/NINR__StratPlan2016__reduced.pdf.

[12] 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.

success rate of 18.7%.[13] To further this vital work, we are requesting a total of at least $199.755 million for the National Institute of Nursing Research.

From the classroom to the frontlines, nurses and nursing students are integral members of the healthcare team. Strong investments in Title VIII Nursing Workforce Development Programs and NINR have a direct impact on sustaining pathways into nursing and patient access to high-quality, evidence-based care in all communities across the nation. During these unprecedented times, AACN respectfully requests bold support in FY 2022 of at least $530 million for the Title VIII Nursing Workforce Development Programs and at least $199.755 million for the National Institute of Nursing Research. Together, we can ensure that such investments promote innovation and improve health and 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) strongly supports fiscal year (FY) 2022 funding for the following programs important to the osteopathic medical education (OME) community:

—$46.1 billion for the National Institutes of Health (NIH)
—$6.1 billion for the Teaching Health Centers Graduate Medical Education (THCGME) Program
—$9.2 billion for discretionary Health Resources and Services Administration (HRSA)
—$980 million for the Title VII health professions workforce development programs under the Public Health Service Act
—Permanent funding for the Rural Residency Planning and Development (RRPD) Program
—$130 million for discretionary National Health Service Corps (NHSC) Scholarship and Loan Repayment programs
—$67 million for the Area Health Education Center (AHEC) Program
—$125 million for the Primary Care Training and Enhancement (PCTE) Program
—$500 million for the Agency for Healthcare Research and Quality (AHRQ)
—$10 billion for the Centers for Disease Control and Prevention (CDC)

AACOM leads and advocates for the full continuum of OME to improve the health of the public. Founded in 1898 to support and assist the nation's osteopathic medical schools, AACOM represents all 37 accredited colleges of osteopathic medicine—educating nearly 31,000 future physicians, 25 percent of all U.S. medical students—at 58 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.

Osteopathic medicine plays an essential role in our nation's healthcare delivery system and is a growing field. According to recent data, AACOM received more than 28,000 applicants to osteopathic medical school for the 2020–2021 application cycle, representing a 19.26 percent increase over the previous year. Osteopathic physicians focus on treating the whole person, and over half practice in the primary care specialties of family medicine, internal medicine, and pediatrics. Importantly, osteopathic medical students receive 200 hours of additional training in osteopathic manipulative treatment, a hands-on treatment used to diagnose and treat illness and injury, giving us a unique voice and perspective in the medical community. However, the clinician workforce and scientists at osteopathic medical schools are underutilized in NIH funding opportunities and underrepresented on NIH Advisory Councils and standing study sections.

AACOM urges Congress to overcome the historic bias against osteopathic medical research by expanding representation on NIH Councils and study sections and increasing NIH funding. Expanding engagement by osteopathic medical schools and professionals will result in innovative healthcare delivery solutions, expanded evidence-based research, and broader community-focused treatment models. OME investment will advance research in primary care, prevention, and treatment and employ an already diverse physician population that is enriched in socioeconomically disadvantaged rural communities. AACOM's request of $46.1 billion for NIH will support scientific advancements that incorporate the osteopathic philosophy and

[13] Ibid.

strengthen the United States position as the world's research and development leader.

OME has a proven history of establishing educational programs for medical students and residents that target the healthcare needs of rural and underserved populations. With health disparities on the rise, and worsening because of the COVID–19 pandemic, we are proud to help make healthcare access more equitable for all our country's patients and communities. In fact, recent AACOM data show that 40 percent of graduating 2019–2020 osteopathic medical students plan to practice in a medically underserved or health shortage area; of those, 45 percent plan to practice in a rural community.

AACOM expresses its strong support for $6.1 billion for the THCGME Program and our desire for permanent, mandatory funding for this critical program. 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 health care services to underserved communities. AACOM is pleased that Congress supported this highly successful bipartisan program through the Consolidated Appropriations Act, 2021 and American Rescue Plan Act of 2021, which extended the THCGME Program through fiscal year 2023 and provided additional funding. However, new funding is needed to extend the THCGME Program to meet economic challenges caused by the COVID–19 pandemic and support additional expansion to underserved areas that face existing shortages of primary care physicians.

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 IMMUNOLOGISTS

The American Association of Immunologists (AAI), the nation's largest professional association 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 (FY) 2022 appropriations for the National Institutes of Health (NIH). AAI recommends an appropriation of $52 billion for NIH for FY 2022, including at least $46.1 billion for the regular NIH budget, to enable the agency to fund needed research to prevent dangerous infectious diseases and treat debilitating chronic illnesses, support meritorious scientists at all career stages, and ensure a robust research enterprise that maintains U.S. preeminence in biomedical science and innovation. Because the COVID–19 pandemic has posed difficult challenges, including lab closures and other interruptions, to many biomedical (particularly early career) scientists, NIH needs, and AAI strongly supports, an infusion of additional funding that would likely be considered outside of the annual appropriations process.

AAI also supports the appropriation of substantial funding to launch the newly proposed Advanced Research Projects Agency for Health (ARPA–H). While AAI is enthusiastic about ARPA–H's potential, we believe that any funding provided must supplement, and not supplant, the NIH regular budget, and that this new agency must enhance, and not interfere with, NIH's historic commitment to funding basic research. AAI also urges that NIH solicit stakeholder input to help answer many outstanding questions, including whether existing programs—and which research areas—will be integrated into ARPA–H. Finally, AAI believes that funding for ARPA–H projects should be provided for longer than three years to ensure sufficient time for the kind of innovative, collaborative, and transformative research that is contemplated.

ILLUSTRATING THE IMPORTANCE OF UNDERSTANDING THE IMMUNE SYSTEM: COVID–19

The COVID–19 pandemic has highlighted both the importance, and high stakes, of biomedical research. Our lives, health, security, and prosperity depend on scientific understanding and advances. What felt remote to many people—scientists toiling away unseen in their laboratories—has become urgent, everyday news. The surge of interest in immunology—and scientists' ability to meet this historic moment—have been bright spots in an otherwise tragic, painful, and unprecedented year, and rapidly developed vaccines to prevent COVID–19 infection have been a historic success story.

But SARS–CoV–2, the virus that causes COVID–19, continues to mutate, giving rise to new variants. We know that this is what viruses do, and we know that this is what our immune systems must be primed to fight. Despite excellent news on the vaccine front, the regular appearance of new variants, our paucity of therapeutics for those who contract COVID–19, and our lack of understanding of, and treatments for, Post-Acute Sequelae of SARS–CoV–2 infection (PASC, or "long COVID") all render as premature any declaration of victory. We must continue to invest robustly not only in a deeper understanding of how the immune system responds to this virus and these vaccines, but also in research devoted to the basic understanding of the immune system. Such research will help us both emerge from this pandemic and prevent—and more rapidly extinguish—any future ones.

But the study of immunology is about much more than infectious diseases. Research on the immune system has taught us how to harness it to kill malignant tumors and treat other chronic diseases (immunotherapy); how it prevents or exacerbates chronic conditions such as Alzheimer's, multiple sclerosis, and cardio-vascular disease; how it enables—or prevents—the successful transplantation of a lifesaving organ; and how it can protect its host from (natural or man-made) agents of bioterrorism.

HOW BASIC IMMUNOLOGY RESEARCH LED TO RAPID APPROVAL OF VACCINES AND TREATMENTS FOR COVID–19

In this pandemic era, there is no better way to illustrate the importance of a long-term commitment to biomedical research, and specifically to immunological research, than to describe how science achieved the near-impossible: the successful testing, manufacture, and distribution of multiple, highly effective, and safe vaccines against COVID–19 in less than a year after the identification of the causative agent. The development of both treatments and vaccines for SARS–CoV–2 infection and COVID–19 was a result of decades of basic research, much of which was funded by, or performed at, NIH. This work includes understanding the virus, identifying good antigens for a vaccine, and defining immune system responses to infection.

SARS–CoV–2 is a member of the beta-coronavirus family responsible for two other recent outbreaks, SARS–CoV–1 (2003) and MERS (2012) and is related to the coronaviruses that cause 15–30% of common colds. More than 50 years of research on this virus family has allowed us to understand key portions of the viral genome and viral life cycle, as well as the importance of the spike protein for infection. While work at NIH's National Institute of Allergy and Infectious Diseases' Vaccine Research Center identified how to manipulate the spike protein so it could be used in a vaccine, work on other infectious diseases and some cancers facilitated the implementation of the mRNA platform into a ready-to-use state. After developing mRNA vaccines for 10–15 years, scientists launched some of the first clinical trials using the mRNA platform against Zika virus and influenza. As a result, the platform was ready to be quickly adapted to target the SARS–CoV–2 spike protein.

In other work, scientists rapidly characterized immune responses in people who experienced SARS–CoV–2 infection. Patients with poor outcomes had over exuberant immune responses; blocking these responses with steroids improved survival. Immunologists also identified several immune molecules that are at too high levels (e.g., IL–6) or too low levels (e.g., interferon). Work is ongoing to understand what protective immunity looks like, including the types of antibodies and cellular immunity that prevent reinfection and characterize immunity after vaccination. These studies will support the generation of booster vaccines and give us insight into how well current vaccines protect against new viral variants.

Finally, because of this longstanding research into coronaviruses, scientists can reasonably infer how long protective immunity will last following infection with, or vaccination against, SARS–CoV–2, giving the public confidence to resume their daily activities while providing the scientific community with a needed window in which to develop booster vaccines that will protect against circulating viral variants.

VACCINES AGAINST OTHER INFECTIOUS DISEASES AND NEWLY EMERGING THREATS

Vaccines remain the most effective method of disease prevention. Vaccination against more than two dozen viral, bacterial, and fungal diseases prevents about 2.5 million deaths globally and reduces the severity of illness for millions of people annually.[1] As the world's population grows and as travel enables people to become even more interconnected, we will continue to experience the very real threat of new emerging pathogens causing a deadly pandemic. Lessons we learn from developing

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

and administering vaccines against SARS–CoV–2 will be essential to protecting against other infectious diseases and a future pandemic.

Last year, I testified that there was no approved vaccine against SARS–CoV–2, but that NIH-funded research conducted on other causative pathogens in recent epidemics, including SARS and MERS, had made possible the rapid development of vaccine candidates against SARS–CoV–2.[2] Since then, three vaccine candidates have received an Emergency Use Authorization (EUA) from the Food and Drug Administration (FDA), and two will be considered soon for licensure.[3] AAI is confident that previously conducted research, together with new research now being urgently pursued, will result in additional vaccines and treatments to prevent and/or reduce both the lethality of, and long-term symptoms caused by, COVID–19.

NIH: THE ESSENTIAL ROLE OF THE NATION'S LEADING BIOMEDICAL RESEARCH AGENCY

As the nation's major funding agency for biomedical research, NIH is an indispensable scientific leader both in the U.S. and around the world. The steward of nearly $43 billion in federal funds, NIH distributes more than 80% of its budget via a competitive peer review process to more than 300,000 researchers at ~2,500 universities, medical schools, and other research institutions across the nation and internationally.[4] About 10% of its budget supports ~6,000 additional researchers and clinicians who work at NIH facilities around the country.[5] By funding these researchers and laboratories, NIH not only advances scientific achievement, it also helps strengthen state and local economies; in 2020, NIH funding supported more than 536,000 jobs and accounted for $91 billion in economic activity across the U.S.[6] The basic research that NIH funds is an essential and irreplaceable part of the biomedical research pipeline; data show that it contributed to all 210 of the new drugs approved by the FDA from 2010–2016.[7]

NIH plays an essential role in responding to emerging health threats; throughout the coronavirus pandemic, NIH leaders and researchers have provided critically needed scientific advice to the President, Congress, and the American public while also utilizing their expertise to help develop a vaccine and treatments. NIH also regularly apprises our nation's leaders about other scientific advancements and research priorities, and its unparalleled peer review process fosters the wise distribution of taxpayer dollars.

CONTINUED FUNDING INCREASES NEEDED TO REBUILD AND GROW NIH CAPACITY

Leadership by this subcommittee has helped Congress provide generous increases to the NIH budget over the last six years. Although these increases have helped restore much of the purchasing power that NIH lost after years of inadequate budgets and erosion from biomedical research inflation, NIH's purchasing power remains below its 2003 peak funding level. Meaningful budget growth will help close this gap and allow NIH to invest not just in important research priorities across its Institutes and Centers, but also in the research workforce. While NIH should continue to support meritorious senior scientists, it is urgent to ensure that we will have sufficient mid- and early career scientists ready to take on increasingly complex scientific challenges. We must provide NIH with the resources needed to provide a dynamic research environment that allows for the training, development, and support of our next generation of researchers, doctors, professors, and inventors—and give them the confidence to pursue these careers.

CONCLUSION

AAI greatly appreciates the subcommittee's strong support for NIH and urges a budget for NIH of $52 billion for FY 2022. Within that, AAI recommends an appropriation of at least $46.1 billion for the regular NIH budget to help the agency grow its ability to invest in critically important research, including vital immunologic research, support meritorious scientists at all career stages, and help scientists discover new ways to prevent, treat, and cure deadly and debilitating diseases that af-

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

[3] https://www.fda.gov/emergency-preparedness-and-response/coronavirus-disease-2019-covid-19/covid-19-vaccines; https://www.pfizer.com/news/press-release/press-release-detail/pfizer-and-biontech-initiate-rolling-submission-biologics; https://investors.modernatx.com/news-releases/news-release-details/moderna-announces-initiation-rolling-submission-biologics.

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

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

[6] https://www.unitedformedicalresearch.org/wp-content/uploads/2021/03/NIHs-Role-in-Sustaining-the-U.S.-Economy-FINAL-3.23.21.pdf.

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

flict people in the U.S. and throughout the world. AAI also urges a substantial appropriation to launch the new ARPA–H, which could greatly advance human immunology at a time in our history when pressing public health needs, and unprecedented scientific opportunities, have converged.

[This statement was submitted by Ross M. Kedl, Ph.D., Chair of the Committee on Public Affairs, American Association of Immunologists.]

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF NEUROMUSCULAR & ELECTRODIAGNOSTIC MEDICINE

FISCAL YEAR 2022 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.
—Please provide the National Institutes of Health (NIH) with $46.1 billion in discretionary funding, an increase of $3.2 billion over FY 2021. Please also provide proportional increases for various NIH Institutes and Centers, including the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), the National Institute of Allergy and Infectious Diseases (NIAID), and the National Institute of Neurological Disorders and Stroke (NINDS).
—Please support adequate funding to establish the new Advanced Research Projects Agency for Health (ARPA–H) at NIH to facilitate robust and swift scientific progress on a variety of neuromuscular conditions.

Chairwoman Murray, Ranking Member Blunt, 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 FY 2022 L–HHS appropriations. First and foremost, thank you for the ongoing investment in medical research and patient care programs. Please continue this investment in FY 2022.

In regards to fraud and abuse, 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, 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 5,400 members across the country. Our mission is to improve quality of patient care and advance the science of neuromuscular (NM) 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 impulse 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.—These tests evaluate 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.

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 FY 2022 appropriations process to recommend greater community collaboration and to encourage meaningful and timely progress in the area of EDX fraud and abuse.

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. My most recent case involved 56 EDX studies, all of which were performed AFTER the NCS codes were changed in 2013, and every single one of the reports were deemed so far below the standard of care that none of them could be considered a reliable representation of the true medical status of the patients who received those tests. Therefore, none of those tests should have been billed or reimbursed.

RECENT EXAMPLES FROM DR. PETER GRANT

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 US 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% 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).

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

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF UNIVERSITY PROFESSORS

Dear esteemed Members of Congress:

The American Association of University Professors (AAUP) is the oldest organization of its kind, representing faculty and graduate employees in institutions of higher education. Since its founding in 1915, the AAUP has been an active and influential voice in higher education. The AAUP defines and develops fundamental professional values, standards, and procedures for higher education; advances the rights of academics, particularly as those rights pertain to academic freedom and shared governance; and promotes the interests of higher education teaching and research.

On behalf of all faculty, and our chapters across hundreds of institutions, we write to thank you for your historic investments in higher education over the course of the past year. Across the country, funding provided by the CARES Act and subsequent COVID–19 relief bills have stopped the worst financial impacts from hitting our campus communities. However, as appreciated as the unprecedented $135 billion has been, faculty and staff have not shared in all the benefits, to the detriment of the student experience. According to a survey we recently ran of faculty senate chairs, 10 percent of institutions had laid off tenured faculty and 28 percent had laid off contingent faculty in the past year,[1] despite the influx of federal funds that explicitly said that they could be used to meet payroll budget gaps. Faculty working conditions are student learning conditions. To us, it is clear that our institutions need sustained, increased funding to invest more in the people and infrastructure that make them run.

We are pleased to see the historic levels of funding proposed in the American Families Plan and the President's FY22 budget. This funding makes meaningful progress towards our call for a New Deal for higher education,[2] which calls for free college, faculty and staff job security, and student debt cancellation. These planks of our New Deal platform will provide institutions the resources they need to better foster innovation and ensure high quality instruction. Beyond that, in a time of political division and heightened social tension, open access to a college education might also help us strengthen civic engagement and advance racial and economic justice. However, as ambitious and appreciated as the President's proposals have been, in some ways they fall short of what students need—and don't go far enough to equitably fund our institutions.

The AAUP recommends that the Appropriations Committee prioritize the following to better meet the needs of faculty and students:

1. Double the Pell Grant, the purchasing power of which has fallen to less than a third of the annual cost of tuition at the average public institution. More than a thousand organizations have called on Congress to increase Pell Grant funding dramatically, and that call seems more urgent than ever given increased student need during the pandemic. Furthermore, we strongly encourage you to maintain the Pell Grant reserve, and not rescind it to fund other programs within the Labor-HHS-Education budget.

2. Increase funding for programs that support students of color, non-traditional students, and low-income students, such as but not limited to Title III funds to minority serving institutions, TRIO, SEOG, work study, and CCAMPIS. These programs ought to see more generous funding to help close equity gaps between non-traditional students and their peers, and to begin to address historic underfunding that minority-serving institutions have faced.

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[1] https://www.aaup.org/report/survey-data-impact-pandemic-shared-governance.

[2] https://newdealforhighered.org/.

3. Increase funding to scientific research programs, which are a significant source of funding to support graduate students in their pursuit of knowledge and a degree. The cutting-edge academic and scientific discoveries made by researchers at American institutions makes our higher education system one of the most respected in the world. Many of these discoveries lead to robust partnerships with private industry that result in job creation and economic growth. And, the scientific breakthroughs of the past year make a clear case for increased funding for broad and exploratory research.

4. Create a federal-state partnership to make college free, so that any qualified student might pursue an associate's or bachelor's degree at the institution of their choice. Congress should also consider how to increase funding to private institutions so that they too can offer reduced costs, such as Title III programs and noting in report language that states may use these funds for student grant aid to subsidize the cost of attendance at private institutions in their home state.

5. As a condition of this new funding, it ought to protect faculty and staff job security by setting a baseline of support for workers. Gig work and the exploitation of contingent faculty erodes the foundations of what makes American higher education so respected internationally. Beyond supporting an increase in the share of faculty on the tenure track, where applicable, positions on college campuses should provide a guarantee of good pay, continuity of employment, and parity in wages and benefits between full and part time positions. Institutions should work as much as possible to convert existing short-term contracts with employees to longer-term or tenure-track appointments.

6. Promote shared governance, by making clear in bill and report language that federal funding to institutions and states in the aftermath of the COVID–19 pandemic ought to maintain instructional spending levels and faculty jobs, ahead of administrative costs or debt financing. Furthermore, faculty and staff must have meaningful input when administration seek to cut costs in moments of financial uncertainty.

We would again like to thank you for your generous and historic funding to meet the needs of students and institutions of higher education during the pandemic. We look forward to working with you to help our country recover from the pandemic, strengthen our communities and civil society, and create thousands more good-paying jobs on campus in the process.

[This statement was submitted by Kaitlyn Vitez, Government Relations Officer, and John McNay, Government Relations Committee Chair, American Association of University Professors.]

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) and Centers for Disease Control and Prevention (CDC) in FY21. To continue this important progress in FY22 and beyond, and to adequately fund public health and research infrastructure in response to the COVID–19 pandemic, ACC urges members of Congress to appropriate the following funds toward agencies doing vital work in cardiovascular disease (CVD) treatment and prevention: $3.963 billion for the National Heart Lung & Blood Institute (NHLBI) 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, $10 million toward CDC's Million Hearts to prevent 1 million heart attacks and strokes, $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 valvular heart disease research at the NHLBI since clinical predictors of patients at higher risk of sudden cardiac death are still lacking.

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-re-

nowned 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 the long-term complications of COVID–19 and patients with heart disease, 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.

Preventing and treating CVD applies to long-term COVID–19 patients. Recent studies have shown that cardiovascular consequences of COVID–19 extend beyond initial infection, and many COVID–19 survivors experience some type of heart damage, even if they did not have underlying heart disease and were never hospitalized. Imaging tests taken months after recovery from COVID–19 have shown lasting damage to the heart muscle in people who experienced only mild symptoms, which may increase the risk of heart failure or other heart complications in the future.[5] As CVD continues to be the country's leading cause of death while COVID–19 infections also present risks to cardiovascular health, we recommend the NHLBI be funded at $3.965 billion to support research on COVID–19 by leveraging existing NIH-funded studies and infrastructure, and to maintain current activities and investment toward new research and emerging technologies related to heart disease.

More than 11 million Americans have heart valve disease (HVD) which involves damage to one or more of the heart's valves and leads to disrupted blood flow by not opening or closing properly.[6] HVD can lead to major complications and some people with HVD do not always have symptoms, even if their disease is severe. ACC recommends that the NHLBI address gaps in understanding heart valve disease to better recognize indicators of patients at higher risk of sudden cardiac death. We propose report language to better understand and develop guidelines for treatment of high-risk patients: The committee recognizes that heart valve disease involves damage to one or more of the heart's valves, and symptoms can be difficult to detect and lead to major complications. The committee encourages the NHLBI to expand research on valvular disease to better understand and develop guidelines for treatment of high-risk patients by using precision medicine and advanced technological imaging to generate data, identifying and developing a cohort of individuals with valvular heart disease and available data, and corroborating data generated through clinical trials to develop a prediction model to identify patients at high risk for sudden cardiac arrest or sudden cardiac death from valvular disease.

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 relating to heart disease. We recommend that the CDC Division for Heart Disease and Stroke Prevention be funded at $160 million to explore the intersections between COVID–19 and cardiovascular disease; build or enhance critical data infrastructure;

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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] HHS/NIH/NHLBI FY2017 Congressional Justification Report; https://www.nhlbi.nih.gov/sites/default/files/media/docs/Final%20NHLBI%202017%20CJ__R508__v1__0.pdf.

[5] https://www.mayoclinic.org/diseases-conditions/coronavirus/in-depth/coronavirus-long-term-effects/art-20490351.

[6] Heart Valve Disease Awareness Day; https://www.valvediseaseday.org/the-issue/.

and expand current work in priority areas through new partnerships, programs, and projects, all focused on eliminating disparities in health outcomes.

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 in 5 years. 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. New funding would frontload the success of Million Hearts by facilitating extensive partner input into the design of the next five-year phase; integration of insights gleaned from the pandemic, including and especially the inequities further exposed by COVID–19; and analysis of the individual, community, and healthcare actions with the greatest impact on cardiovascular health for all. We recommend that Million Hearts be funded at $10 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[7] women believes heart disease is her greatest health threat, and 11 percent[8] of women remain uninsured. We recommend that $46.7 million be allocated for WISEWOMAN to provide preventive health services, referrals to local health care 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. From 2012–2018, the CDC estimates that more than 16.4 million people who smoke have attempted to quit and about 1 million have successfully quit because of the OSH Tips from Former Smokers campaign.[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.

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 and understand the cardiovascular consequences of COVID–19. Stable funding for medical research and healthy lifestyle promotion will save lives and health care costs in the long term 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 Dipti Itchhaporia, MD, FACC, President, American College of Cardiology.]

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.

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

[8] 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/.

[9] CDC Office on Smoking and Health; https://www.cdc.gov/chronicdisease/pdf/aag/osh-H.pdf.

[10] FDA Tobacco Products Public Health Information; https://www.fda.gov/tobacco-products/public-health-education/health-information.

We thank Chairwoman Murray, Ranking Member Blunt, and the entire Subcommittee for this opportunity to provide comments on some of the most important programs to support and advance women's health in FY22. 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 appropriate:

—*Centers for Disease Control & Prevention (CDC):* At least $10 billion for the CDC, including $102.5 million for the Safe Motherhood Initiative, including $30 million for maternal mortality review committees and $30 million for perinatal quality collaboratives; and $250 million for public health surveillance;

—*National Institutes of Health (NIH):* $46.1 billion for the NIH, including at least $1.7 billion for Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), and $50 million shared evenly between CDC and NIH, for research into firearm morbidity and mortality prevention;

—*Health Resources & Services Administration (HRSA):* $750 million for the Title V Maternal and Child Health Block Grant, including $15 million for the Alliance for Innovation on Maternal Health (AIM) within the Special Projects of Regional and National Significance (SPRANS); $10 million to expand depression screening and treatment for pregnant and postpartum women; and $5 million to establish, identify, and distribute clinicians in maternity care health professional target areas;

—*Office of Population Affairs (OPA):* $737 million for the Title X Family Planning Program; and

—$500 million for the Agency for Healthcare Research and Quality (AHRQ).

Safe Motherhood Initiative at CDC: The United States has the highest rate of maternal mortality and severe morbidity of any industrialized country. The Safe Motherhood Initiative at CDC works with state health departments to collect information on pregnancy-related deaths, supports maternal mortality review committees (MMRCs), tracks preterm births, and improves maternal outcomes through perinatal quality collaboratives. Important strides have been made as nearly every state either currently has, is in the process of implementing, or is making plans to develop a state MMRC. In addition, the CDC currently supports 13 perinatal quality collaboratives (PQCs), often considered the implementation arm of MMRCs. We must continue to build on this progress and improve maternal health outcomes. ACOG requests that you fund the Safe Motherhood Initiative at $102.5 million, including $30 million to help states expand or establish maternal mortality review committees, and $30 million to support state-based perinatal quality collaboratives in every state.

Women's Health Research at NIH: Women represent half of the US 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 research mission and portfolio of NICHD, 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 existing initiatives to produce new insights and solutions to benefit women and families. ACOG supports an appropriation of $46.1 billion for the NIH in FY22, including at least $1.7 billion for NICHD.

Maternal Therapeutics at NIH: In the United States each year, more than 4 million women give birth 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 P.L. 114–255), Congress created the Task Force on Research Specific to 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 August 2020, PRGLAC produced an implementation plan for each of the 15 recommendations made in 2018 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.

Title X Family Planning Program at OPA: Title X is the only federal program dedicated to providing family planning services for people with low incomes. 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. Title X has been cut or flat-funded every year for the past decade. A significant investment is needed to support robust restoration of the program and ensure demand for services is met. ACOG requests $737 million for Title X in FY22 to ensure individuals in need have access

to evidence-based care. ACOG is pleased that the Biden administration has proposed to eliminate the 2019 Title X regulations that decreased access to health care services and disproportionately imposed barriers to care for Black, Latinx, and Indigenous communities. ACOG urges Congress to show its strong support for transparent, respectful, evidence-based, and comprehensive reproductive health care by funding this critical program.

Title V Maternal and Child Health Block Grant at HRSA: The Title V Maternal and Child Health (MCH) Block Grant at HRSA is the only federal program that exclusively focuses 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 SPRANS discretionary grant, the Block Grant supports the Alliance for Innovation on Maternal Health (AIM) program—a program that works with states and hospital systems to implement evidence-based best practices to improve maternal health outcomes and reduce rates of maternal mortality and severe maternal morbidity. For FY22, ACOG requests at least $750 million 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 AHRQ: AHRQ is the federal agency with the sole purpose of improving health care quality. AHRQ produces data with the mission of making health care 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 $500 million for AHRQ in FY22, which reflects the FY10 funding level for the agency adjusted for inflation and additional funding to respond to the pandemic.

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 US. 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. ACOG urges Congress to include a robust investment in public health surveillance, and requests funding to be used to modernize these systems to improve health. ACOG requests $250 million in FY22 for public health surveillance at CDC 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 FY22, 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 women be screened, yet barriers to accessing treatment remain. ACOG commends Congress for funding Sec. 10005 of P.L. 114–255 to support the establishment of a program at HRSA to expand depression screening and treatment for pregnant and postpartum individuals. ACOG urges you to fund the program at $10 million for FY22, a $5 million increase over FY21, and increase support for the maternal mental health hotline to $5 million.

Maternity Care Target Areas (HRSA): Major pockets of the U.S. do not have adequate access to needed maternity care, due to both a workforce shortage and maldistribution of clinicians. This disproportionately impacts access to obstetric care in rural communities. Maternity care shortages threaten the ability of pregnant individuals to receive timely prenatal and labor/delivery services. According to the latest available data, more than half of pregnant people living in rural areas reside more than 30-minutes by car from the nearest hospital offering perinatal services. Further, a 2019 study that analyzed severe maternal morbidity and mortality during childbirth hospitalizations among rural and urban residents found that when controlling for sociodemographic factors and clinical conditions, rural residents had a 9 percent greater probability of severe maternal morbidity and mortality, compared with urban residents.

The Improving Access to Maternity Care Act of 2018 (P.L. 115–320) requires HRSA to identify maternity care health professional target areas that are suffering from a shortage of maternity care clinicians, including obstetrician-gynecologists

and certified nurse-midwives, so that those participating in the National Health Service Corps can be placed in the communities most in need of their services. ACOG urges you to fulfill the President's request for $5 million in FY22 to implement the Improving Access to Maternity Care Act. Funding would be used to establish criteria for and identify maternity care health professional target areas, distribute maternity care health professionals to those areas, and collect and publish data on the availability and need for maternity care services within primary care health professional shortage areas.

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

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 (FY) 2022. ACP is the largest medical specialty organization and the second-largest physician group in the United States. ACP members include 163,000 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 FY2022, ACP is urging funding for the following proven programs to receive appropriations from the Subcommittee:

—Health Resources Services Administration (HRSA), $9.2 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), $500 million;
—Centers for Medicare and Medicaid Services (CMS), Program Operations for Federal Exchanges, $296.5 million;
—Centers for Disease Control and Prevention (CDC), $10 billion, Injury Prevention and Control, Firearm Injury and Mortality Prevention Research, $50 million; National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), Social Determinants of Health program, $153 million;
—National Institutes of Health (NIH), $46.1 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 21,400 to 55,200 primary care physicians by 2033. 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. A recent report by the National Academy of Sciences, calls on policymakers to increase our investment in primary care as evidence shows that it is critical for achieving health care's quadruple aim (enhancing patient experience, improving population, reducing costs, and improving the health care team experience. Therefore, we urge the Subcommittee to provide $9.2 billion for HRSA programs for FY2022 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 health care providers to enhance the supply, diversity, and distribution of the health care 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 FY2018, 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 grants for primary care training in rural and underserved areas that have helped prepare physicians for a career in primary care.

The College urges at least $860 million in total program funding for the NHSC in FY2022. In FY2021, 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 which have been extended through FY2023. The NHSC awards scholarships and loan repayment to health care professionals to help expand the country's primary care workforce and meet the health care needs of underserved communities across the country. In FY2020, with a projected field strength of over 14,000 primary care clinicians, NHSC members are providing culturally competent care to a target of almost 15 million patients at a targeted 18,000 NHSC-approved health care 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 FY2016, there were 2,275 applications for the scholarship program, yet only 205 new awards were made. There were only 150 scholarship awards in FY2020. There were 7,203 applications for loan repayment and only 3,079 new awards in FY2016. Accordingly, ACP urges the subcommittee to double the NHSC's overall program funding to $860 million to meet this need and to sustain the American Rescue Plan Act's $800 million for the NHSC for when the pandemic subsides.

AHRQ is the leading public health service agency focused on health care quality. AHRQ's research provides the evidence-based information needed by consumers, clinicians, health plans, purchasers, and policymakers to make informed health care 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 $500 million, restoring the agency to its FY2010 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, and to make the healthcare more efficient by providing quality measures to health professionals.

ACP supports at least $296.5 million in discretionary funding for federal exchanges within CMS' Program Operations, which has been funded at $2.8 billion in FY2020. 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, especially with increased need for health coverage due to the COVID–19 pandemic.

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 $10 billion overall for this mission, especially in light of the ongoing COVID–19 public health emergency (PHE). The College also supports $50 million for the CDC's Injury and Prevention Control to fund research on firearm Injury and mortality prevention research and support 10 to 20 multi-year studies to continue to continue to rebuild lost research capacity in this area. ACP greatly appreciates funding for this research in FY2020 and FY2021 after many years of no federal resources for researching the prevention of firearms-related injuries and deaths. The College also supports the administration's budget request of $153 million for the NCCDPHP to fund its Social Determinants of Health program. The PHE caused by the COVID–19 has highlighted the urgent need to collect racial, ethnic, and language preference demographic data on testing, infection, hospitalization, and mortality during a pandemic. These data should be shared with local, state, territorial, and tribal governments. Frequent, granular, and high-quality disaggregated demographic data are needed to fully understand the impact on racial and ethnic minority communities and better offer targeted care not only for COVID–19, but for health care overall.

Lastly, the College strongly supports $46.1 billion for NIH in FY2022 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 FY2022 appropriations process.

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

PREPARED STATEMENT OF THE AMERICAN COLLEGE OF SURGEONS

Chairwoman Murray, Ranking Member Blunt, 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 (FY) 2022 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. ACS 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 FY 2022:

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

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 that one in four military trauma deaths and one in 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 lives both on the battlefield and at home, 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 grant program, within the U.S. Department of Health and Human Services (HHS), 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, further advancing trauma care and providing greater patient 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 that 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 FY 2022.

Funding for Cancer Research and Prevention

The ACS Cancer Programs, including the Commission on Cancer (CoC), is dedicated to improving survival and quality of life for cancer patients through advocacy on 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 supports the following funding increases for FY 2022.

To ensure a robust, long-term commitment to cancer research and prevention, Congress should increase the overall budget of the National Institutes of Health (NIH) to at least $46.111 billion including $7.609 billion for the National Cancer Institute (NCI). The ACS also urges the inclusion of $559 million for cancer programs at the Centers for Disease Control and Prevention (CDC), including $50 million for the National Comprehensive Cancer Control Program, and $70 million for the National Program of Cancer Registries (NPCR).

Firearm Morbidity and Mortality Prevention Research

According to the Centers for Disease Control and Prevention (CDC), there were more than 39,000 firearm-related fatalities in 2019, a measured increase over previous years. ACS believes this number can be reduced through federally funded firearms research. As with other injury prevention related efforts, public health research can play a role in reducing the number of firearm-related injuries and deaths.

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 that a similar approach can provide necessary data to inform efforts to reduce firearm-related injuries and deaths. The ACS supports $50 million specifically for public health research into firearm morbidity and mortality prevention through the CDC for FY 2022.

Removal of Language in Section 510

Serious patient safety concerns arise if a patient's health record is mismatched or includes inaccurate or incomplete information, potentially resulting in missed allergies, medication interactions, or duplicate tests ordered. Unfortunately, there is no accurate or consistent way for surgeons to link patients to their health information across the continuum of care, due to long-standing federal statutory language. The language, located in Section 510 of the LHHS Appropriations bill, has prohibited HHS from spending any federal dollars to promulgate or adopt a Unique Patient Identifier, thereby hampering public-private sector collaborative efforts to advance a nationwide patient identification strategy that is cost-effective, scalable, secure, and prioritizes patient privacy.

Removing the language in Section 510 will provide HHS with the ability to evaluate a range of patient identification solutions and enable the agency to work with the private sector to explore potential challenges. ACS supports removal of Section 510 from the Labor-HHS appropriations bill that prohibits HHS from spending any federal dollars to promulgate or adopt patient identification strategies.

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 EDUCATIONAL RESEARCH ASSOCIATION

Chair Murray, Ranking Member Blunt, and Members of the Subcommittee, thank you for the opportunity to submit written testimony on behalf of the American Educational Research Association (AERA). AERA recommends that the Institute of Education Sciences (IES) within the Department of Education receive $737.47 million for FY 2022, aligned with the top line included in the president's budget request. 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 the base funding level of $46.1 billion for the National Institutes of Health (NIH) in fiscal year 2022, 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. Located within the Department of Education to provide essential education data, statistics, and science to the Department, the federal government, and the nation, the mission of IES is analogous to other prominent federal research agencies such as the National Science Foundation and the National Institutes of Health.

We appreciate the increase to IES appropriations over the past few fiscal years and the funding provided in the American Rescue Plan Act, the latter of which will go toward needed resources in data and special education research to understand how schools will work to address learning gaps due to lost instructional time. Throughout the pandemic, IES has served as an important resource in providing information about distance learning; pursuing interventions to address socioemotional needs; and collecting salient data on schools offering remote, hybrid, and in-person learning. The increased demand for evidence-based programs since the onset of COVID–19 and the need to address potential learning recovery only further speaks to the priority importance of support for education research and statistics at IES to inform policy and practice.

We see numerous examples of bipartisan support for scientific research and evidence-based decision making. The Department of Education is implementing the provisions of the bipartisan Foundations of Evidence-Based Policymaking Act, which directs federal agencies to leverage data and evaluations to inform policy decisions. A bipartisan bill that has been introduced to inform the forthcoming reauthorization of the Workforce Investment and Opportunity Act (WIOA) would call for investment in research in adult education. 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 that are used in classrooms across the country. For example, IES has funded research on multi-tiered systems of support, including positive behavior interventions and supports, that have been highlighted in the Department of Education's COVID–19 handbook to guide school reopening. Several webinars and resources produced by the Regional Educational Laboratories highlighting evidence-based practices for educators, school support staff, and school leaders are incorporated in the Safer Schools and Campuses Best Practices Clearinghouse. As the nation continues to emerge from the pandemic, this is a critical time to invest in education research to produce essential knowledge about teaching and learning across all levels of education as well as to identify lessons learned that can foster educational innovations.

States are increasingly seeking ways to determine the long-term impact of state policies, including in education, and they turn to information in their Statewide Longitudinal Data Systems (SLDS). Initially developed to help states measure accountability, data has transformed from a hammer to a flashlight, increasing understanding about student performance and teacher effectiveness. To date, IES has been unable to meet the state demand for SLDS grants. For the FY 2019 competition, 28 of 44 states that submitted applications received grants, although the average amount of grants was reduced by half compared with those awarded in FY 2015. Growing interest in using data from these systems, including an IES research competition encouraging the research use of these data for examining longitudinal impacts of state policies, show the importance of continuing investment in these data systems.

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 the National Center for Education Statistics (NCES). As the second-oldest principal federal statistical agency in the United States, 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, reliable, and trustworthy data, 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.

In addition to IES, AERA recommends $46.1 billion for the National Institutes of Health (NIH) in fiscal year 2022 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 ways to foster health literacy, potential influencers of family environments on child well-being and cognitive development, and interventions for students with learning disabilities who struggle with reading. Investment in NICHD will allow the institute to continue research to both increase understanding how best to support executive functioning, 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. OBSSR has long recognized the interdependence of education and health and in terms of prevention, intervention, and the health-risk consequences of a lack of or limited educational exposure.

Thank you for the opportunity to submit written testimony in support of $737 million for IES and $46.1 billion in base level funding for NIH in fiscal year 2022. 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

The American Foundation for Suicide Prevention (AFSP), the nation's largest nonprofit dedicated to saving lives and bringing hope to those effected by suicide is submitting testimony on behalf of our over 30 thousand volunteer Field Advocates nationwide. AFSP has Chapters in all 50 states and sponsors a variety of community-based programming across the country each year.

The following testimony outlines suicide in the United States and AFSP's recommendations to the Subcommittee for Fiscal Year 2022.

SUICIDE: A NATIONAL PUBLIC HEALTH CRISIS

Suicide is the second leading cause of death for ages 10–34 in the United States and in 2019 was the 10th leading cause of death.[1] Provisional 2020 suicide death data from the CDC show that deaths by suicide in the U.S. declined from 47,511 to 44,834 (5.6%) between 2019 and 2020.[2] Suicide reportedly moved from the tenth to the eleventh leading cause of death as COVID–19 became the third leading cause of death in 2020.[3] While the decreases in suicide deaths are promising and the curve may be beginning to shift downward, efforts must continue to be expanded and built upon to ensure there are mental health resources as the pandemic continues to shift and impact different populations disproportionately. Historically, suicide rates have initially gone down during some periods of wartime and other disasters and have shown mixed results during or after previous epidemics. Provisional 2020 data appear consistent with this trend. It is possible, though not pre-determined, that we could experience an increase in suicide risk as the immediate COVID–19 threat lessens and in the aftermath period if community cohesion diminishes and if less attention is paid to intentional social connections, proactive resilience and mental health self-care, and the importance at key times of engaging in mental health treatment and crisis care. Helping those who are struggling with basic needs can also mitigate suicide risk.

While provisional 2020 mortality data show a declining rate of suicide for the overall U.S. population, we do not yet have the full picture as to how this translates to geographic areas within states or specific populations. The pandemic has had a disproportionate impact on certain populations; there are concerning signals of increasing suicide rates in some non-White populations during the pandemic, e.g., in Maryland and Connecticut.[4] It may be a year or longer until data and research are available to understand the entire impact of COVID–19 on suicide.

Furthermore, during the COVID–19 pandemic, data show 50–70% of the population report elevations in experiences of depression, anxiety, loneliness, trauma, loss, grief and increased substance use.[5] Numerous studies have kept abreast of the nation's mental health experiences and suffering during the pandemic through various mechanisms such as the CDC Household Pulse Survey during COVID which has been surveying 60–90,000 Americans adults every 3–5 weeks during the pandemic. The portion of the American public experiencing anxiety, isolation, symptoms of depression, insomnia and increased substance use has been rising.

As the pandemic progressed during 2020, the proportion of respondents who reported detrimental effects on their mental health continued to rise—39% in May 2020 and 53% in July 2020. It was only until just recently, in March 2021, that we are seeing the first decreases in distress—8–10 percentage points—for depression and anxiety across age and demographic groups.[6] However, the CDC reported on June 18, 2021 there was a 51 percent rise in suspected suicide attempts among girls ages 12–17 from February 2021 to March 2021 compared to the same time period in 2019, prior to the pandemic.[7] While this does not mean that there was necessarily an uptick in suicide deaths, the statistic is certainly alarming, and we do not yet have race and ethnicity data for when this study was conducted.

RECOMMENDATIONS

As instances of suicidal ideation and attempts increase, funding and resources must meet the needs of those most at risk. Therefore, AFSP is advocating for Fiscal Year 2022 funding increases to ensure that communities are adequately prepared to respond to crisis, implement community-based programming for those most at risk, collect data to improve prevention, and to invest in research to meet patients where they are, in healthcare settings. We thank Chairwoman Murray and Ranking Member Blunt for the opportunity to share our below priorities.

Substance Abuse and Mental Health Services Administration (SAMHSA)

The National Suicide Prevention Lifeline coordinates a network of over 180 crisis centers across the United States by providing 24/7 free and confidential suicide prevention and crisis intervention services for people in distress, their loved ones, and best practices for professionals. The Lifeline routes calls from anywhere in the coun-

[1] https://www.cdc.gov/injury/wisqars/index.html.
[2] https://jamanetwork.com/journals/jama/fullarticle/2778234?utm__source=newsletter&utm__medium=email&utm__campaign=newsletter__axiosvitals&stream=top.
[3] Ibid.
[4] https://jamanetwork.com/journals/jamapsychiatry/fullarticle/2774107.
[5] https://www.cdc.gov/nchs/covid19/pulse/mental-health-care.htm.
[6] https://www.cdc.gov/mmwr/volumes/69/wr/mm6932a1.htm.
[7] https://www.cdc.gov/mmwr/volumes/70/wr/mm7024e1.htm?s__cid=mm7024e1__w.

try to a network of certified local crisis centers that can then link callers to local emergency, mental health, and social services resources. Last year, over 2.5 million calls were made to the Lifeline, resulting in longer wait times and a strain on local crisis centers. Additional funding is needed to ensure that the Lifeline is adequately equipped to handle increasing call and outreach volume.

We request at least $102 million for the National Suicide Prevention Lifeline, as included in the President's Fiscal Year 2022 Budget Request. Following passage of the National Suicide Hotline Designation Act in September 2020, the easily accessible 9–8–8 dialing code was designated to replace the Lifeline's current 1–800 number. 9–8–8 will be the new easy to remember and universal phone number for suicide prevention and mental health crisis by July 2022. This presents an urgent need to ensure that local crisis call centers and the national infrastructure for the Lifeline are prepared for the anticipated increase in calls and strain on an already overburdened system. Additional funding to the Lifeline would facilitate the development of a unified call center platform and data analytics, telecom costs for each contact and routing to local crisis centers, provision of specialized services at national back up centers for calls, chat, and text, targeted funding for call centers and national backup centers, multi-lingual assistance, quality assurance and training standards, and supporting partnership outreach. Based on an initial analysis from Vibrant Emotional Health, the current administrator of the Lifeline, year one implementation estimates for 988 could grow to as much as $240 million. It is expected that SAMHSA and the Department of Veterans Affairs (VA) will jointly release a final cost estimate report to Congress regarding Lifeline funding needs later in the summer of 2021 which will help better inform the critical resource needs that are urgently needed. We hope the Appropriations Committee will work with us to adequately address this critical resource, in Fiscal Year 2022 and beyond.

The Centers for Disease Control (CDC)

As the nation's leading health protection agency, it is a natural fit that the CDC expand their suicide prevention efforts. Through investing further in the CDC's new suicide prevention line, there is a more holistic approach to suicide prevention programming beyond the work that SAMHSA and the National Institutes of Health (NIH) are implementing, evaluating, and researching. There is a need to make strategic investments that will help save lives and reduce the suicide rate. Therefore, AFSP advocates for $36 million for Suicide Prevention initiatives at CDC's Center for Injury Prevention and Control. Created in Fiscal Year 2020, the Congress has generously provided $22 million for the program over the last two fiscal years. Enhanced funding in Fiscal Year 2022 will help expand these community-based grants into approximately 25 states. The grants are used to implement and evaluate a comprehensive public health approach to suicide prevention, with attention to vulnerable populations, such as Veterans, tribal and rural communities, LGBTQ, or homeless citizens. These groups account for a significant proportion of the suicide burden and have suicide rates greater than the general population. A key outcome of this funding is a 10% reduction in suicide and suicide attempts among vulnerable populations. Through these cooperative agreements, CDC aims to build a national program that will help reverse increasing suicide trends across our nation and contribute to the national goal of reducing suicide by 20% by 2025.

Data collection as it relates to suicide deaths is an important piece of preventing future deaths and implementing prevention strategies within our communities. AFSP advocates for a $10 million increase for the National Violent Death Reporting System (NVDRS) as included in the President's Fiscal Year 2022 Budget Request. NVDRS is the most comprehensive database on circumstances surrounding violent deaths in the U.S., including suicide. Since the program's inception in 2002, NVDRS has grown to a nationwide program with funding to support implementation in all 50 states and select territories. Yet, the current funding is not sufficient for long-term program success. States are clamoring for additional resources to address various implementation challenges and support investments in program infrastructure, as well as program growth and innovation. NVDRS stakeholder organizations support a funding level of $50 million by FY 2027 to strengthen the program.

National Institute of Mental Health

As the largest private funder of suicide prevention research in the US, AFSP continues to advocate for increased federal funding and prioritization of suicide prevention research. The National Institutes for Health and more specifically the National Institute of Mental Health (NIMH) play a key role in advancing the Nation's suicide prevention research priorities. AFSP encourages the continued implementation of the Prioritized Research Agenda for Suicide Prevention released by the National Action Alliance for Suicide Prevention, that is meant to advance the National Strategy

for Suicide Prevention. To note, more recently, in January 2021, there was a Surgeon Generals Call to Action to Implement the National Strategy for Suicide Prevention, which further outlines the six actions and associated strategies that will move the U.S. further towards implementation of the National Strategy. Overall imparting the need for increased federal investment in suicide prevention research and programmatic needs.

As the COVID–19 pandemic shifts, there is a need to ensure that when individuals are visiting the Emergency Department or their primary care physician that screening tools and resources meet them, so if they are in need of mental health and crisis services, they are able to receive comprehensive care. This is an especially prominent area for necessary research as, up to 45 percent of people who die by suicide visit their primary care physician in the month prior to their death.[8] AFSP recommends the following report language for Fiscal Year 2022, to place a special emphasis on the primary care setting, given the great number of Americans seeking mental health care from their primary care physician.

PROPOSED FISCAL YEAR 2022 REPORT LANGUAGE: SUICIDE PREVENTION

The Committee is encouraged that 2019 was the first year in two decades in which the suicide rate decreased. But death by suicide remains the tenth leading cause of death in the United States, and the Committee remains committed to providing the resources necessary to address this alarming crisis. The Committee commends NIMH for consistently expanding resources for suicide screening and prevention research over the last four fiscal years and strongly encourages the Institute to provide additional increases for this purpose in fiscal year 2022, with special emphasis on producing models that are interpretable, scalable, and practical for clinical implementation, including utilization of healthcare, education and criminal justice systems that serve populations at risk. In addition, the Committee encourages NIMH to prioritize research efforts related to primary care settings to evaluate suicide prevention interventions, strategies, and programs, including assessments of the effects of the COVID–19 epidemic. The Committee requests that NIMH provide an update on these efforts in the fiscal year 2023 Congressional Justification.

The American Foundation for Suicide Prevention is grateful for the Subcommittee's continued support of suicide prevention efforts and looks forward to additional conversations about the vital resources needed to help save lives and prevent suicide. Please do not hesitate to contact Natalie Tietjen, Manager of Federal Policy (ntietjen@afsp.org) on my staff with additional questions or clarifications.

[This statement was submitted by Laurel Stine, JD, MA, Senior Vice President, Public Policy, American Foundation for Suicide Prevention.]

PREPARED STATEMENT OF THE AMERICAN GASTROENTEROLOGICAL ASSOCIATION

NATIONAL CANCER INSTITUTE

Chairwoman Murray, Ranking Member Blunt, 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 (FY) 2022 appropriations bill. I am Dr. Fola May, and I am an associate professor of medicine at the University of California, Los Angeles, and researcher at the UCLA Center for Cancer Prevention Control Research (CPCR) and UCLA Kaiser Permanente Center for Health Equity. I am submitting testimony on behalf of the American Gastroenterological Association (AGA). 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 want to first thank you for your ongoing bipartisan investment in the National Institutes of Health (NIH). We respectfully request the subcommittee to support our FY 2022 NIH funding recommendation of at least $46.111 billion, a $3.177 billion increase over the comparable FY 2021 funding level for the NIH, which would allow for the NIH's base budget to keep pace with the biomedical research and development price index of 2.3 % and allow meaningful growth of 5%. Additionally, we request report language to support research to better understand the impact of COVID–19 on colorectal cancer disparities.

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[8] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3146379/#:~:text=A%20review%20of%20studies%20analyzing,the%20month%20before%20their%20death.&text=Only%2020%25%20saw%20a%20mental,10%20in%20the%20preceding%20month.

Colorectal Cancer Incidence

Colorectal cancer (CRC) remains the second leading cause of cancer deaths in the United States. The American Cancer Society (ACS)[1] estimates 149,500 new cases of CRC and 52,980 CRC-related deaths in the U.S. in 2021. The ACS 2021 cancer report also shows an emerging trend of CRC in a younger demographic; The data shows a 2% increase in CRC in individuals under 50 years.

CRC has a higher impact on communities of color. Specifically, Black, and Native American individuals have the highest incidence of CRC; Black Americans have the highest rate of CRC-related death, and Latinos have CRC screening rates far below White and Black Americans.[2]

COVID–19's Impact on CRC Screenings

Screening can prevent colorectal cancer deaths by detecting precancerous polyps early, allowing for early treatment and full recovery. Unfortunately, as with other health care services, the COVID–19 pandemic significantly reduced the volume of preventive screenings. According to a report,[3] CRC screenings were estimated to have dropped by 86% in the first few months of the pandemic and have not yet fully recovered.

With the drop in screenings, delay in diagnosis, lack of access to care, abandonment of care, interruption or alteration in treatment and job loss resulting in lapsed health insurance coverage etc., cancer mortality rates across numerous cancers have increased. The National Cancer Institute (NCI) estimates a 1% increase in deaths from breast and colon cancer over the next 10 years, which equates to an additional 10,000 deaths due to the pandemic's impact on screening and treatment.[4]

As communities across the U.S. fight the pandemic locally, community-based health care facilities that typically would offer cancer screenings and other preventative health services have reallocated their limited resources and shifted workforce deployment to address the pandemic. This reduction in cancer screening resources has heightened the ongoing health care access issues that impact vulnerable populations, and their worsening clinical outcomes. Specifically, racial, and ethnic minority communities, who, including before the pandemic, have lower rates of CRC screening and higher rates of incidence and mortality from CRC.

Health disparities and CRC

Colorectal cancer (CRC) during the pandemic places a spotlight on the health disparities and inequities stemming from social determinants of health that continue to plague medically underserved populations. COVID–19 cases, hospitalizations and deaths were highest among communities of color, especially those with comorbidities like obesity, diabetes, and asthma. Although screening rates are resuming, the rates in minority communities likely still lag due to access, financial, transportation and other socioeconomic factors exacerbated by the pandemic.

The NIH resources spent on COVID–19 and health disparities have been essential to better understand the long-term impact of the pandemic on the medically underserved population in the U.S. To improve CRC screening, prevention and treatment, AGA recognizes the continued need to collect systemic data on the short and long-term outcomes of COVID–19 and CRC disparities. Therefore, AGA urges the subcommittee to include the following report language that would allow NIH to continue its support of studies focused on CRC disparities heightened by the COVID–19 pandemic.

COVID–19 Pandemic Impact on Colorectal Cancer Disparities.—Given the impact that screening can have on reducing mortality and morbidity in colorectal cancer (CRC), the Committee encourages the NIH to study the impact of the COVID–19 pandemic on the incidence of CRC in minority communities. The committee is hopeful that such information will provide policymakers with a better understanding of the effects on minority communities and help develop strategies to address barriers to screening and reduce health inequities and cancer deaths.

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[1] American Cancer Society. Cancer Facts & Figures 2021. Atlanta: American Cancer Society; 2021. https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2021/cancer-facts-and-figures-2021.pdf.

[2] Balzora, S., Issaka, R. B., Anyane-Yeboa, A., Gray, D. M., 2nd, & May, F. P. (2020). Impact of COVID–19 on colorectal cancer disparities and the way forward. Gastrointestinal endoscopy, 92(4), 946–950. https://doi.org/10.1016/j.gie.2020.06.042.

[3] EPIC Health Research Network. Delayed Cancer Screenings-A Second Look. Available at: https://ehrn.org/articles/delayed-cancer-screenings-a-second-look/. pdf. Accessed May 17, 2021.

[4] Sharpless, N. E. (2020). COVID–19 and cancer. https://tcjl.com/wp-content/uploads/2020/06/Science-COVID-19-and-Cancer-editorial-copy.pdf.

On behalf of AGA, its members, and the GI community, 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. Fola May, MD, PhD, MPhil, Associate Professor of Medicine, University of California, Los Angeles.]

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 (FY) 2022 appropriation for the National Institute of Environmental Health Sciences (NIEHS). AGU, on behalf of its community of 130,000 Earth and space scientists, respectfully requests that the 117th Congress appropriate $875 million for the NIEHS. AGU's appropriations request takes into consideration any previous budget cuts is driven by the need for significant investment in federal research and development 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.

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 couple of years 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

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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.

[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.

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

At a time when our nation is recovering and has many pressing priorities that need to be addressed, the future of the U.S. will be strengthened by strong and sustained investments 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. AGU appreciates the Subcommittee's leadership in this area, as well as the opportunity to submit this testimony. Thank you for your thoughtful consideration of our request.

[This statement was submitted by Michael Villafranca, Senior Specialist, Science Policy & Government Relations.]

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 (FY) 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 Title VII of the Public Health 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 Geriatrics Health Professions Programs at the Health Resources and Services Agency (HRSA), which includes the Geriatrics Workforce Enhancement Program (GWEP) and Geriatrics Academic Career Award (GACA) program. 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 FY 2022:

—At least $105.7 million to support the GWEP and GACA program (PHS Act Title VII, Sections 750 and 753(a))

—An increase of no less than $3.3 billion over the enacted FY 2021 level in the FY 2022 budget for total spending at NIH for current institutes and operations; a minimum increase of $500 million to invest in biomedical, behavioral, and social sciences aging research efforts across NIH; and a minimum increase of $289 million for research on Alzheimer's disease and related dementias over the enacted FY 2021 level in the FY 2022 budget

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 54.1 million today[1] to more than 94 million by 2060,[2] while those 85 and older is projected to more than triple from 6.4 million today to 19 million by 2060.[3] 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.

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[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.

[1] U.S. Census Bureau. 2019 American Community Survey 1–Year Estimates Subject Tables. Available at https://data.census.gov/cedsci/table?q=S0101&tid=ACSST1Y2019.S0101&hidePreview=false.

[2] U.S. Census Bureau. An Aging Nation: Projected Number of Children and Older Adults. Available at https://www.census.gov/library/visualizations/2018/comm/historic-first.html. Published March 13, 2018.

[3] Ibid.

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 Award Program (at least $105.7 million)

Our healthcare workforce receives little, if any, training in geriatric principles,[4] which leaves us ill-prepared to care for older Americans as health needs evolve, especially during the current COVID–19 public health emergency. 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 FY 2021 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 GWEP awardees 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. Due to GWEPs' partnerships with primary care and community-based organizations, GWEPs are uniquely positioned to rapidly address the needs of older adults and their caregivers. 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.

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 four 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.

Most recently, the GWEPs and GACAs have been an asset for states as many states and localities grapple with the rollout of the COVID–19 vaccine and address vaccine hesitancy. GWEPs have been staffing call lines to assist older adults to register for the vaccine, advising local authorities on making the sign-up websites age-friendly, and working with health systems to participate in the rollout and outreach to vulnerable and hard-to-reach populations, preventing widening the health disparity gap exacerbated by the pandemic. Looking forward, these programs will be critical in providing assistance for proactive public health planning with their geriatrics expertise and knowledge of long-term care and can help ensure states and local governments have improved plans for older adults in disaster preparedness for future pandemics and natural disasters. Furthermore, as the U.S. population rapidly ages, 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.

To address this issue, we ask the Subcommittee to provide a FY 2022 appropriation of at least $105.7 million for the GWEP and GACA program. This increase in funding over FY 2021 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. As laid out in President Biden's American Jobs Plan, the infrastructure of care

[4] 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 health care 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.

in the U.S. needs substantial investments so that access to long-term services and supports is expanded while the healthcare workforce is adequately supported and prepared to care for us all as we age.

RESEARCH FUNDING INITIATIVES

National Institutes of Health/National Institute on Aging (additional $500 million for aging research efforts and a minimum increase of $289 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 FY 2022 budget for biomedical, behavioral, and social sciences aging research efforts across NIH and a minimum increase of $289 million for research on Alzheimer's disease and related dementias over the enacted FY 2021 level.

The federal government spends a significant and increasing amount of funds on healthcare costs associated with age-related diseases. By 2050, for example, the number of people age 65 and older affected by dementia is estimated to reach 12.7 million cases—nearly double the number in 2021—and is projected to cost $355 billion which does not include the $256.7 billion in unpaid caregiving by family and friends.[5] Further, chronic diseases related to aging, such as diabetes, heart disease, and cancer continue to afflict 80 percent of people age 65 and older[6] and account for more than 75 percent of Medicare and other federal health expenditures.[7] 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 no less than a $3.3 billion increase over the enacted FY 2021 level in the FY 2022 budget for total spending at NIH for current institutes and operations. We believe that a meaningful increase in NIH-wide funding, in combination with aging and increase in prevalence of diseases, 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.

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

Chair Murray, Ranking Member Blunt, and members of the subcommittee, thank you for the opportunity to testify today. My name is Dr. Keith Churchwell, and I am President of Yale New Haven Hospital and a volunteer for the American Heart Association where I Chair the National Advocacy Committee. As a cardiologist for over 25 years, a hospital administrator who has worked in a number of roles across the country to improve and expand care for our patients, along with more than 20 years as a volunteer with the American Heart Association, I understand firsthand the burden of heart disease as the world's leading killer, and the importance of research and prevention.

I'm pleased to testify today on two specific opportunities to improve Americans' health in the fiscal year (FY) 2022 Labor, Health and Human Services, Education and Related Agencies appropriations bill. I respectfully request you work over the next three years to triple the budget of the Centers for Disease Control and Prevention (CDC) National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) to $3.75 billion. I also respectfully request that, within this increase,

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[5] Alzheimer's Association. 2021 Alzheimer's Disease Facts and Figures. Alzheimers Dement. 2021; 17(3):327–406. https://doi.org/10.1002/alz.12328.

[6] National Prevention Council. Healthy Aging in Action: Advancing the National Prevention Strategy. Available at https://www.cdc.gov/aging/pdf/healthy-aging-in-action508.pdf. Published November 2016.

[7] Erdem, E, Prada, SI, Haffer, SC. Medicare Payments: How Much Do Chronic Conditions Matter?. Medicare & Medicaid Research Review. 2013;3(2). http://dx.doi.org/10.5600/mmrr.003.02.b02.

you provide $20 million in new funding to expand an existing COVID–19 Cardiovascular Disease (CVD) registry in partnership with NCCDPHP.

FUNDING FOR THE NATIONAL CENTER FOR CHRONIC DISEASE PREVENTION AND HEALTH PROMOTION

Chronic diseases represent 7 of the 10 leading causes of death,[1] and account for 90% of the nation's $3.8 trillion in annual health care costs.[2] Heart disease remains the number one cause of death in the United States, with approximately 655,000 individuals in America dying from heart disease each year. In 2018, stroke accounted for about 1 of every 19 deaths in the United States.[3] Chronic diseases are best managed by consistent access to health care services and treatments, for example, a 10% increase in hypertension treatment could prevent 14,000 deaths each year.[4]

My positions at Yale New Haven Hospital and the American Heart Association have provided me a unique perspective on what individuals and families need to prevent disease, cure illness, and manage chronic health conditions, and I can personally attest to the importance of cardiovascular disease prevention programs specifically supported by the CDC. The burden of chronic disease is growing faster than our ability to ameliorate the growth, putting an increasing strain on the health care system, health care costs, our productivity, educational outcomes, military readiness and well-being.[5] Current funding for CDC NCCDPHP falls far short of what is needed to prevent chronic disease, slow its spread, and protect patients. The COVID–19 pandemic has only exacerbated these challenges, and the underfunding of NCCDPHP has made the nation more vulnerable to the pandemic. For example:

—COVID–19 poses elevated health risks for people with chronic conditions-including severe illness and death-and may lead to heart failure, stroke, kidney failure, chronic lung disease, blood pressure abnormalities, neurological conditions, and other long-term health complications in people who have survived the virus.

—Deaths from ischemic heart disease and hypertensive diseases in the United States increased during the COVID–19 pandemic, while globally, COVID–19 was associated with significant disruptions in cardiovascular disease testing, diagnosis and timely treatment.[6]

After more than a decade of stagnant funding, a congressional commitment to triple CDC NCCDPHP's budget over the next three fiscal years is long overdue to respond to the increasing threat chronic diseases pose to Americans. A robust investment, appropriate to the magnitude of the problem, will allow CDC NCCDPHP to fulfill its mission by expanding the current patchwork of existing programs nationwide and by implementing new programs to address emerging health challenges, including the emerging chronic disease cohort of COVID–19 "long-haulers."

COVID–19 CARDIOVASCULAR DISEASE REGISTRY

Since the start of the pandemic, researchers have made great advances in our knowledge of the disease characteristics, associated health risks, and appropriate mitigation and treatment of COVID–19. We have learned that COVID–19 has a disproportionate impact on patients who face endemic inequities, such as lower paying and hourly wage jobs deemed "essential." Unstable or unsafe housing and decreased availability of health care and insurance coverage also add to that impact. COVID–19 has laid bare the health inequities that have long affected communities of color in the United States as the burden of COVID–19 remains higher among African

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[1] Centers for Disease Control and Prevention. Leading causes of death. Morality in the United States, 2019. Accessed online February 17, 2021.

[2] Buttorff C, Ruder T, Bauman M. Multiple Chronic Conditions in the United States. Santa Monica, CA: Rand Corp.; 2017 and Martin AB, Hartman M, Lassman D, Catlin A. National Health Care Spending In 2019: Steady Growth for The Fourth Consecutive Year. Health Aff. 2020;40(1):1–11.

[3] Heart Disease and Stroke Statistics-2021 Update: A Report From the American Heart Association https://www.ahajournals.org/doi/10.1161/CIR.0000000000000950.

[4] Call to Action: Urgent Challenges in Cardiovascular Disease: A Presidential Advisory From the American Heart Association, Mark McClellan, MD, PhD, Nancy Brown, BS, Robert M. Califf, MD, MACC, John J. Warner, MD, FAHA (2019) https://www.ahajournals.org/doi/10.1161/CIR.0000000000000652.

[5] Heidenreich PA, Trogdon JG, Khavjou OA, et al. Forecasting the future of cardiovascular disease in the United States: a policy statement from the American Heart Association. Circulation. 2011;123:933–944.

[6] COVID–19 Pandemic Indirectly Disrupted Health Disease Care. American College of Cardiology. January 11, 2021. Accessed online February 17, 2021.

Americans, American Indians/Alaska Natives, Hispanics/Latinos, and Asian Americans and Pacific Islanders, compared with whites.[7]

In April 2020, the American Heart Association launched the COVID–19 Cardiovascular Disease (CVD) Registry, which captures data on hospitalized COVID–19 patients' clinical characteristics, medications, treatments, biomarkers and outcomes, and focuses on real-time, granular data from acute care hospitals to better help clinicians and researchers understand and provide feedback on how to best treat COVID–19 patients. To date, the COVID–19 CVD Registry includes nearly 170 hospitals and health systems across 35 states, reporting more than 40,000 adult COVID–19 patient records. Approximately 50 percent of the registry patients identify as Black or Hispanic, making the registry representative of communities disproportionately affected by the pandemic.

According to initial research based on the COVID–19 CVD registry data, obese patients experienced some of the worst outcomes of all patients hospitalized with COVID–19, including increased risks for blood clots, the need for breathing assistance and dialysis, and death. Research has already found that patients with COVID–19 who are hospitalized with a stroke have worse outcomes than stroke patients without COVID–19. We are also now beginning to understand the long-term health implications of COVID–19 in the population referred to as "long-haulers." These patients have an increased risk of developing myocarditis, or inflammation of the heart, that can lead to heart failure, thromboembolic disease or blood clots, and other lingering health conditions.

Additional funding is needed to expand the registry infrastructure nationally to enhance geographic representation for both urban and rural hospitals. A more robust, representative registry will provide clinicians and researchers with the tools to advance our understanding of post-COVID syndromes and provide much needed insights into this new chronic disease cohort. Once expanded, this registry also will provide an at-the-ready, adaptable infrastructure to respond to new and emerging public health threats. Therefore, within the new funding provided to the CDC NCCDPHP, the American Heart Association respectfully requests that the Committee provide $20 million to expand the COVID–19 CVD registry nationwide to include hundreds more hospitals-including sole community hospitals, safety net hospitals, and disproportionate share hospitals-and support CDC NCCDPHP in collecting, curating, analyzing, and publishing the registry data.

As the pandemic has demonstrated, chronic diseases and infectious diseases are inextricably linked. Therefore, any efforts to improve pandemic preparedness and prevent the spread of infectious disease must also include efforts to prevent chronic disease, address health disparities, and ultimately, improve underlying health and wellness for all. A significant investment in NCCDPHP is essential to that goal. We must make these investments if we are to preserve health, well-being, productivity, and longevity for all in America. I thank you for the opportunity to offer my perspective today, and for your continued leadership.

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 FY 2022 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): $53,080,000 (discretionary)

—Perkins Career and Technical Education Programs (Sec. 117): $15,000,000

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

[7] Lopez L, Hart LH, Katz MH. Racial and Ethnic Health Disparities Related to COVID–19. JAMA. 2021;325(8):719–720. https://jamanetwork.com/journals/jama/fullarticle/2775687.

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 nearly half are first generation students. In total, TCUs serve over 160,000 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 FY 2022 funding requests.

U.S. DEPARTMENT OF EDUCATION

Strengthening Tribal Colleges (HEA Title III—Part A—Section 316): TCUs urge the Subcommittee to provide $53,080,0000 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 (FY 2021, $38.08 million) and Part F mandatory funding (FY 2020, $28.2 million). In 2019, 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 (P.L. 116–91) was signed into 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. AIHEC strongly supports the President Budget Request for FY 2022, and we urge the Subcommittee to fund these programs at the President's requested levels: HEA Title III Part A (discretionary funding) at $53,080,000 and HEA Title III Part F (mandatory funding) at $89,000,000.

Carl D. Perkins Career and Technical Education Programs

Tribally Controlled Postsecondary Career and Technical Institutions: AIHEC requests $15,000,000 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 FY 2020, the Special Programs for Indian Children account received $67,993,000, of which $13,668,000 was allocated for 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 FY 2022.

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 FY 2020 LHHS appropriations bill and continued with $4,000,000 within the FY 2021 LHHS appropriations bill. TCUs have had marked success in training early childhood educators and Head Start teachers who 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 degree 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 AI/AN children.

Substance Abuse and Mental Health Services Administration (SAMHSA)

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 program for HBCUs, is to grow a highly 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 to earn 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 FY 2022 appropriations requests. Thank you.

PREPARED STATEMENT OF THE AMERICAN LIVER FOUNDATION

SUMMARY OF FISCAL YEAR 2022 APPROPRIATIONS RECOMMENDATIONS

—Provide the National Institutes of Health (NIH) with at least $46.1 billion and provide individual NIH Institutes and Centers, such as NIDDK, NIMHD, and NCI with proportional discretionary increases.
  —Please support establishment and adequate funding for the new Advanced Research Projects Agency for Health (ARPA–H) at NIH as proposed in the Administration's Budget Request to Congress to facilitate robust scientific progress on cancers and other conditions.
—Provide the Centers for Disease Control and Prevention (CDC) with at least $10 billion to facilitate timely public health efforts along with proportional increases for CDC Centers and Divisions, such as NCCDPHP and NCHHSTP.
  —Please provide $134 million for the Division of Viral Hepatitis at CDC.
  —Please provide $120 million for the Opioid and Infectious Diseases Program at CDC.
  —Please provide $5 million for the new Chronic Disease Education and Awareness Program at CDC.
—Provide the Health Resources and Services Administration (HRSA) with a funding level of at least $9.2 billion and ensure that the agency has sufficient resources to enhance organ donation through awareness activities and partnerships.
—Please support timely committee recommendations on liver diseases and health disparities, NASH/NAFLD, organ donation, and related areas.

Thank you for the opportunity to submit testimony on behalf of the American Liver Foundation (ALF) and the liver disease community. Chairwoman Murray, Ranking Member Blunt, and distinguished members of the subcommittee, we extend our thanks for the significant investments in HHS, particularly NIH, provided over recent years. Please maintain this commitment and further enhances support for public health programs as you work on appropriations for Fiscal Year (FY) 2022. 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?4?million individuals each year with health information, education and support services via its national office 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% of adults and 3–10% 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.

CDC CHRONIC DISEASE EDUCATION & AWARENESS PROGRAM

Thank you for establishing the CDC Chronic Disease Education & Awareness Program in FY 2021 and providing $1.5 million in initial support. Many patient organizations seek valuable collaborations with CDC that can directly impact patients and improve public health. A few contemporary examples include raising awareness of NASH/NAFLD, and sharing public health information that can slow or stop the progression of various liver conditions into liver cancer. This new program provides a

competitive mechanism that allows CDC to award meritorious cooperative agreements on an annual basis. Since there is tremendous demand in this area, and no shortage of quality opportunities for CDC, we ask that funding be systematically increased with $5 million provided for FY 2022.

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". This epidemic has been further fueled by the well-documents rise in opioid abuse during the COVID–19 pandemic. Due to the ongoing increase in rates of injection drug use, CDC recently identified a 400% increase in rates of hepatitis C among 20—29 year olds an 300% increase among 30—39 year olds. A few years ago, the elimination initiative was established at CDC, and the current funding level is $13 million. We ask that this allocation be systematically increased along with the annual funding for the Division of Viral Hepatitis to ensure CDC has adequate resources to make progress.

COVID–19 AND LIVER DISEASES

There is a growing body of work focused on COVID–19's impact on the liver and persistent impacts for COVID "long haulers". We appreciate that a well-resourced NIH and public health response can continue to advance research in this critical area. Moreover, in regards to vaccination, please note that the American Association for the Study of Liver Diseases (AASLD) recommends that providers advocate for prioritizing patients with compensated or decompensated cirrhosis or liver cancer, patients receiving immunosuppression such as SOT recipients, and living liver donors for COVID–19 vaccination based upon local health policies, protocols, and vaccine availability.

NASH BILL OF RIGHTS

Nonalcoholic steatohepatitis or NASH is liver inflammation and damage caused by a buildup of fat in the liver. The prevalence of NASH has been rising and innovative treatment options have been coming to market along with improved healthcare. To better serve patients, ALF crafted a NASH Patient Bill of Rights that provides critical information on non-invasive testing options and coordinating multidisciplinary healthcare. The Foundation looks forward to working with the U.S. Public Health Services to disseminate critical information about NASH to patients and providers.

PATIENT PERSPECTIVES

(Alison).—Alison is now a healthy 25-year-old from Trumbull, Connecticut, only five 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 life-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 ten 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% 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 Lorraine Stiehl, Chief Executive Officer, American Liver Foundation.]

PREPARED STATEMENT OF THE AMERICAN LUNG ASSOCIATION

SUMMARY OF FISCAL YEAR 2022 APPROPRIATIONS RECOMMENDATIONS

$10 billion for the Centers for Disease Control and Prevention (CDC)

—National Center for Chronic Disease Prevention & Health Promotion (NCCDPHP)
Provide $3.75 billion for NCCDPHP
—Provide $310 million for CDC's Office of Smoking and Health (OSH)
—Provide $5 million for CDC's Chronic Disease Education and Awareness Program

—National Immunization Program at CDC's National Center for Immunization and Respiratory Diseases (NCIRD)
Provide $1.13 billion for NCIRD

—National Center for Environmental Health (NCEH)
Provide $322 million for NCEH
—Provide $110 million for CDC's Climate and Health Program
—Provide $35 million for CDC's National Asthma Control Program (NACP)

$46.1 billion for the National Institutes of Health (NIH)

—Provide $3.94 billion for the National Heart, Lung, and Blood Institute
—Support establishment of, and adequate funding for, the new Advanced Research Projects Agency for Health (ARPA–H) at NIH

The American Lung Association is the leading public health organization working to save lives by improving lung health and preventing lung disease through education, advocacy and research. Chairwoman DeLauro, Ranking Member Cole, and distinguished members of the subcommittee, we extend our thanks for the significant investments in the Department of Health and Human Service (HHS), including the robust response to the COVID–19 pandemic. Please maintain this commitment and further enhance support for public health programs as you work on appropriations for Fiscal Year (FY) 2022. The American Lung Association also asks for your leadership in opposing all policy riders that would weaken key lung health protections.

The COVID–19 pandemic has underscored the need for significant and sustained investments in our nation's public health infrastructure, especially at CDC. For years, the Lung Association has requested for robust CDC funding. Unfortunately, funding for CDC has remained stagnant, and the failure to adequately invest has become evident during the public health emergency that has taken the lives of over a half a million people in the US. We ask that CDC funding be increased to at least $10 billion for fiscal year 2022. This funding must be in addition to, not in lieu of, emergency funds to respond to the current pandemic.

The COVID–19 pandemic has also highlighted the importance of preventing and managing chronic lung conditions. Individuals living with certain lung diseases and people who smoke are among the most at risk for severe illness from COVID–19. Research also shows that long-term exposure to air pollution leads to worse COVID–19 outcomes. The Lung Association recognizes the tremendous challenges Congress has faced in responding to the pandemic and appreciates all that it has done thus far. Continued investment in CDC programs that help smokers quit; promote asthma control; support prevention and treatment of lung and other chronic diseases,

including chronic obstructive pulmonary disorder (COPD) and lung cancer; and prepare for and respond to the health impacts created by a warming climate is vital.

The American Lung Association strongly supports substantial federal investments in key public health and biomedical research activities, especially at CDC and NIH, respectively. For FY22, the Lung Association encourages Congress to take a balanced approach in its increases for these vital agencies and urges Congress to make significant investments in public health programs at CDC.

Provide $10 billion for the Centers for Disease Control and Prevention (CDC): The nation is relying on CDC more than ever before. CDC is faced with unprecedented challenges and responsibilities, especially in the respiratory space. Consequently, the American Lung Association strongly supports the CDC Coalition's request of $10 billion for CDC for FY22 and sustained, robust and predictable funding moving forward annually.

Provide $3.75 billion for National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP): In 2019, COPD was one of seven chronic diseases included in the top 10 causes of death in the United States. Chronic diseases can be prevented and/or managed through supportive public health interventions including tobacco prevention and cessation; however, they continue to be a major problem in the United States. Over 90% of the nation's $3.8 trillion in annual health care costs result from chronic diseases. The American Lung Association strongly supports tripling the NCCDPHP budget over three years (FY22–FY24). Such funding will allow NCCDPHP to fulfill its mission by expanding the current patchwork of existing programs to all jurisdictions nationwide and by implementing new efforts to address health challenges currently without programs, including the chronic disease cohort of COVID–19 "long-haulers." It will also enable a significant investment in CDC's Social Determinants of Health (SDOH) program, which seeks to work with communities to identify and remedy SDOH.

Provide $310 million for CDC's Office of Smoking and Health (OSH): One in four high school students continues to use at least one tobacco product. OSH is the lead federal agency for tobacco prevention and control. The American Lung Association is appreciative of the $7.5 million increase in funding for OSH in FY21 and asks for an additional $72.5 million for FY22. The additional funding will be used to continue to address the e-cigarette pandemic, to enhance the "Tips from Former Smokers" campaign so that it can be run year-round, to invest in youth prevention efforts and to work to eliminate health inequities among racial, ethnic, sexual, rural and socio-economic groups.

Provide $5 million for CDC's Chronic Disease Education and Awareness Program: Far too many individuals in the United States have or are at risk of potentially devastating chronic diseases without knowing. COPD is one of the leading causes of death and disability in the United States. Approximately 16 million people in the United States have COPD, and millions more remain undiagnosed. Given this significant gap in knowledge, the Lung Association greatly appreciates the creation and funding of the Chronic Disease Education and Awareness competitive grant program at CDC in FY21. In FY22, the Lung Association asks for this program to be increased to $5 million to continue the momentum and allow CDC to expand its work with stakeholders to respond to chronic diseases, such as COPD, that do not have standalone programs.

Provide $110 million for CDC's Climate and Health Program: 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 (which include worsening air pollution; diseases that emerge in new areas; stronger and longer heat waves; and more frequent and severe droughts and wildfires) and provides guidance to states in adaptation. Currently, projects in 16 states and two city health departments develop and implement health adaptation plans and address gaps in critical public health functions and services. Unfortunately, the level of investment thus far has been insufficient for this program to reach its full, possibly lifesaving, potential. The President's budget requests $110 million, which would allow CDC to implement a 50-state climate and health program.

Provide $35 million for CDC's National Asthma Control Program (NACP): It is estimated that 24.8 million Americans currently have asthma, of whom 5.5 million are children. The NACP tracks asthma prevalence promotes asthma control and prevention and builds capacity in states. This program has been highly effective: asthma mortality rates have decreased despite the rate of asthma increasing. Additional funding would allow approximately four to five additional states beyond the current 25 states and localities to be funded to implement these lifesaving programs.

Provide $1.13 billion for the National Immunization Program at CDC's National Center for Immunization and Respiratory Diseases (NCIRD): The success of the nation's vaccination programs has enabled many individuals to forget about the impact

of many vaccine preventable diseases, such as polio, that once wreaked havoc. The COVID–19 pandemic, however, has provided a stark reminder of the need and significance of vaccines and a robust national vaccination program. The National Immunization Program must receive strong and sustained funding. The Lung Association asks for $1.13 billion for NCIRD to enhance COVID19 vaccinations, bolster the nation's immunization infrastructure and address any gaps in routine immunizations that may have emerged as a result of the pandemic.

Provide $46.1 billion for the National Institutes of Health (NIH): The Lung Association supports increased funding for NIH research on the prevention, diagnosis, treatment and cures for tobacco use and all lung diseases including lung cancer, asthma, COPD, pulmonary fibrosis, influenza and tuberculosis. The Lung Association also 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. Lastly, the Lung Association urges increased funding for lung cancer research in addition to the Cancer Moonshot and the All of Us Program.

Thank you for your consideration of our recommendations. Below please find a vignette demonstrating the importance of CDC programs.

SHARON L. FROM OKLAHOMA: LUNG CANCER & COVID–19 SURVIVOR

"I now live with cancer. I am not a cancer patient; I am a patient who has cancer."

Sharon was diagnosed with Stage 4 lung cancer in October 2015. After six rounds of aggressive chemotherapy, followed by another two rounds shortly thereafter, Sharon is currently six years out from her diagnosis and living without the need for additional treatment. This past year, Sharon became one of the over 32 million individuals in the United States diagnosed with COVID–19.

"I can't emphasize how important funding for the CDC is. Having had COVID, it is even more important, but it has always been important to me."

Sharon and husband tenaciously fought to quit smoking, her husband with the help of a CDC-funded quitline, and they were ultimately successful in doing so. From her experiences, Sharon believes that public health programs are critical to raising awareness about lung cancer prevention and increasing tobacco cessation.

"What the CDC does with smoking cessation is vitally important, so people don't end up like me, thinking they have 14 months to live and watching every plan they have for growing old with their husband flash before their eyes. It is vitally important. Public health is important for everybody. You either pay for it now, or you pay for it at the end. And it always costs more at the back end than now."

MICHIGAN ASTHMA PREVENTION AND CONTROL PROGRAM (MIAPCP)

Michigan is one of the 23 states that receive funding through the National Asthma Control Program (NACP). Through funding from CDC, Michigan was able to create the Asthma Initiative of Michigan website, www.GetAsthmaHelp.org, which enables access to a plethora of resources for those struggling with asthma. The MiAPCP has also worked to facilitate and support Managing Asthma Through Case-Management in Homes (MATCH) throughout parts of Michigan with the highest burden of asthma. Through MATCH programs, individuals can benefit from home visits, an environmental assessment, access to a certified asthma educator, and a physician care conference. As a result, Michigan saw a 60% decrease in asthma-related emergency room visits, 82% decrease in hospitalizations and a 58% decrease in the number of children who missed one or more school days due to asthma.

"Interventions and policy efforts by our program that impact asthma care and environments cannot be sustained without CDC's support."

—John Dowling, Lead Asthma Coordinator of the MiAPCP

Most recently, MiAPCP launched a cohesive effort to improve asthma surveillance and data collection.

[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 written testimony for the record to the Senate Subcommittee on Labor, Health and Human Services, and Education Subcommittee in support of continued robust funding in FY 2022 for the National Center for Complementary and Integrative Health (NCCIH) within the National Institutes of Health (NIH) as well as for

suggested report language for both NCCIH as well as the Centers for Disease Control (CDC).

Established in 1943 and numbering over 95,00 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 46 states and the District of Columbia.

We appreciate and acknowledge the Committee's ongoing support for massage therapy, including past report language urging the adoption of recommendations from the groundbreaking and widely supported 2019 HHS final report from the Pain Management Best Practices Task Force (Task Force). Unfortunately, most recommendations from that task force—including those that support inclusion of massage therapy and other integrative and complementary health treatments for pain—have still not been adopted.

COVID–19 has exacerbated the already existing public health crisis of acute and chronic pain from delayed access to health care, as well as a rise in substance abuse and overreliance on opioids. We encourage the Committee to include report language in the FY 2022 bill that focuses on the need for greater public awareness on treatment options for pain that include complementary and integrative approaches such as massage therapy. We request the Committee to direct NIH to coordinate with the DoD and VA to launch a much-needed public awareness campaign about these non-opioid treatment options and to widely disseminate the Task Force recommendations to health care providers and public health stakeholders. Last, we request the Committee's continued support to direct all relevant HHS agencies to update their pain management practices to reflect the Task Force recommendations, including those that support massage therapy.

We also support the inclusion of report language accompanying the FY 2022 bill that would direct the CDC to collect and publish population research data that provides a comprehensive assessment of the nature of pain management, who is affected by pain, and direct and indirect costs to society related to pain.

Over recent years, research continues to increase support for massage therapy, which has thus increased policymakers' awareness of the benefits of massage therapy as a non-pharmacologic alternative to opioid use to manage pain. As noted above, massage is specifically addressed throughout the 2019 Task Force report and is even included in the Task Force "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. 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.

Despite the demonstrated value and efficacy of massage therapy through research, we know that more needs to be done. As recently as last August, a national survey of 1,581 people with pain indicated that massage therapy is the most desired treatment for pain (at 48.4%, followed by pain physician at 32.9% and acupuncture at 29%), but unfortunately a majority of those surveyed indicated that cost prevented them accessing massage therapy. This underscores the disconnect between the best practices that already exist in pain management and those that are realistically available to patients, due to cost and lack of 3rd party insurance coverage, as well as insufficient provider awareness of the benefits of massage and other complementary therapies.

For over 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 benefits of massage therapy for pediatric populations, patients with heart failure, and those with muscle atrophy, among others. Many of these efforts have been specifically designed to include racially diverse and underserved populations.

We know that massage therapy can improve health outcomes and is also among the most cost-effective therapies that can save health care 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 encourage a sustained and robust finding stream 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.

Thank you for your consideration, and AMTA would be happy to provide more information as needed.

Sincerely,

James Specker, AMTA Director, Industry and Government Relations at jspecker@amtamassage.org.

PREPARED STATEMENT OF THE AMERICAN NATIONAL RED CROSS AND THE UNITED NATIONS FOUNDATION

Chairwoman Patty Murray, Ranking Member Roy Blunt, and Members of the Subcommittee on Labor, Health and Human Services, Education and Related Agencies, the American Red Cross and the United Nations Foundation appreciate the opportunity to submit testimony. We are writing to request that Congress invest $60 million for CDC's global measles and rubella elimination efforts for fiscal year 2022.

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 elimination activities for FY2022 at $60 million, which is part of the overall Global Immunization Division line.

COVID–19 ENVIRONMENT

COVID–19 has had an unprecedented impact on global immunization programs. As of June 1st twenty-three measles and rubella vaccination campaigns that were scheduled for 2020 continue to be postponed as a result of the COVID–19 pandemic, leaving an estimated one hundred and thirty-five million children unvaccinated and vulnerable to the diseases. This growing immunity gap is creating a looming cliff in global public health, as social distancing measures are lowered, the measles virus will quickly spread amongst unvaccinated individuals and communities. Because the measles virus is one of the most transmissible human viruses—with each infectious person capable of infecting as many as 18 unvaccinated individuals—a drastic increase in measles outbreaks around the world is anticipated. Failing to close these immunity gaps will leave millions of children at risk and will compromise U.S. global health security by disrupting economies, trade, and country stability, and increasing the likelihood of the virus infecting U.S. communities. Investments that will quickly close these global immunity gaps will help to ensure that gains made in reducing maternal and child mortality and morbidity are maintained, and that the global health infrastructure established through these investments is preserved and strengthened. Among other benefits, this global health architecture is vital to protecting global health security. Measles investments have established networks of laboratories around the world capable of processing diagnostics, and has bolstered the global public health workforce of trained professionals and volunteers who are often the first responders during health crises. During the pandemic, for instance, these assets and infrastructure investments were pivoted to detect and test cases of COVID–19, giving vulnerable countries a head start in their pandemic response. With this context in mind, we respectfully provide the following justification for continued robust investment in CDC's global measles and rubella elimination efforts.

WHY MEASLES AND RUBELLA?

U.S. leadership has saved the lives of 25.5 million children between 2000 and 2019, with the Measles & Rubella Initiative driving measles deaths down by 62%.

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 567 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 as part of congenital rubella syndrome (CRS) that can impact vision, hearing, heart health, overall development. Each year roughly 100,000 babies are born with CRS despite the preventable nature of the disease.

Since 2000, measles vaccines have been the single greatest contribution in reducing preventable child deaths globally. We have had safe and effective vaccines against both rubella and measles for over 50 years, but unfortunately vaccination rates globally have stagnated for over a decade.

DOMESTIC IMPLICATIONS

In the U.S., 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. In 2019, for example, 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 by unvaccinated U.S. residents returning from trips to Israel and Ukraine. Controlling measles and rubella around the world reduces the likelihood of similar disease importations in the future.

Responding to measles outbreaks is resource intensive and costly for health systems, including in the U.S. In a literature review that included 10 studies on measles outbreaks from 2001 to 2018 in the U.S., researchers estimated the cost per case to range from about $7,000 to $76,000 and the total cost per outbreak ranged from $10,000 to $1 million. A recent study of a 72-case outbreak in the U.S. cost local public health and government authorities an estimated $3.4 million for response activities, medical costs, and productivity losses.

THE MEASLES & RUBELLA INITIATIVE

The Measles & Rubella Initiative (M&RI)—which includes the American Red Cross, CDC, UNICEF, the United Nations Foundation, and WHO, all working in collaboration with Gavi, the Vaccine Alliance as well as the Bill & Melinda Gates Foundation—supports countries to prevent, identify, and respond to measles outbreaks through key interventions like surveillance, supplementary vaccination campaigns, and emergency response.

M&RI has achieved outstanding results by helping to vaccinate nearly 3 billion individuals in over 90 countries since 2001, saving the lives of more than 25.5 million children. In part due to M&RI, global measles mortality has dropped 62%, from an estimated 545,000 deaths in 2000 to an approximately 207,000 in 2019 (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 57%.

Despite these gains, we continue to see unfortunate and preventable deaths and complications due to both measles and rubella. In 2019, every day approximately 567 children died of measles-related complications. These deaths could have been prevented with a safe, effective, and inexpensive vaccine that is typically available for less than $2 USD in lower income countries, which protects against both measles and rubella.

Thanks to M&RI leadership, most measles vaccination campaigns have been able to reach more than 90% of their target populations. Countries recognize the opportunity that measles vaccination campaigns provide in reaching mothers and young children and integrating the campaigns with other life-saving health interventions. These include administering vitamin A, which is crucial for preventing blindness in under nourished children; de-worming medicine to reduce malnutrition; doses of oral polio vaccines; distributing insecticide treated bed nets to help prevent malaria and screening for malnutrition. 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.

In addition to the lifesaving benefits of the measles-rubella vaccine, immunization makes sound economic sense. A 2016 Johns Hopkins University study compared the costs for vaccinating against 10 disease antigens in 94 low- and middle-income countries between 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 found to be the greatest with $58 saved for every $1 invested.

Securing sufficient funding for measles and rubella-elimination 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 increasing measles vaccination coverage to 95%. Implementation of timely measles and rubella vaccination 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. The combined factors of a highly contagious disease, growing immunity gaps exacerbated by COVID–19 disruptions, and our highly interconnected world means measles is poised to spread quickly, with devastating results that could even threaten 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 able to effectively reach and vaccinate all its children.

THE ROLE OF CDC IN GLOBAL MEASLES MORTALITY REDUCTION

Since FY 2001, Congress has generously provided funding to protect children and their families from the threat of measles and rubella in developing countries, thereby also protecting the U.S. population from the threat of measles importations. Funding for measles and rubella globally has remained level since FY 2010 at $50 million dollars. The COVID–19 pandemic has gravely disrupted immunization systems around the world, leaving millions of children vulnerable to measles and other vaccine-preventable diseases. We must quickly "catch up" vaccination coverage rates to reach unvaccinated populations and prevent devastating measles outbreaks. The CDC plays an essential role within this space by providing support for vaccination programs and surveillance to detect outbreaks early and stop them at their source. An increase in resources for these and other critical activities provided by the CDC are needed to prevent needless childhood deaths around the globe.

In 2019, thanks in part to U.S. funding, M&RI supported 62 immunization campaigns in 53 countries, resulting in the vaccination of nearly 203 million children. Funding for CDC permitted the provision of technical support to Ministries of Health that 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 serving as the leading worldwide reference laboratory for measles and rubella; and 4) conducting operations research to guide cost-effective and high-quality measles and rubella elimination programs.

Since FY10, the CDC's measles and rubella elimination program has been funded at approximately $50 million. In FY 2022, the American Red Cross and United Nations Foundation respectfully request an increase of $10 million to raise funding to $60 million. This investment will allow CDC to help countries to close the immunization gap created by COVID–19, safeguard the progress made over the last decade and protect Americans by preventing measles cases and deaths in the U.S. The CDC Global Immunization Division, through which the Measles & Rubella Initiative is funded, has been highly effective and we strongly support fully funding this work. All the programs funded through the Global Immunization Division budget line also help to build stronger health systems. We respectfully request $60 million for CDC's measles elimination activities, as part of the overall funding for the entire Global Immunization Division account in FY2022.

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 NURSES ASSOCIATION

The American Nurses Association (ANA), representing the interests of the nation's 4.2 million registered nurses, thanks Chair Murray, Ranking Member Blunt, and the U.S. Senate Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies for the opportunity to provide written testimony for Fiscal Year (FY) 2022.

ANA is committed to advancing the nursing profession by fostering high standards of nursing practice, promoting a safe and ethical work environment, bolstering the health and wellness of nurses, and advocating on health care issues that affect

nurses and the public. ANA is at the forefront of improving quality of health for all.

NURSING WORKFORCE AND HEALTH EQUITY

Investments in the Title VIII Nursing Workforce Development Programs are essential to ensuring nurses and nursing students have the resources to tackle our nation's health care needs, remain on the frontlines of the COVID–19 pandemic, and be prepared for the public health challenges of the future. Funding for Title VIII has become even more crucial during the pandemic, 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.

ANA believes there are multiple policy levers to eliminate or reduce health disparities. Our Principles for Health System Transformation [1] call for expanded access to care through universal coverage and other steps to improve the quality and affordability of health care. We also believe policymakers must consider and account for an adequate health care workforce of the future. The nursing workforce, in particular, can play a tremendous role in efforts to create a more equitable health care system. Nurses provide the type of care and coordination that can help people manage their chronic conditions, including links to community resources they need to be healthy. Registered nurses and advanced practice registered nurses are often the backbone of health care delivery in rural and underserved areas, providing access to primary care, maternity care, and prevention. These roles should be strengthened through meaningful reforms.

Expanding the minority health care workforce would be one of the most meaningful steps we could take to improve access and health care in African American population groups. We know that positive patient experience and trust in health care providers can be powerful drivers of health outcomes. The National Sample Survey of Registered Nurses recently reported an increase in the minority nursing workforce between 2008 and 2018.[2] This is encouraging, but there is a long way to go. An increased funding in minority nursing education, to develop a workforce that is more reflective of the patient population would be a first step in the right direction.

ANA is a member of the Nursing Community Coalition which is comprised of 63 national nursing organizations who collectively represent the cross section of education, research, practice, and regulation within the nursing profession. Together, we respectfully request supporting at least $530 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) in FY 2022.

PUBLIC HEALTH INFRASTRUCTURE

The nation's public health infrastructure and workforce have been underfunded for decades, and we have witnessed the highlighted impacts of this chronic underfunding throughout the COVID–19 public health emergency. Federal funds for state, local, and tribal public health preparedness shrunk from $940 million in 2002 to $675 million in 2019.[3] During the same time period, hospital emergency preparedness was cut by nearly fifty percent, from $515 million in 2004 to $265 million in 2019. This has resulted in a loss of 55,000 public health workers since 2008. The current COVID–19 public health emergency has underscored that our nation must be better equipped with preparedness and response personnel, measures and processes. A robust public health infrastructure and workforce is not only important during the time of crisis, but generally to address the overall health and well-being of our population.

The public health nursing workforce touches every aspect of health care and community well-being. Unfortunately, we can only imagine how different the coronavirus response would have been had greater federal public health infrastructure investment afforded availability of sufficient numbers of nurses and other public health personnel in areas of the greatest need. Nurses could have played an enhanced role in encouraging and administering COVID–19 tests in high-risk populations, conducting contact tracing at an effective pace, educating the public about vaccine safety and all facets of COVID–19 prevention and mitigation, informing

[1] https://www.nursingworld.org/4afd6b/globalassets/practiceandpolicy/health-policy/principles-healthsystemtransformation.pdf.

[2] https://bhw.hrsa.gov/data-research/access-data-tools/national-sample-survey-registered-nurses.

[3] https://www.tfah.org/wp-content/uploads/2020/04/TFAH2020PublicHealthFunding.pdf.

school opening protocols, and collecting data for feedback to pandemic response efforts.

MENTAL HEALTH

Nurses, particularly those early in their career, continue to feel exhausted and overwhelmed. According to the findings of an American Nurses Foundation survey of nearly 13,000 nurses, 51 percent of nurses surveyed continue to feel exhausted and 43 percent report feeling overwhelmed. A breakdown of findings demonstrates that the mental health of early-career nurses, 34 and under, is impacted most, with 81 percent reporting they are exhausted, 71 percent saying they are overwhelmed, and 65 percent who report being anxious or unable to relax. Nurses who are 55 and older reported some strain on their mental health, with 47 percent reporting feeling exhausted and 31 percent reporting they had a desire to quit.[4]

ANA is a member of the Mental Health Liaison Group. We count the American Psychiatric Nurses Association as a premier Organizational Affiliate and many psychiatric nurses as members. We request that the Committee approve the appropriations request put forward by the Mental Health Liaison Group for FY 2022 for mental health and addiction policies and programs.[5]

MINORITY FELLOWSHIP PROGRAM

ANA supports funding and expanding the Minority Fellowship Program (MFP), which is currently administered by the Substance Abuse and Mental Health Services Administration (SAMHSA).[6] The program provides scholarships to minority mental health and addiction professionals in nursing, but also in the fields of psychiatry, psychology, social work, marriage and family therapy, counseling and addictions. The program's mission is to increase the number of culturally competent behavioral health professionals who provide mental health and substance use disorders services to underserved populations.

The MFP was created in 1974 to provide fellowships to minority mental health professionals, and, since then, more than 4,400 fellowships have been issued to nurses, psychiatrists, psychologists, social workers, marriage and family therapists, counselors, and addiction specialists. According to HHS, minorities are less likely to receive diagnosis and treatment for their mental illness, have less access to and availability of mental health services, and often receive a poorer quality of mental health care. The MFP is the only federal program financing culturally competent mental health and substance use disorders professionals.

ANA, along with the MFP Coalition, urges Congress to increase funding for the MFP to $20,200,000 in FY 2022 in order to expand access to nurses and other mental health professionals who provide culturally competent mental health and substance abuse services to ethnic minority populations.

Thank you for the opportunity to provide written testimony as the Subcommittee continues its important work. If you have any questions, please contact Ingrida Lusis, Vice President of Policy and Government Affairs, at Ingrid.Lusis@ana.org.

[This statement was submitted by Debbie D. Hatmaker, PhD, RN, FAAN, Chief Nursing Officer/EVP.]

PREPARED STATEMENT OF THE AMERICAN PSYCHOLOGICAL ASSOCIATION SERVICES, INC.

The American Psychological Association (APA) is the largest scientific and professional organization representing psychology in the United States, with more than 122,000 researchers, educators, clinicians, consultants, and students as its members. Our mission is to promote the advancement, communication, and application of psychological science and knowledge to benefit society and improve lives.

Many programs in the Labor-HHS-Education Appropriations bill are critical to strengthening the mental health workforce, supporting psychology-based research and education, and improving access to needed mental and behavioral health services, particularly for underserved communities. As the COVID–19 pandemic continues to present broad challenges for our nation in both the short and long term, federal investments are needed to bolster research, expand equitable access to pri-

[4] https://www.nursingworld.org/practice-policy/work-environment/health-safety/disaster-preparedness/coronavirus/what-you-need-to-know/mental-health-and-wellness-survey-2/.

[5] https://www.mhlg.org/wordpress/wp-content/uploads/2021/04/MHLG-FY2022-Approps-Request-Final-4.7.21.pdf.

[6] https://www.samhsa.gov/minority-fellowship-program/about.

mary and mental health services, and support data-informed approaches to education and public welfare at all levels. To boost critical research funding, support the psychology workforce, improve access to mental and behavioral health services across the lifespan, and address social determinants of health, APA requests the following funding levels for FY22 within the U.S. Department of Health and Human Services, U.S. Department of Education, and U.S. Department of Labor.

Boosting Critical Research Funding: APA requests at least $46.111 billion for NIH in FY22, including $48.9 million for the NIH Office of Behavioral and Social Sciences Research (OBSSR). This funding would allow OBSSR to continue leading the coordination and support of research designed to address the social, behavioral, and economic effects of COVID–19 and its associated containment and mitigation efforts. Understanding these impacts will help policymakers improve their long-term response to the pandemic and prepare more effectively and efficiently for the country's next public health emergency. APA encourages the Committee to resist calls to limit the availability or use of non-human animal models in research, and to ensure this research continues to be conducted appropriately and ethically.

APA recommends at least $700 million for the Institute of Education Sciences (IES), which supports and disseminates scientific evidence on which to base education policy and practice and funds innovative research into many aspects of teaching and learning, including research on pandemic-related learning loss. Finally, APA urges the Committee to provide $50 million in funding shared evenly between the CDC and NIH to conduct public health research into firearm morbidity and mortality prevention. This research is fundamental to helping our nation better understand and address our gun violence public health crisis.

Supporting the Psychology Workforce: The nation's mental and behavioral health workforce must be expanded to adequately respond to the long-term mental health and substance use disorder ramifications of the COVID–19 pandemic, particularly the needs of long-underserved communities like communities of color and older adults. This includes foundational investments in higher education, as well as workforce training programs that support the integration of behavioral healthcare. To address this, APA supports increased funding for the following programs within the Department of Education and HHS' Health Resources and Services Administration (HRSA), Substance Abuse and Mental Health Services Administration (SAMHSA).

Given the heavy burden of student loan debt, APA supports added investments in grant programs for graduate study within the Department of Education, including $35 million for the Graduate Assistance in Areas of National Need (GAANN) Program. The most recent funding cycle marked the first time in nearly a decade where psychology was among the designated areas of national need under this program. As the mental health impact of the pandemic continues to unfold, APA requests that the committee again direct the Secretary to include academic areas that fall under the Classification of Instructional Programs (CIP) 51.15 Mental Health Services in the next grant competition.

Within HRSA, APA joins the Mental Health Liaison Group (MHLG) in urging the Committee to provide $23 million for the Graduate Psychology Education Program; $90 million for the Behavioral Health Workforce Education and Training (BHWET) Grant Program; and $37 million for the Mental and Substance Use Disorder Workforce Training Demonstration. These essential programs increase work to increase our nation's supply of health service psychologists trained to provide integrated services to high-need, underserved populations in rural and urban communities. 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).

Within SAMHSA, APA requests $20.2 million for the Minority Fellowship Program (MFP). This increase will support the program's dual mission to both increase the diversity of the mental and behavioral health workforce while improving access to mental health and substance use disorder services in underserved communities.

Improving Access to Mental and Behavioral Health Care Across the Lifespan: Given the rise in COVID-related mental health concerns, APA joins MHLG in requesting $833 million for SAMHSA's Community Mental Health Block Grant (MHBG) and $1.9 billion for the Substance Abuse Prevention and Treatment (SAPT) Block Grant in FY22. To address rising suicide rates, we urge the Committee to provide $240 million for the National Suicide Prevention Lifeline; $5 million for 988 implementation, $37 million for the State/Tribal Youth Suicide Prevention Program; $6.7 million for the Campus Mental and Behavioral Health Program; and $9.3 million for the Suicide Prevention Resource Center.

To ensure that our K–12 students receive a well-rounded education, and access to school-based mental health services and programs that foster safe and healthy

schools, APA requests $2 billion for Title IV–A, the Student Support and Academic Enrichment (SSAE) block grant. Additionally, to increase the number of mental health providers working in school settings, APA requests $606 million for the Safe Schools National Activities Program in order to support new competitions for the School Based Mental Health Services Professional Demonstration Grant and the School-Based Mental Health Services Grant Program. APA also urges the Committee to include $15.5 billion for Part B (Grants to States) of the Individuals with Disabilities Education Act (IDEA) to help provide an equitable education for students with disabilities.

Given that maternal mental health conditions are the most common complication of pregnancy and childbirth, APA joins the Maternal Mental Health Leadership Alliance and more than 100 other organizations in requesting $5 million for HRSA's Maternal Mental Health Hotline, and $10 million for the Screening and Treatment of Maternal Depression and Related Behavioral Disorders Program. APA urges to Committee to provide $750 million for Title V Maternal and Child Health Services Block Grant Program, which supported 92% of all pregnant women in the U.S. in FY19.

Finally, APA urges the Committee to provide much-needed funding to support Mental Health Parity and Addiction Equity Act (MHPAEA) enforcement. Within the DOL's Employee Benefits Security Administration, APA requests $25 million for MHPAEA enforcement, with 10% allocated to Office of Solicitor for parity litigation. To support MHPAEA enforcement within HHS, APA requests $10 million for CMS' Center for Medicaid and CHIP Services (CMCS).

Addressing Social Determinants of Health & Social Safety Net: Within HHS' Administration for Children and Families, APA supports $1.7 billion for the Social Services Block Grant, which provides vital social services, such as protective services agencies and special services to people with disabilities. In addition, APA urges the Committee to provide $10.7 billion for the Head Start Program, $5.9 billion for Preschool Development Grants, and $500 million for CAPTA Title I to support state child abuse prevention and treatment.

To expand the reach out various federal HIV programs, APA requests $100 million for the CDC Division of Adolescent and School Health (DASH), to increase access to health services, implement evidence-based sexual health education, and foster supportive environments for young people to learn. APA also supports $160 million for the SAMHSA Minority AIDS Initiative to expand efforts at preventing domestic HIV transmission and to increase treatment options for those living with comorbid conditions. APA urges the Committee to provide $120 million for the infectious diseases and opioid program at CDC. Currently funded at a level well below its actual need, this program increases prevention, testing, and linkages to provide a strong ground-level response to the intersecting crises of opioid addiction, HIV, and hepatitis. Finally, to strengthen public health surveillance activities, APA requests $250 million for the CDC's Data Modernization Initiative (DMI).

[This statement was submitted by Katherine B. McGuire, Chief Advocacy Officer, American Psychological Association Services, Inc.]

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 request of at least $10 billion for the Centers for Disease Control and Prevention and at least $9.2 billion for the Health Resources and Services Administration in FY 2022. Robust funding for CDC and HRSA programs that promote public health and prevention, support surveillance of infectious disease and bolster America's public health workforce will be critical in addressing both the short-term and long-term health impacts of COVID–19 and the many other health challenges we face as a nation. We are thankful for the emergency supplemental funding provided to CDC and HRSA to support the nation's response to COVID–19 and we urge the committee to ensure that all CDC and HRSA programs are adequately funded in FY 2022.

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% 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 urge a funding level of at least $10 billion in FY 2022. We are grateful for the important increases provided for CDC programs in FY 2021 and for the critical emergency funding provided to the agency to address COVID–19. We 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% 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 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.

We strongly support the president's budget request for $400 million in new funding to bolster core public health infrastructure and capacity at the federal, state, territorial and local levels. This flexible funding is critical to addressing the gaps in core public health infrastructure and capacity at all levels as well as ensuring our nation's health departments are able to attract and retain experienced leaders and respond to future public health emergencies and disease outbreaks. Sustained, flexible funding is critical to rebuilding and strengthening the nation's public health system.

CDC serves as the lead agency for bioterrorism and other public health emergency preparedness and response programs. 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 during public health emergencies. We also urge you to provide adequate funding for CDC's infectious disease, laboratory and disease detection capabilities 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. Your continued support for CDC's public health Data Modernization Initiative is critical to ensuring we have both the world-class data workforce and data systems that are ready for the next public health emergency.

We thank Congress for providing CDC with dedicated funding for firearm morbidity and mortality prevention research in FY 2020 and FY 2021 and we strongly urge you to increase this funding in FY 2022 to $50 million for CDC and NIH, as requested in President Biden's FY 2022 discretionary budget proposal. This 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 $322 million for NCEH in FY 2022, including $110 million for CDC's Climate and Health program, as requested in President Biden's FY 2022 discretionary budget request. Climate change is threating our health in many ways 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 provide funding to all 50 states and to support additional, cities, counties and tribes to help them prepare for and respond to the health impacts of climate change in their communities.

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 costliest 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 strongly urge increased investments in these critical programs that are essential to reducing death, disability and health care costs. In particular, we urge your support for the president's request of $153 million for CDC's Social Determinants of Health Program. This increased funding would allow CDC to provide public health departments, academic institutions and nonprofit organizations funding and tools to support cross sector efforts to address the impact that social determinants of health such as unsafe and unstable housing, income insecurity, lack of transportation, and underlying health inequities have on the health of their communities.

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 health care and services; fostering a health care 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 health care system.

We are grateful for the increases provided for HRSA programs in FY 2021 and for the emergency supplemental funding to battle the COVID–19 pandemic, but HRSA's discretionary budget authority is far too low to effectively address the nation's current public health and health care needs. We recommend Congress build upon the important increases they provided HRSA in FY21 and provide at least $9.2 billion for the Health Resources and Services Administration in FY 2022

HRSA programs and grantees are providing innovative and successful solutions to some of the nation's greatest health care challenges including the rise in maternal mortality, the severe shortage of health professionals, the high cost of health care 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 nearly 13,000 health center sites in medically underserved communities across the U.S., providing access to high-quality preventive and primary care to nearly 30 million people including 1 in 3 people living in poverty.

Health Workforce supports the health workforce across the 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 health care needs of the nation.

Maternal and Child Health supports initiatives that reduce infant mortality, minimize disparities, prevent chronic conditions and improve access to quality health care for vulnerable women, infants and children; and serves 60 million people through the MCH block grant.

HIV/AIDS programs deliver a comprehensive system of care to more than 519,000 individuals impacted by HIV/AIDS, improving health outcomes for people with HIV and reducing the chance of others becoming infected, and provides training for HIV/AIDS health professionals. 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 88.1% of clients achieving viral suppression, compared to just 64.7% of all people living with HIV nationwide.

Family Planning Title X services ensure access to comprehensive family planning and preventive health services for over 3.1 million people, reducing unintended pregnancy rates, limiting sexually transmitted infection transmission and increasing early detection of cancers.

Rural Health supports community 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 and promote the use of health information technology and telehealth.

HRSA has also been active in the COVID–19 pandemic response, awarding billions of dollars to health centers to administer COVID–19 tests and reimbursing providers who offer COVID–19 care to uninsured individuals.

In closing, we emphasize that the public health system requires stronger financial investments at every stage. It is critical that Congress increase its investments in CDC and HRSA programs to enable the nation 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 ENGINEERING EDUCATION

This written testimony is submitted on behalf of the American Society for Engineering Education (ASEE) to the Senate Subcommittee on Labor, Health and Human Services, Education, and Related Agencies for the official record. ASEE appreciates the Committee's support for the Department of Education (ED) in fiscal year (FY) 2021 and asks you to robustly fund student aid, teacher preparation, and STEM programs in FY 2022. Additionally, ASEE requests federal funding to support initiatives aimed at increasing the diversity of the STEM pipeline and support

for Minority-Serving Institutions (MSIs). The strong support of the National Institutes of Health (NIH) in FY 2021 was greatly appreciated and ASEE requests continued support of NIH.

The American Society for Engineering Education (ASEE) advances innovation, excellence, and access at all levels of education for the engineering profession and is the only society representing the country's schools and colleges of engineering and engineering technology. Membership includes over 12,000 individuals hailing from all disciplines of engineering and engineering technology including educators, researchers, and students as well as industry and government representatives. As the pre-eminent authority on the education of engineering professionals, ASEE seeks to advance the development of innovative approaches and solutions to engineering education and advocates for equal access to engineering educational opportunities for all.

Student Aid

Student aid programs like Pell Grants, Federal Work-Study (FWS), TRIO, and others make higher education accessible and affordable for millions of students. We appreciate the commitment the Biden Administration has made to affordable education through its preliminary Presidential Budget Request and the American Families Plan. ASEE joins the higher education community in requesting funding to support doubling the maximum Pell Grant award to $12,990. Pell Grants are essential to low-income students being able to afford higher education. These awards are vital in helping students access the significant life and career benefits that higher education provides. These benefits are especially prevalent for engineering education, which provides a proven pathway to the middle class, especially for students from low-income backgrounds. ASEE requests funding for Federal Work Study (FWS) at $1.480 billion and $1.061 billion for Supplemental Educational Opportunity Grant (SEOG). These programs are need-based, and often this aid provides the resources a student needs to complete their education. ASEE asks the Committee to consider ways to support work-based learning, such as co-operative education and apprenticeships, within the FWS program. ASEE firmly believes in ensuring access to engineering and engineering technology education for all students, not just those who can afford it, which is why ensuring student aid programs for graduate students is also very important. ASEE requests funding for the Graduate Assistance in Areas of National Need (GAANN) program, which provides fellowships, through academic departments and programs of institutions of higher education, to assist graduate students with excellent records who demonstrate financial need. ASEE requests $35 million for GAANN.

Teacher Preparation

The need for well-prepared and content-confident teachers in early childhood, elementary, and secondary education is high, particularly in STEM subjects. The lack of teacher training focused on STEM, and engineering in particular, is an important issue facing K–12 education. Problem-based learning that incorporates engineering design and analysis skills are often absent from teacher preparation and professional development programs. ASEE supports vigorous funding for Title II of the Elementary and Secondary Education Act (ESEA), which supports the preparation and professional development of school personnel, and Title II of the Higher Education Act, which supports teacher preparation programs at institutions of higher education. ASEE also supports President Biden's proposal to invest $9 billion in training and diversifying the teaching workforce presented in the American Families Plan. Efforts to support teaching skills for STEM postsecondary faculty should also be considered and could include partnerships between STEM disciplines and Schools of Education to support STEM faculty and support for teaching and learning centers at postsecondary institutions. Support of postsecondary faculty and their promotion of STEM learning should utilize research-based methods. Our future is dependent on today's students finding solutions to tomorrow's problems. This can only be accomplished if those students have teachers who are prepared to guide them in developing the knowledge and skills needed to solve those problems.

STEM

Support for science, technology, engineering, and mathematics (STEM) continues to grow and ASEE appreciates the support many STEM programs received in FY 2021. ASEE supports funding for Title IV of the Elementary and Secondary Education Act (ESEA) at its authorized amount of $1.6 billion, which will allow states and school districts additional resources to pursue STEM programs. ASEE supports robust funding for STEM programs for higher education students including the Hispanic-Serving Institutions (HSI) STEM and Minority Science and Engineering Improvement (MSEIP) programs. The STEM workforce is a driving force behind inno-

vation and our economic development. These and other programs targeted towards increasing the representation of historically underrepresented populations, including women, will ensure a healthy STEM workforce pipeline.

Career and Technical Education (CTE)

ASEE knows that high-quality Career and Technical Education (CTE) prepares students for careers and further postsecondary education while fulfilling employer needs in high-demand sectors of the economy.[1] ASEE supports CTE and wants to ensure best practices and high-quality programs are embedded in its programs, for example through faculty professional development and connections to the National Science Foundation -supported Advanced Technological Education (ATE) programs. ASEE also wants to strengthen pathways between CTE at the associate degree level to 4-year engineering technology and engineering degrees. ASEE believes that students should have lifelong options for continuing study and career advancement and that CTE programs can help students achieve their goals. In order for states and their CTE educators to provide high-quality CTE opportunities for students and strengthen pathways between two- and four-year institutions of higher education, ASEE urges Congress to robustly fund the Perkins Basic State Grant funding program in FY 2022 and encourage the program to build connections with NSF's ATE program.

National Institutes of Health—National Institute of Biomedical Imaging and Bioengineering (NIBIB)

NIBIB is the major NIH Institute focused on engineering applications to human health and training the next generation of biomedical engineers. ASEE is grateful to the committee for its strong bipartisan support of the NIH in FY 2021. NIBIB funding is critical for the development of devices and tools that can improve the detection, treatment, and prevention of disease, and also plays a critical role in assessing the effectiveness of new drugs and treatment procedures. NIBIB also supports training programs to enhance and expand education and training for the next generation biomedical engineering workforce. Through grant programs like the Enhancing Science, Technology, and Math Education Diversity Research Education Experiences, and Team-Based Design in Biomedical Engineering Education, NIBIB is committed to supporting all stages of the biomedical engineering career pathway and increasing the participation of traditionally underrepresented groups in engineering. ASEE urges the Committee to provide NIH with $46.1 billion in FY 2022 so that NIBIB can continue to support critical biomedical engineering research and training.

CONCLUSION

Engineering and engineering technology academic programs play critical roles in the STEM ecosystem. The requests made here support the development of a skilled technical workforce, broadening participation, and transdisciplinary study. Thank you for the opportunity to submit this testimony.

[This statement was submitted by Sheryl Sorby, Ph.D., President, and Norman Fortenberry, Sc.D., Executive Director, American Society for Engineering Education.]

PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR MICROBIOLOGY

The American Society for Microbiology (ASM) is the 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 $46.1 billion for the National Institutes of Health (NIH) and at least $10 billion for the Centers for Disease Control and Prevention (CDC) in fiscal year (FY) 2022. Within the CDC budget, we request $60 million for the Advanced Molecular Detection (AMD) program in the National Center for Emerging and Zoonotic Infectious Diseases.

Achieving Remarkable Outcomes Through a Strong Investment in the NIH

We thank 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 Chairman Leahy,

[1] https://www.acteonline.org/wp-content/uploads/2021/04/2021__ACTE__Legislative__Priorities__April.pdf.

Vice Chairman Shelby, Chair Murray and Ranking Member Blunt and members of the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies for their unwavering support for the NIH and leadership over the past six years, during which they and their Senate counterparts have worked in a bipartisan manner to place the NIH budget back on the path of meaningful growth above inflation.

Thanks to a renewed commitment to NIH, researchers were able to pivot when SARS–CoV–2 emerged and the race to develop tests, vaccines and therapeutics commenced. Researchers built on decades of federally-funded basic science and technological advances to develop safe and effective vaccines at record speed. This remarkable achievement has reenergized existing and aspiring scientists worldwide, allowed our country to begin moving past the pandemic, and demonstrated the power of public-private partnerships. Continuing to provide 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 demands that future infectious disease outbreaks will place on our society.

NIH Funding has Transformed the Microbial Sciences

Even before the COVID–19 pandemic, investments in microbial research at NIH led to great strides in protecting and improving human health as illustrated by 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% 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.

—Since 2007, the NIH has been on the forefront of supporting microbiome research with the Common Fund's Human Microbiome Project (HMP), which was formed to develop research resources to study of microbial communities and how they impact human health and disease. Microbiome research has increased over 40 times since the inception of the HMP, and the work engages over 20 NIH Institutes and Centers. This important research has had implications for our understanding of microbiome interactions in pregnancy and preterm birth, inflammatory bowel disease, and diabetes, among other topics.

Continued Progress Requires Sustained Funding and Support for Investigators

Even in the face of the promise and progress highlighted above, well known pathogens and pathogen resistance threaten our nation's health with serious economic and social ramifications. Seasonal flu continues to cost the U.S. billions annually in direct medical costs and lost productivity due to illness, and claims the lives of thousands of Americans each year. Through sustained funding to NIAID, scientists continue the quest for a universal flu vaccine. Antimicrobial resistance (AMR) is a daunting public health challenge and considered a global crisis by the World Health Organization, the G20 and the United Nations. Continued investment in research to better understand how microbes become resistant, and develop more precise clinical diagnostics, novel therapeutics and vaccines is greatly needed.

The COVID–19 pandemic has exacted a toll on the broader research enterprise, especially early career investigators and those who were unable to pivot to work on SARS–CoV–2. Pandemic-related laboratory closures disrupted ongoing research, resulted in loss of animal colonies and cell lines, and loss of laboratory positions. Experiments will need to be restarted, animal colonies repopulated and fieldwork rescheduled for an indeterminate later time. 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. Congress should consider additional "research relief" funding to NIH to assist in the recovery of our research workforce and projects negatively affected by the pandemic.

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 extraordinary emergency funding provided to the agency in FY 2021 to meet the needs presented by the pandemic. However, had Congress provided necessary support for CDC and public health infra-

structure over time, our country would have been in a better position to address the public health crisis more effectively from the start. With this in mind, we urge Congress to build on emergency investments in FY 2022, including robust funding for the Data Modernization Initiative 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. As we have seen over the course of the pandemic, states, communities, and international partners rely on CDC for accurate information, direction, and resources to ensure they continue to be prepared in a crisis or outbreak.

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. The program has played an indispensable role by leading genomic surveillance efforts and sequencing of SARS-CoV–2 samples, especially aimed at getting in front of emerging variants. We thank Congress for providing transformational funding for AMD in the American Rescue Plan Act, and with increased base funding, the AMD program can continue to promote innovation, expand workforce development, and enter into productive partnerships with academic research institutions and state/local public health agencies. ASM requests $60 million for AMD in FY 2022.

—Multiple programs support antimicrobial resistance, one of the most daunting health challenges we face today. ASM requests funding for the Antibiotic Resistance Solutions Initiative at $672 million, the National Healthcare Safety Network at $100 million, and the Division of Global Health Protection at $465.4 million, which 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. We urge you to consider additional funding for resources to this area, particularly as we consider ways to bolster lab capacity in times of public health emergency.

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 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 Murray and Ranking Member Blunt:

Thank you for the opportunity to provide testimony regarding Fiscal Year (FY) 2022 appropriations. The American Society for Nutrition (ASN) respectfully requests at least $46.1 billion dollars for the National Institutes of Health (NIH) and $200 million dollars for the Centers for Disease Control and Prevention/National Center for Health Statistics (CDC/NCHS) in Fiscal Year 2022. ASN is dedicated to bringing together the world's top researchers to advance our knowledge and application of nutrition, and has more than 8,000 members working throughout academia, clinical practice, government, and industry.

National Institutes of Health (NIH)

The NIH is the nation's premier sponsor of biomedical research and is the agency responsible for conducting and supporting the largest percentage of federally funded basic and clinical nutrition research with $3.2 billion estimated for nutrition and obesity research in 2020. Although nutrition and obesity research make up just five 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 1990 to 2019, U.S. diet-related

death rates decreased from 154 to 101 deaths per 100,000 population, although the proportion of deaths attributable to dietary risks was largely stable.[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. ASN recommends at least $46.1 billion dollars for NIH in Fiscal Year 2022 to support NIH nutrition-related research that will lead to important disease prevention and cures. A budget of $46.1 billion will allow NIH to provide support to the new NIH Common Fund's Nutrition for Precision Health, powered by the All of Us Research Program, while still providing much needed increases to other parts of the portfolio. 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 (CDC NCHS)

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 2022 funding level of $200 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 health care 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. Additional support would enable collection of more data on under-represented groups, such as pregnant and lactating women, and assessment of nutritional status indicators for nutrients on which we have no, or inadequate, information.

Thank you for the opportunity to submit testimony regarding FY 2022 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.

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[1] https://www.ahajournals.org/doi/10.1161/CIR.0000000000000950.

[This statement was submitted by Lindsay H. Allen, Ph.D., 2020–2021 President, American Society for Nutrition.]

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF HEMATOLOGY

The American Society of Hematology (ASH) represents more than 17,000 clinicians and scientists committed to the study and treatment of blood and blood-related diseases, including malignant disorders such as leukemia, lymphoma, and myeloma; conditions including thrombosis and bleeding disorders; and congenital diseases such as sickle cell disease, thalassemia, and hemophilia.

FY 2022 Request: National Institutes of Health (NIH)

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 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.

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. The Society recently updated the ASH Agenda for Hematology Research, which serves as a roadmap to prioritize research within the hematology field and includes recommendations for areas of additional federal investment that will equip researchers to make truly practice-changing discoveries in hematology and other fields of medicine for years to come.

Additionally, the extraordinary research that has occurred 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. In response to the emergence of hematologic complications from COVID–19 infection, ASH developed the COVID–19 Research Agenda in Hematology, which highlights fundamental questions that experts in hematology and blood research deem of critical importance to researchers, physicians, and patients.

ASH thanks Congress for the robust bipartisan support that has resulted in several consecutive years of welcome and much needed funding increases for NIH. For FY 2022, ASH joins nearly 400 organizations and institutions across the NIH stakeholder community to strongly support the Ad Hoc Group for Medical Research recommendation that NIH receive a program level of at least $46.1 billion. 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.

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 emergency supplemental investments for the NIH as Congress considers future legislation to promote the nation's physical, health, and economic resilience to the COVID–19 pandemic.

The pandemic's impact on biomedical research has been serious and far-reaching. Researchers in every state were forced to suspend many laboratory activities for their own personal safety and to comply with physical distancing guidelines. The closure of many research facilities impacted 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. While many institutions have been implementing plans to ramp this work back up again as safely as possible, challenges associated with the disruptions continue to linger. For example, certain types of research—such as clinical trials and other research projects with human participants—have been slower to recover. Additionally, as a result of the lags, we risk undoing progress we have made in recent years in strengthening the research workforce, including among women, underrepresented minorities, and early-career investigators and others at a pivotal point in their career trajectories.

To enable NIH to mitigate the pandemic-related disruptions without foregoing promising new science, ASH strongly supports emergency funding for federal re-

search agencies as outlined in the bipartisan Research Investment to Spark the Economy (RISE) Act (H.R. 869/S. 289), including $10 billion for NIH.

FY 2022 Request: Centers for Disease Control and Prevention (CDC)

The Society also recognizes the important role of the 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.

The Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018 (P.L. 115–327) authorized CDC, through its Sickle Cell Data Collection program, to award 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. Currently eleven states participate in the data collection program. Funding through the CDC Foundation has allowed Georgia and California to collect data since 2015; seven additional states (Alabama, Indiana, Michigan, Minnesota, North Carolina, Tennessee, and Wisconsin) were able to begin their programs in FY 2021 with the $2 million in funding provided by Congress in the FY 2021 Consolidated Appropriations Act. In early March 2021, the program expanded to Colorado and Virginia with additional funding from the CDC Foundation. These eleven states are estimated to include just over 35% of the U.S. SCD population.

ASH thanks Congress for the $2 million provided for the data collection program in FY 2021 and for the Administration's request for $2 million in funding for the program in FY 2022. The Society strongly supports providing CDC with at least $5 million in FY 2022 to continue to phase in the data collection program in the currently participating states and to allow for an expansion to additional states with the goal of covering the majority of the U.S. SCD population over the next five years.

FY 2021 Request: Health Resources and Services Administration (HRSA)

Finally, ASH supports the Administration's funding requests for the SCD programs within HRSA's Maternal and Child Health Bureau, including $7.205 million for the SCD Treatment Demonstration Program (SCDTDP) and $5 million for the SCD Newborn Screening Program, which is part of HRSA's Special Projects of Regional and National Significance (SPRANS) program. The grantees funded by these programs work to improve access to quality care for individuals living with SCD and sickle cell trait. The SCDTDP funds five geographically distributed regional SCD grants that support SCD providers to increase access to high quality, coordinated, comprehensive care for people with SCD, while the SCD Newborn Screening Program provides grants to support the comprehensive care for newborns diagnosed with SCD. ASH also supports the inclusion of language in the report accompanying the FY 2022 appropriations bill asking HRSA to provide Congress with a report detailing how the Sickle Cell Disease Treatment Demonstration Program is supporting the growth of comprehensive sickle cell disease centers.

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 FY 2022 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 $1.25 billion increase provided for Fiscal Year (FY) 2021 reinforces our nation's commitment to the health and well-being of all Americans—at a time when investing in biomedical research and scientific innovation is most needed to defeat the COVID–19 pandemic. ASHG urges the Subcommittee to appropriate $46.1 billion for NIH in FY 2022.

ASHG was delighted to see President Biden propose a major increase to NIH's budget in FY 2022. We note that President Biden proposes a significant investment

for the creation of a new Advanced Research Projects Agency for Health (ARPA–H). We look forward to learning more about ARPA–H and how research on human genetics and genomics might play a role in its mission.

SAVING LIVES: GENETICS RESEARCH IN THE FIGHT AGAINST COVID–19

Less than a year after the first case of COVID–19 was reported, the U.S. Food and Drug Administration (FDA) authorized the use of two COVID–19 vaccines.[1] This record speed in vaccine development was built on decades of research and scientific knowledge, including NIH-funded basic research and private investments that have led to rapid and inexpensive DNA sequencing technologies.[2] Our ability to quickly and inexpensively analyze the genome of the SARS—CoV–2 virus has been crucial for developing diagnostics and vaccines, testing, tracking variants, and trying to understand the range of responses to infection. NIH Director Dr. Francis Collins noted that the ability to rapidly sequence the new coronavirus "...made it possible within 24 hours for the first vaccine design to get started!"[3]

Human geneticists across the world mobilized quickly to try to understand why some individuals were asymptomatic while others suffered from severe disease, including so-called "Long COVID." Early data supports that genetic differences between individuals play a part in determining susceptibility to the disease. The COVID–19 Host Genetics Initiative and the COVID–19 Human Genetics Effort brought together researchers from dozens of countries to share resources and data to understand how human genetics affects COVID–19 susceptibility, severity, and outcomes.[4,5]

RETURN ON INVESTMENT: GENETICS RESEARCH BENEFITS THE ECONOMY

The pandemic has demonstrated that federally funded research is critical for us to return to normalcy and recover economically. In addition, investments in research and development continue to be a strong driver of economic activity overall. A new study commissioned by ASHG and conducted by TEConomy Partners highlights the growth of a dynamic ecosystem derived from human genetics research, and that the development and manufacturing of genomic technologies, diagnostics and therapeutics, and the associated healthcare services, "generate substantial U.S. economic activity and support a large volume of jobs across the nation."[6] The report estimates that the human genetics and genomics sector supports 850,000 jobs and generates $265 billion in total economic activity annually,[7] demonstrating that this sector has grown around five-fold in the last decade. Beyond the economic impact, the study also catalogues the many ways in which human genetics and genomics is being integrated into routine clinical care across a broad range of diseases.[8] Key data from the report are shown below.

GENETICS & GENOMICS: STRIVING FOR EQUITY

The COVID–19 pandemic has disproportionately affected racial and ethnic minorities in the U.S., reinforcing that there are social factors in this country that cause major health disparities.[9] It is imperative that the application of genetic science in healthcare does not worsen existing health disparities, but instead advances health to benefit all Americans. Indeed, NIH-funded research has demonstrated how genetics and genomics research can be a tool for health equity through deliberate inclusion and participation of individuals from diverse groups. As genetics research is foundational to our understanding of human biology, gleaning the full scope of genetic variation will improve both healthcare and health equity. Inclusion of populations from diverse ancestries in studies is revealing novel insights about drug responses, diagnostic accuracy, and disease risk, demonstrating the need for increased

[1] https://covid19.nih.gov/research-highlights/vaccine-development.
[2] Ibid.
[3] https://www.forbes.com/sites/billfrist/2021/01/20/nih-director-dr-francis-collins-connecting-the-dots-from-the-human-genome-project-to-the-covid-19-vaccine/?sh=36f948a27543.
[4] https://www.covid19hg.org/partners/.
[5] https://www.covidhge.com/.
[6] Tripp, S., and Grueber, M. 2021. The Economic Impact and Functional Applications of Human Genetics and Genomics. https://www.ashg.org/wp-content/uploads/2021/05/ASHG-TEConomy-Impact-Report-Final.pdf.
[7] Ibid.
[8] Ibid.
[9] https://www.cdc.gov/coronavirus/2019-ncov/community/health-equity/racial-ethnic-disparities/index.html.

diversity in research studies and clinical trials.[10] In ensuring broad cohort diversity in biomedical research, we need to consider all types of diversity, including engagement with both urban and rural communities, and taking into account social demographics such as gender, age, and economic status.

The Society commends NIH's efforts to advance diversity and equity in research, which are made possible by the strong support of this Subcommittee in providing robust funding for the NIH. The great strides made by the All of Us Research Program in having its research cohort reflect the diversity of the United States is one such example.[11] Furthermore, UNITE, NIH's new initiative to address "racial equity in the biomedical research workforce" and "long-standing health disparities and issues related to minority health inequities in the United States"[12] comes at a crucial time for our nation.

America's greatest asset is its people—all of its people. From the research workforce to research participants, increasing diversity is essential if we are to realize the full promise of genomics research and the equitable application of genetic discoveries in healthcare and society. Sustained budget increases for NIH are necessary to fund programs that emphasize diversity and equity in the workforce and that broaden participation by the public in research.

NIH FUNDING FOR THE FUTURE

The COVID–19 pandemic caused unprecedented disruptions to the biomedical research enterprise in 2021. This was especially true in the human genetics and genomics community, where researchers either closed laboratories or repurposed their genome sequencing machines for performing SARS–CoV–2 testing, tracking and tracing. Strong funding is needed in FY2022 to help the workforce recover.

ASHG joins its fellow members of the Federation of American Societies for Experimental Biology (FASEB) and the Ad Hoc Group for Medical Research in recommending a $46.1 billion base budget for NIH for FY 2022. This funding level would allow NIH's base budget to keep pace with inflation, specifically the biomedical research and development price index, and support crucial research on human genetics and genomics across all of the NIH's 27 Institutes and Centers.

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, clinicians, genetic counselors, nurses and others who have a special interest in the field of human genetics.

[This statement was submitted by Gail Jarvik, MD, PhD, President, American Society of Human Genetics.]

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, $25 million be included for KidneyX, a public-private partnership to accelerate innovation in the prevention, diagnosis, and treatment of kidney diseases, in the Fiscal Year (FY) 2022 Labor, Health and Human Services, Education and Related Agencies Appropriations bill.

More than 37 million people in the United States are living with kidney diseases, and nearly 800,000 have kidney failure, for which there is no cure. This under-recognized epidemic disproportionately affects communities of color. For instance, Black Americans comprise 13 percent of the U.S. population but represent 33 percent of Americans receiving dialysis, the most common therapy for kidney failure.

The COVID–19 pandemic is especially deadly for kidney patients. Americans with kidney diseases are among the most at risk among Medicare beneficiaries for severe outcomes from COVID–19—including hospitalization and death,i,ii,iii,iv and COVID–19 damages the kidneys of as many as 40–50% of all hospitalized COVID–19 patients, even those without a prior history of kidney diseases.v,vi

The status quo for treating and managing kidney diseases is far too costly to taxpayers to continue without intervention. Before the COVID–19 pandemic, Medicare dedicated $130 billion, or 25 percent of all traditional Medicare fee-for-service

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[10] Collins, F., Doudna, J.A., Lander, E., and Rotimi, C.N. Human Molecular Genetics and Genomics—Important Advances and Exciting Possibilities. N.Engl.J.Med 2021. 384:1–4.

[11] https://allofus.nih.gov/.

[12] https://www.nih.gov/ending-structural-racism/unite.

spending, to the care of all kidney diseases, including $50 billion, or 7 percent of Medicare fee-for-service spending, to manage kidney failure alone. Relative to other chronic diseases with comparable federal spending and disease burden, people with kidney diseases have had a lack of innovation in the prevention, diagnosis, and treatment of kidney diseases, but hope is on the horizon: KidneyX is attracting a new generation of innovators and investors and transforming kidney care.

KidneyX is incentivizing innovators to fill unmet patient needs through a series of prize competitions, de-risking the commercialization process by fostering coordination among federal agencies and creating a sense of urgency on behalf of patients and families. To date, KidneyX has provided funding to more than 50 innovators across 4 prize competitions for solutions ranging from patient-generated solutions that improve quality of life while living with kidney diseases to steps toward paradigm-shifting technologies such as a wearable or implantable artificial kidney. In 2020, KidneyX awarded the COVID–19 Kidney Care Challenge to identify solutions that will reduce the risk of COVID–19 to kidney patients and launched the Artificial Kidney Prize to accelerate the development of an artificial kidney. Winners of Phase 1 of the Artificial Kidney Prize will be announced in September 2021. FY 22 funding will support continued development of an artificial kidney through Phase 2 and 3 of the Artificial Kidney Prize and other innovations to catalyze further private investment in meeting the long unmet needs of this underserved population.

Winning innovations awarded KidneyX prizes have supported innovators in 22 states, including those highlighted below:

—Applying advances in science and technology to improve current kidney failure therapies, such as nanomaterials to reduce infections in dialysis grafts and an innovative catheter which might exponentially reduce infections in the provision of dialysis, both seeded through the Redesign Dialysis Phase 1 and Redesign Dialysis Phase 2 prize competitions

—Patient generated solutions to better manage their care, such as clothing which provides health care staff easy access to dialysis ports without having to remove or scrunch up clothing, seeded through the Patient Innovator Challenge

—Novel methods for maintaining kidney health during the pandemic such as a "Good Humoral Immunity Truck" to deliver vaccines to patients in hard-to-reach communities, and a new reusable N–95 respirator to aid in the high-touch care setting of a dialysis unit, seeded through the COVID–19 Kidney Care Challenge

—New technologies as innovative treatment options, such as an implantable silicon filter cartridge that mitigates the need for dialysis needles or a method to grow human kidney cells on animal kidney scaffolds that could increase the number of transplantable organs, both seeded through the Redesign Dialysis Phase 1 and Redesign Dialysis Phase 2 prize competitions

A bipartisan achievement, KidneyX was first unveiled as a concept at the 2016 Obama White House Organ Summit and was a central pillar of Former President Donald J. Trump's July 2019 Executive Order on Advancing American Kidney Health. KidneyX is a true public-private partnership: the private sector has already committed $25 million to KidneyX and is committed to matching federal funding to achieve a total $250 million in the first 5 years. KidneyX has received $10 million since FY 20 in enacted appropriations. Since its inception, KidneyX has demonstrated the success of its public-private prize funding model, delivering on its mission of accelerating innovation in kidney care, attracting new innovators and investors to the kidney space, and broadening the availability of novel ideas and capital to improve the lives of the 37 million Americans with kidney disease.

In light of this strong track record, we respectfully request that the Labor-HHS Subcommittee continue its commitment by appropriating $25 million in FY 2022 for KidneyX, catalyzing private sector investment in kidney health including to develop the world's first artificial kidney. 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 people in the United States are living with kidney diseases, and for nearly 800,000 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% of Medicare spending (approximately $50 billion) in CY 2018, yet therapeutics for kidney failure remain limited and 50% of patients starting dialysis, the most common therapy for kidney failure, will die within 5 years.

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 FY 2022 and that those funds be made available to support KidneyX. These funds will accelerate the development and adoption

of the artificial kidney and other novel therapies and technologies that improve the diagnosis and treatment of people with kidney diseases.

Thank you for your consideration of this important request. Should you have questions or need additional information, do not hesitate to contact Zach Kribs, Senior Government Affairs Specialist of the American Society of Nephrology, at (202) 618–6991 or zkribs@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 21,000 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.

v Birkelo, B C. et al. Comparison of COVID–19 versus influenza on the incidence, features, and recovery from acute kidney injury in hospitalized United States Veterans. Kidney Int. 2020;0(0). doi.org/10.1016/j.kint.2021.05.029

vi Chan L, et al. AKI in Hospitalized Patients with COVID–19. JASN. 2021;32(1):151–160. doi: 10.1681/ASN.2020050615

[This statement was submitted by Zachary Kribs, Senior Government Affairs Specialist, American Society of Nephrology.]

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF PLANT BIOLOGISTS

On behalf of the American Society of Plant Biologists (ASPB), we would like to thank the Subcommittee for its support for the National Institutes of Health (NIH). ASPB and its members strongly believe that sustained investments in scientific research are a critical component of economic growth, job creation, and innovation for our nation. ASPB supports continued robust funding for NIH in fiscal year (FY) 2022 and asks that the Subcommittee encourage increased support for plant-related research with relevance to health within the agency.

ASPB, founded in 1924 as the American Society of Plant Physiologists, was established to promote the growth and development of plant biology, to encourage and publish research in plant biology, and to promote the interests and professional advancement of plant scientists in general. ASPB members educate, mentor, advise, and nurture future generations of plant biologists; they work to enhance understanding of plant biology and its impacts on public health and wellbeing, as well as science in general, in K–16 schools and among the general public; they advocate in support of plant biology research; work to convey the relevance and importance of plant biology; and they provide expertise in policy decisions world-wide. Overall, ASPB members, as representatives of the society, work to disseminate information and to excite future generations about plant sciences, especially through ASPB's advocacy, outreach activities, conferences, and publications.

PLANT BIOLOGY RESEARCH AND AMERICA'S FUTURE

Among many other functions, plants are the building blocks at the base of the food chain upon which all life depends. Importantly, plant research is also helping make many fundamental contributions to the study of human health, including that of a sustainable supply and discovery of plant-derived pharmaceuticals, nutriceuticals, and alternative medicines. One example is the antimalarial compound artemisinin, purified from sweet wormwood plants, whose biosynthetic pathway was defined and transplanted into yeast to create a low-cost source of this pharmaceutical for the developing world. Plants are potential resources to produce vaccines against infectious diseases such as Ebola, hepatitis B, cholera, and coronavirus. At least one plant-derived COVID–19 vaccine candidate, developed by GlaxoSmithKline and Medicago, is already in phase III clinical trials and could be a valuable asset in ending the COVID–19 pandemic.[1] Nearly 120 pure compounds extracted from plants are used globally in medicine, hinting at the significant possibilities for future discoveries applicable to human health, agriculture, and manufacturing.[2] Plant research also contributes to the continued, sustainable, development

[1] https://www.medicago.com/en/media-room/medicago-and-gsk-start-phase-3-trial-of-adjuvanted-covid-19-vaccine-candidate/.

[2] Page 19, Decadal Vision, https://plantsummit.files.wordpress.com/2013/07/plantsciencedecadalvision10-18-13.pdf.

of better and more nutritious foods and the understanding of basic biological principles that underpin improvements in public health and human nutrition.

PLANT BIOLOGY AND THE NATIONAL INSTITUTES OF HEALTH

Plant science and many of our ASPB member research activities have enormous positive impacts on the NIH mission to pursue "fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to extend healthy life and reduce the burdens of illness and disability." In general, plant research aims to improve the overall human condition-be it food, nutrition, medicine, clean air, or agriculture-and the benefits of plant science research readily extend across disciplines. In fact, plants are often the ideal model systems to advance our "fundamental knowledge about the nature and behavior of living systems" as they provide complexity of multi-cellular organisms including humans while affording ease of genetic manipulation, a lesser regulatory burden, and maintenance requirements that are less expensive than those required for the use of animal systems.

Fundamental Biological Research.—Many fundamental biological components and mechanisms are shared by plants and animals. Examples include but are not limited to genetic principles, cell division, host-pathogen interactions, organism-environment interactions, polar growth, DNA methylation and repair, innate immunity signaling, and circadian (biological) rhythms. Fundamental hereditary laws were derived from the study of garden peas. The phenomenon of RNA interference, which has application in gene therapies for human disease, was first discovered in plants. Contributions of plant genetics to advancing human health were exemplified when Barbara McClintock, an American scientist and cytogeneticist, was awarded the Nobel Prize in Physiology for the discovery of "jumping genes" or transposable elements in maize, which function as mobile DNA sequences within a genome. Similar elements constitute ~40% or more of the human genome. More recently, plants are among organisms that have been used to develop revolutionary technologies such as gene editing (CRISPR), capable of precisely editing genomes to potentially correct mutations that lead to disease. These technologies will benefit plant biology and agriculture to produce healthy food and feed the world. Furthermore, many treatments and therapies are based on metabolites derived from plants, which exemplifies the application of plant biology research to improving human health. These important discoveries, among many others in science and technology, reflect the fact that some of the most important biological discoveries applicable to human physiology and medicine can find their origins in plant-related research endeavors.

Health and Nutrition.—Plant biology research is also central to the application of basic knowledge to "extend healthy life and reduce the burdens of illness and disability." Without good nutrition, there cannot be good health. Indeed, a World Health Organization study on childhood nutrition in developing countries concluded that over 50% of child deaths under the age of five could be attributed to malnutrition's effects on weakening the immune system and exacerbating common illnesses such as respiratory infections and diarrhea;[3] this is expected to worsen as global populations increase. One example of how advances in plant biology have been applied to tackling nutritional deficiencies is golden rice, designed to address vitamin A deficiency and reduce blindness risk in vulnerable children. Golden rice was engineered to include additional genes that switch on production of beta-carotene, and a bowl of this golden rice can provide 60% of a child's daily requirement of vitamin A to prevent blindness. Significant advances have also been made in the production of value-added and resilient crops capable of withstanding drought, natural disasters, and extreme temperature shifts. DroughtGard Hybrid corn, engineered to maximize water storage, usage, and crop yield in unfavorable drought conditions, is just one example of the progress being made towards health, nutrient, and food security through innovations made in plant science.

Obesity, cardiac disease, and cancer also take a striking toll globally. Research to improve and optimize concentrations of plant compounds known to have, for example, anti-cancer properties, will help in reducing disease incidence rates. Ongoing development of crop varieties with value-added nutraceutical content is an important contribution that plant biologists are making toward realizing a common goal of personalized, preventative medicine.

Drug Discovery.—Plants are fundamentally important as sources of both extant drugs and drug discovery leads. In fact, 60% of anti-cancer drugs in use within the last decade are of natural product origin-plants being a significant source. An excellent example is the anti-cancer drug Taxol, which was discovered as an anti-carcino-

[3] https://www.who.int/bulletin/archives/78(10)1207.pdf.

genic compound from the bark of the Pacific yew tree through collaborative work involving scientists at the NIH National Cancer Institute and plant natural product chemists. While the pharmaceutical industry has invested some efforts on natural products-based drug discovery, research support from NIH remains a crucial component of the drug development pipeline. Multidisciplinary teams of plant biologists, bioinformaticians, and synthetic biologists are being assembled to develop new tools and methods for natural products discovery and creation of new pharmaceuticals. We appreciate NIH's current investment into understanding the biosynthesis of natural products through transcriptomics and metabolomics of medicinal plants and support more funding opportunities similar to the "Genomes to Natural Products" which will enhance new plant-related medicinal research.

CONCLUSION

Plants play unique and pivotal roles in nutrient and health, agriculture, and food supply, as well as basic science discoveries directly or indirectly relevant to public health. Plant biology research integrates seamlessly and synergistically with many different disciplines and core missions at NIH. As such, ASPB asks the Subcommittee to provide continued robust funding for NIH and direct the agency to support additional plant research in order to continue to pioneer new discoveries and new methods with applicability and relevance in biomedical research. Thank you for your consideration of ASPB's testimony. For more information about ASPB, please see www.aspb.org.

[This statement was submitted by Crispin Taylor, Ph.D., Chief Executive Officer, American Society of Plant Biologists.]

PREPARED STATEMENT OF THE AMERICAN SPEECH-LANGUAGE-HEARING ASSOCIATION

Chairwoman Murray and Ranking Member Blunt: The American Speech-Language-Hearing Association (ASHA) thanks you for the opportunity to submit testimony on the fiscal year (FY) 2022 Labor-HHS-Education funding bill. My name is A. Lynn Williams, PhD, CCC–SLP, ASHA's President for 2021. As the Subcommittee begins its work on this critical legislation, I offer support for the following funding requests:

—$15.5 billion for Individuals with Disabilities Education Act (IDEA) Part B State Grants, $598 million for IDEA's Part B Section 619 Preschool Grants, and $732 million for IDEA Part C Infants and Toddlers with Disabilities within the Department of Education.

—$11,851,488 for the Centers for Disease Control and Prevention (CDC) and $19,522,758 for the Health Resources and Services Administration (HRSA) for the Early Hearing Detection and Intervention programs within the Department of Health and Human Services. In addition, ASHA urges the Subcommittee to include report language to address hearing health care disparities in medically underserved communities.

—$15.5 million increase in funding for the National Institute on Deafness and Other Communications Disorders (NIDCD) at the National Institutes of Health (NIH), while ensuring that NIDCD receives an equitable funding share from any increases to NIH funding in FY 2022.

—$122,970,000 for the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) at the Administration for Community Living (ACL) within the Department of Health and Human Services.

INDIVIDUALS WITH DISABILITIES EDUCATION ACT

ASHA thanks members of the Subcommittee for increasing funding for the Individuals with Disabilities Education Act (IDEA) last year. Children and youth (ages 3–21) receive special education services and related services under IDEA Part B, and infants and toddlers (birth-2 years old) with disabilities and their families receive early intervention services under IDEA Part C. Congress must continue to make appropriate investments in IDEA to ensure children with disabilities receive the free appropriate public education (FAPE), which they are entitled to under law. A substantial increase in funding for IDEA is a step toward fulfilling the promise that Congress made to fund 40% 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] ASHA appreciates the Administration's budget request for IDEA, which would pro-

[1] U.S. Department of Education. (n.d.). About IDEA. https://sites.ed.gov/idea/about-idea/.

vide substantial increases for IDEA Part B State Grants, Section 619 Preschool Grants, and Part C Infants and Toddlers early intervention services, and that is a significant investment toward fully funding this program.

These resources are essential to support states and local education agencies in providing FAPE to all students with disabilities. However, schools and districts continue to grapple with costs associated with the Coronavirus Disease 2019 (COVID–19) pandemic and require additional resources to address challenges associated with ensuring continued education and delivering the services and supports for children with disabilities. ASHA supports robust funding for IDEA as identified to ensure students with disabilities can continue to access the services to which they are entitled.

EARLY HEARING DETECTION AND INTERVENTION PROGRAM

The Early Hearing Detection and Intervention (EHDI) Act is one of the nation's most important public health programs, offering early hearing screening and intervention to all newborns, infants, and young children in every state and territory. 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. When the Children's Health Act of 2000 was passed-which established the state-based universal newborn hearing screening programs-only 46.5% of newborns were screened.[2] However, today approximately 98% of newborns receive an audiologic screening totaling 4 million infants and children in 2016 alone.[3] Funding for hearing screenings and early intervention services has proven to be a wise investment for the United States' economy and saves the country approximately $200 million in education costs each year.[4]

Fully funding EHDI at its authorized level is critical to ensure all newborns are screened for hearing loss and receive follow-up services. 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.[5] Underfunding EHDI 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 health care appointments and treatments have been delayed or canceled due to the COVID–19 pandemic. 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.

Children with hearing loss also face significant barriers in accessing hearing health care services. Variables including socioeconomic factors, geographic location, medical infrastructure, and access to social support contribute to delays in diagnosis and treatment of hearing loss. These disparities particularly impact members of racial and ethnic minority communities. According to a 2017 study, African American infants are 92% more likely to experience loss to follow-up than infants from other ethnic groups.[6] Rural Hispanic children whose caregivers have low English fluency encounter greater difficulty accessing these health care services.[7] According to CDC data, American Indian and Alaskan Native children enroll in early intervention services at a rate 26.4% less than their White counterparts.[8] The CDC must expand its work to improve surveillance, ensure access to timely identification of congenital and acquired hearing loss, and enhance the connection to follow-up services, particu-

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[2] 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; 2010. https://www.cdc.gov/ncbddd/hearingloss/2008-data/ehdi_1999_2008.pdf.

[3] Centers for Disease Control and Prevention (CDC). (2018). Summary of 2016 National CDC EHDI Data. https://www.cdc.gov/ncbddd/hearingloss/2016-data/01-2016-HSFS-Data-Summary-h.pdf.

[4] Gross, S.D. (2007). Education cost savings from early detection of hearing loss: New findings. Volta Voices, 14(6),38–40.

[5] 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. https://www.nidcd.nih.gov/news/2017/childhood-deafness-research.

[6] Bush, M. L., Kaufman, M. R., & McNulty, B. N. (2017). Disparities in access to pediatric hearing health care. Current opinion in otolaryngology & head and neck surgery, 25(5), 359–364. https://doi.org/10.1097/MOO.0000000000000388.

[7] Ibid.

[8] Centers for Disease Control and Prevention (CDC). (2020). Hearing Loss in Children. https://www.cdc.gov/ncbddd/hearingloss/2018-data/15-screening-demographics.html.

larly among racial and ethnic minority populations. ASHA supports fully funding EHDI at its authorized level and encourages the Subcommittee to include the following language in the report on its FY 2022 bill:

The Committee recognizes the importance of access to pediatric hearing health care. The Committee is aware of the significant racial and ethnic disparities in care facing children with hearing loss, and the effect unaddressed congenital hearing loss has on communication skills, psychosocial development, educational progress, and language development. The Committee encourages the CDC to expand their work to improve surveillance of state and territorial-based EHDI systems to ensure access to timely identification of congenital and acquired hearing loss and develop materials to enhance connection to follow up services among racial and ethnic minorities, and other medically underserved populations.

National Institute on Deafness and Other Communication Disorders, and the National Institute on Disabilities, Independent Living and Rehabilitation Research

ASHA applauds the Subcommittee's continued efforts to increase funding for health care research. ASHA strongly supports continued increases in funding for the National Institute on Deafness and Other Communications Disorders (NIDCD) at the National Institutes of Health (NIH), and the National Institute on Disabilities, Independent Living and Rehabilitation Research (NIDILRR) at the Administration for Community Living (ACL). NIDCD investments are needed to ensure groundbreaking research on communication sciences as rehabilitation continues to evolve and expand. Approximately 46 million Americans have a communication disorder.[9] These disorders impact the economy through costs related to lost productivity, special education services, rehabilitation needs, health care expenditures, and lost revenue. Increases in NIDILRR's funding would allow the Institute to support the wide range of applied research and expand into new areas of emerging science to support individuals with disabilities. ASHA urges the Subcommittee to provide necessary funding for NIDCD and NIDILRR to ensure this research continues and evolves to address the needs of individuals with communication disorders.

CONCLUSION

Thank you for the opportunity to provide this testimony for the record. ASHA appreciates the Subcommittee's past investments in these important health and education programs and urges continued support at the recommended funding levels. These investments are crucial to ensuring audiologists and speech-language pathologists can meet the hearing, balance, speech, language, swallowing, and cognition-related needs of their patients, clients, and especially students who are receiving special education services in schools.

If you or your staff have any questions, please contact ASHA's associate director of federal affairs: Erik Lazdins, elazdins@asha.org, 444 North Capitol St NE, Washington, DC 20001.

PREPARED STATEMENT OF THE AMERICAN THORACIC SOCIETY

SUMMARY OF FISCAL YEAR 2022 APPROPRIATIONS RECOMMENDATIONS

—ATS urges Congress to provide at least $46.1 billion for the National Institutes of Health (NIH) for Fiscal Year (FY) 2022, an increase of $3.2 billion over FY2021.
  —$3.94 billion for the National Heart, Lung, and Blood Institute (NHLBI) at NIH.
  —$6.52 billion for the National Institute of Allergy & Infectious Diseases at NIH.
  —$419.9 million for the National Institute on Minority Health and Health Disparities at NIH.
  —$187.9 million for the National Institute of Nursing Research at NIH.
  —$875 million for the National Institute of Environmental Health Sciences (NIEHS).
—ATS urges Congress to provide $10 billion in funding for the Centers for Disease Control and Prevention (CDC) for FY 2022. After decades of under-investment, the COVID–19 pandemic has revealed that we must strengthen our national, state and local public health systems and reinvest in the CDC.

[9] National Institute on Deafness and Other Communication Disorders (NIDCD). (2019). Mission. https://www.nidcd.nih.gov/about/mission.

—$5 million in funding for the Chronic Disease Education and Awareness Program
—$225 million in FY 2022 for the CDC's domestic Division of TB Elimination program and $21 million for the Global TB program
—$35 million in funding for the National Asthma Control Program at CDC
—ATS requests $50 million in FY2022 for CDC's Climate and Health Program
—ATS requests $262.5 million in FY2022 for the Office on Smoking and Health
—$354.8 million in funding for the National Institute of Occupational Safety and Health

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ABOUT THE AMERICAN THORACIC SOCIETY

The ATS is a multi-disciplinary society of 16,000 physicians, scientists, respiratory therapists and nurses dedicated to the prevention, detection, treatment and cure of pulmonary disease, critical illness and sleep disordered breathing. Our members treat a wide range of lung disorders and have been on the frontlines of the COVID–19 pandemic treating individuals and conducting vital scientific research to develop diagnostics, treatments, and prevention interventions for COVID, even as we continue our efforts on other pulmonary, critical illness and sleep disorders.

ATS urges Congress to provide at least $46.1 billion for NIH for FY 2022

ATS thanks Congress for providing funding for NIH's COVID–19-related research which helped develop life-saving vaccines and other important advances. But the evolving pandemic requires the continued mobilization of research resources to improve our understanding of the SARS–CoV2 virus and develop new diagnostics, therapeutics, and updated vaccines to combat new virus variants. African Americans, Native Americans and other racial and ethnic minorities continue to become infected and die from COVID–19 at high rates—we must accelerate efforts to address these disparities and develop prevention and therapeutic interventions for these and other high-risk populations. In addition, thousands of Americans who recovered from COVID–19 are now suffering chronic long-term complications. Studies into the causes, treatment, and prevention of long-term complications, such as pulmonary fibrosis, are urgently needed.

Respiratory disease in America is on the rise. Even before the COVID pandemic, lung disease was the fourth leading cause of death in the US, driven primarily by chronic obstructive lung disease (COPD). Despite the rising lung disease burden, lung disease research is underfunded. Although COPD is the fourth leading cause of death in the U.S., research funding for the disease is a small fraction of what is invested for the other leading causes of death, such as heart disease, cancer, and stroke, as outlined below. Funding for implementation of the COPD National Action Plan would address this disparity.

ATS urges Congress to provide $3.94 billion for NHLBI

Since 1948, the NHLBI has made important progress in the treatment and prevention of cardiovascular disease, respiratory diseases, and blood and sleep disorders. Even with this progress, challenges remain as these conditions continue to account for more than 1 million American deaths each year and cost our nation an estimated $479 billion in medical expenses and lost productivity.

To continue important advances in research, the NHLBI is investing in prevention programs and developing novel therapies for lung diseases such as chronic obstructive pulmonary disease (COPD), asthma, cystic and pulmonary fibrosis and driving precision medicine that is tailored to individual patient needs through data science.

ATS urges Congress to provide $875 million for NIEHS

NIEHS is the leading institute conducting research to prevent human illness and disability by understanding how the environment influences the development and progression of human diseases and illnesses such as cancer, autism, asthma and autoimmune diseases. Researchers funded by NIEHS have highly relevant expertise that will aid our response to COVID–19 and future pandemics through study of mechanisms to protect health care workers facing occupational exposure to SARS-CoV–2 and COVID–19, and how environmental exposures such as air pollution impact individual susceptibility to infection and development and severity of COVID–19 disease.

ATS urges Congress to provide $10 billion for CDC for FY 2022

In order to halt the COVID–19 pandemic and ensure our preparedness for future infectious disease outbreaks, it is critical that the CDC receives sustained annual funding increases. In FY2022, increased CDC funding is needed to ensure resources

for COVID–19 vaccine distribution, administration and public education, testing, contact tracing, disease surveillance and targeted community assistance, including to communities that have been disproportionately impacted by COVID–19 and remain at high-risk, such as minority populations. More than 70 percent of CDC's budget goes directly to state public and local health organizations and academic institutions for programs that protect public health. CDC programs in chronic disease prevention, tuberculosis control, asthma, tobacco control and occupational safety and health are essential to protecting the health of millions of Americans.

ATS urges Congress to provide $225 million for the Division of TB Elimination and $21 million for CDC's Global TB program through the Center for Global Health.

Prior to the COVID–19 pandemic, TB was the leading global infectious disease killer, killing 1.4 million annually. Every state in the U.S. reports cases of TB each year. Further, in its 2019 report on antibiotic resistance, the CDC identified drug resistant TB as a serious health threat to the nation. CDC estimates that up to 13 million Americans have latent TB infection. These cases, which can be preventively treated, are the reservoir of future active TB cases. CDC's domestic TB program has been flat funded since FY2014, leaving states ill-equipped to manage drug resistant TB and unable to do LTBI testing and preventive treatment. In addition, we urge NIH to expand research to develop new tools to address TB.

ATS urges Congress to provide $35 million in funding for the National Asthma Control Program

An estimated 25 million people in the U.S. have asthma, including 6 million children. Asthma is the most common cause of missed school days—about 14 million per year. As recently as 2016, 3,274 Americans died of asthma. About 63% of these deaths were among women.

CDC's asthma program includes the following core functions, 1) provides state grants for asthma control activities including asthma tracking and public health interventions, 2) Improves asthma education and management through coordinated school health programs, and 3) Conducts public health research to help target and inform asthma control efforts.

ATS urges Congress to provide $5 million in funding for the Chronic Disease Education and Awareness Program

In response to advocacy by ATS and disease advocates, in FY2021 Congress created CDC's new Chronic Disease Education and Awareness program to address chronic diseases such as COPD and sleep disorders. The program will fund competitive grants focused on public health initiatives to increase awareness and educate communities on how to prevent chronic diseases. Program grants can be used to support national and local implementation of the COPD National Action Plan, by raising awareness and improving access to COPD care and management and prevention. The program is funded at $1.5 million in FY2021, and additional resources are needed to support new cooperative agreements in meritorious areas. 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).

SLEEP

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 known to include increased mortality, traffic accidents, cardiovascular disease, and other comorbidities. The ATS recommends a funding level of $1 million in FY2022 to support activities related to sleep and sleep disorders at the CDC. The ATS also recommends an increase in funding for research on sleep disorders at the NHLBI's Nation Center for Sleep Disordered Research (NCSDR). Thank you for your consideration of these requests.

[This statement was submitted by Lynn Schnapp, MD, 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 Fiscal Year 2022 report language recommendations for prioritizing research on Overactive Bladder and medications commonly prescribed to treat this condition at the NIH National Insti-

tute on Aging and the National Institute of Diabetes, Digestive and Kidney Diseases. AUGS is a national medical society whose mission is to promote the highest quality of care in female pelvic medicine and reconstructive surgery through excellence in education, research, and advocacy.

Overactive Bladder is a sudden, intense urgency to urinate often followed by an involuntary loss of urine. It can cause the need to urinate frequently, and often throughout the night, because of altered bladder nerve signaling. Overactive Bladder occurs in the absence of a urinary tract infection or other pathology.

Overactive Bladder affects more than 38 million Americans, and 1 in every 3 older adults. It is more common with aging and in women. Overactive Bladder has a significant impact on quality of life and on the healthcare system. Adults with Overactive Bladder are more likely to report anxiety and depression, falls, decreased quality of life, and have 20% higher health care utilization than matched counterparts without this condition. The Centers for Disease Control and Prevention estimated in the U.S., the direct and indirect costs of Overactive Bladder would be approximately $76 billion in 2015 and projected these costs would account for $82.6 billion of U.S. healthcare costs by 2020.

Anticholinergic medications are commonly prescribed to treat Overactive Bladder. These therapies are the most studied, most frequently used, and most often covered by insurance companies as a treatment for Overactive Bladder. However, there is increasing clinical evidence suggesting an association between long-term use of anticholinergic medications and the risk of developing cognitive impairment and Alzheimer's disease and related dementias (ADRD) in some patients with Overactive Bladder. In fact, the evidence is compelling enough that the American Urogynecologic Society's "Choosing Wisely" campaign recommends the avoidance of anticholinergic medications to treat Overactive Bladder in women older than 70.

It is well documented that the prevalence of Overactive Bladder increases with age. Therefore, as the American population continues to age over the next few decades, the personal and public health burden of Overactive Bladder will become more acute. Despite compelling data suggesting the negative impact of Overactive Bladder medications on cognitive function, more robust evidence is needed to guide evidence-based treatment approaches. Thus, current Overactive Bladder medications must undergo additional study to definitively determine their impact on cognition and Alzheimer's disease and related dementias (ADRD) development and to determine if the risks substantially outweigh the benefits of these therapies.

For these reasons, the American Urogynecologic Society urges the Subcommittee to adopt the following report language in the report accompanying the Fiscal Year 2022 Labor-HHS-Education appropriations bill that directs the National Institutes of Health National Institute on Aging (NIA) and the National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK) to study the association between current medications for Overactive Bladder and Alzheimer's disease and related dementias (ADRD) in certain patient populations, in order to advance research resulting in safe and effective treatment initiatives for all patients with Overactive Bladder.

NATIONAL INSTITUTES OF HEALTH

National Institute on Aging and National Institute of Diabetes, Digestive and Kidney Diseases

Overactive Bladder.—The Committee is concerned that anticholinergic medications commonly prescribed to treat Overactive Bladder, a condition that affects one in three older Americans, have been shown in recent studies to increase the risk of developing Alzheimer's disease and related dementias (ADRD). The Committee believes that further research of anticholinergic medications as well as on alternatives to these treatments is urgently needed to establish certainty regarding the safety of these medications as a treatment option for Overactive Bladder in older adults. The Committee urges that the National Institute on Aging (NIA) and the National Institute of Diabetes, Digestive, and Kidney Diseases (NIDDK) prioritize research grants and contracts that study the long-term use of anticholinergic medications and the risk of cognitive impairment and ADRD. The Committee requests an update on this issue and on research activities to advance safe and effective alternative treatments for Overactive Bladder in the fiscal year 2023 Congressional Budget Justification.

Thank you in advance for your favorable consideration of this report language request and for your support for prioritizing research to ensure there are safe and effective treatments for the millions of Americans in this country that suffer from Overactive Bladder.

PREPARED STATEMENT OF THE ANTI-DEFAMATION LEAGUE

On behalf of the Anti-Defamation League (ADL), I write to urge Members of the Subcommittee to adopt legislative and report language that condemns proposals that would effectively curtail anti-bias programming in public schools. During 2021 sessions, a number of state legislatures have considered and adopted proposals that purport to block the teaching of material that is vaguely characterized as "divisive concepts," or as assigning blame or responsibility or creating guilt based on race, ethnicity, or sex. We are deeply concerned that these policies would drastically curb the use and further development of an essential tool in the effort to eliminate hate incidents: lessons and programs that teach young people about the history and institutionalization of hateful ideologies, awareness of biases, and importance of each person vocally opposing expressions of prejudice.

Founded in 1913 in response to an escalating climate of anti-Semitism and bigotry, ADL is a leading anti-hate organization with the mission of protecting the Jewish people and securing justice and fair treatment for all. Today, we continue to fight all forms of hate with the same vigor and passion. A global leader in exposing extremism, delivering anti-bias education, and fighting hate online, ADL's ultimate goal is a world in which no group or individual suffers from bias, discrimination, or hate. To that end, ADL is an advocate for Holocaust education. We strongly believe that learning about the Holocaust, and the unchecked anti-Semitism and racism that set the stage for and sustained it, is one of the best ways to fight prejudice and discrimination, and to help ensure that genocide and other atrocities never happen again.

ADL has actively opposed anti-″divisive concepts" bills and policies including Texas HB 3979, Arizona SB 1532, Louisiana HB 564, and New Hampshire HB 544; similar proposals that have advanced or been enacted in 2021 also include Iowa HF 802, which applies not only to K–12 schools but also to government agencies and public universities and was enacted by the legislature in early May 2021; West Virginia HB 2595, which proposes to end state funding for any agencies that promote "divisive" concepts or acts; and Oklahoma SB 803, which authorizes dismissal of teachers for instructing students in disapproved-of ideas and beliefs about, for example, the fundamentally racist and sexist nature of American society.

Although these bills vary in their details, their common features include vagueness, subjectivity, and the singling out of particular ideas for a prohibition on speech, which constitutes unconstitutional viewpoint discrimination. In fact, a federal judge has already determined that plaintiffs were likely to succeed in a First Amendment-based challenge to a similar federal prohibition adopted by a subsequently-revoked Executive Order. ADL is acutely dismayed that these proposals will have, and already have had, the effect of prompting cautious administrators to cancel or postpone critically important efforts to expand students' knowledge, experience, and sensitivity to systemic biases. The Iowa Department of Education, for example, postponed a conference on social justice and equity in education originally planned for April 2021, noting publicly that, "We are mindful of pending legislation that may impact the delivery and content of certain topics related to diversity, equity and inclusion."

Another common feature of recent legislation billed as taking aim at the spread of "divisive concepts" is language that prohibits teaching that makes an individual "feel discomfort, guilt, anguish or any other form of psychological distress because of the individual's race, ethnicity or sex." We are particularly alarmed that this measure would effectively create a "heckler's veto" of critical education in our public schools. Legitimate Holocaust curricula or educational programs must necessarily condemn the antisemitic and racist ideology of the Nazis, as well as Holocaust denial. As a leading authority on extremism, terrorism, and hate, both foreign and domestic, we also note that today's white supremacists and neo-Nazis are virulently antisemitic, racist, xenophobic, misogynistic, homophobic, and do not consider light-skinned Jews to be "white people." We foresee that under the rules set forth in these bills, any student or employee who is white and holds these odious beliefs, whether or not affiliated with an extremist group, could claim that a Holocaust education program impermissibly makes them feel discomfort, guilt, anguish, or other psychological distress because of their white race. The same could be true for someone holding these beliefs who claims that discussion of the Holocaust and historical antisemitism constitutes discrimination based on their German ethnicity or national origin. This concern is not hypothetical. Only two years ago there was a disturbing issue at a South Florida public high school involving parents who did not believe the Holocaust occurred, who succeeded in impacting the school's delivery of state-mandated Holocaust education.

At a time of rising hate crimes and anti-Semitic incidents, the need to teach young people who are still forming their beliefs and principles the universal lessons of the Holocaust, and the devastating consequences of all forms of bigotry and hate, is acute and urgent. Anti-bias education and the imparting of honest information about the historical and social reasons for persistent disparities among people of different races, ethnicities, religions, genders, sexual orientations, and abilities are essential elements to the deconstruction of stratified, discriminatory systems: we simply cannot create a more just future without examining and confronting our unjust past and its modern-day footprints. Curricula that identify the hallmarks of bigotry and bring unconscious prejudices to light not only bend the moral arc of the universe toward justice, but also teach youth valuable leadership and problem-solving skills, and ensure that classroom environments are conducive to every student's progress. Positive communities that proactively welcome and celebrate inclusion foster academic and life success.

ADL urges Members of the Subcommittee to protect students' access to essential education about discrimination, biases, and the consequences of government and institutional embrace of prejudice by adopting legislative language that withdraws and withholds federal funding for public educational agencies and institutions that implement prohibitions on the teaching of so-called "divisive concepts," to include histories and present-day indicators of endemic hate and discrimination against groups of people based on race, ethnicity, national origin, religion, gender, gender identity, sexual orientation, and disability. In addition, we urge Members to adopt report language that notes the need for and benefits of anti-bias education in schools and that condemns attempts to limit or prohibit anti-bias programming in schools and other government institutions.

Thank you for your consideration.

[This statement was submitted by Erin Hustings, Director of Govt. Relations, Civil Rights Anti-Defamation League.]

PREPARED STATEMENT OF THE ASSOCIATION FOR CAREER AND TECHNICAL EDUCATION AND ADVANCE CTE

Chairwoman Murray, Ranking Member Blunt, 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 Carl D. Perkins Career and Technical Education Act (Perkins V) Basic State Grant program, administered by U.S. Department of Education's Office of Career, Technical, and Adult Education, to $2.5 billion in the Fiscal Year (FY) 2022 Labor, Health and Human Services, Education, and Related Agencies appropriations bill. It is vital that Congress continues to build upon the recent increases to Perkins V in order to fully support the implementation of the law and the over 11 million learners it serves across the nation.[1]

In the Administration's recent budget proposal, the FY 2022 discretionary request proposes only a disappointing 1.5%, or $20 million, increase for the Perkins V Basic State Grant. This is inadequate given the growing need for skilled workers facing employers and learner demand for CTE. The additional $1 billion annually for middle and high school career pathways included in the President's budget request but through the American Jobs Plan would actually have a greater impact if this increase was authorized and appropriated through the Basic State Grant, and thus is included in our request.

CTE at the secondary and postsecondary levels is an integral part of achieving an equitable and efficient economic recovery. COVID–19 (the coronavirus) has affected the most foundational aspects of our society. With millions of Americans unemployed, or underemployed, and some industry sectors shuttered or undergoing rapid transformation, Black and Latinx workers, workers with a high school education or less and female workers have been disproportionately impacted. Now, more than ever, CTE is vital to our nation's learners, employers and economic recovery. Consider:

—The unemployment rate reached 14.8 percent in April 2020, the highest unemployment rate since data collection started in 1948. As of May 2021 unemploy-

[1] Perkins Collaborative Resource Network, State Profiles. Retrieved from https://cte.ed.gov/profiles/national-summary.

ment remained higher than it had been in February 2020, before the pandemic came to the forefront (5.8 percent compared to 3.5 percent).[2]

—The unemployment rate for teenagers aged 16–19 hit 31.9 percent in April 2020, the highest it has even been in over 70 years. The only other time the unemployment rate for this population reached over 25 percent was during the Great Recession.[3]

—As of May 2021, 7.9 million workers reported that they were not able to find a job because their original employer either closed or was not hiring because of the pandemic.[4]

—The unemployment rates are also much worse for non-White young adults—35.5 percent and 31.1 percent for Black and Latino teenagers respectively, compared to 29 percent for White teenagers.[5]

For those individuals just at the beginning of their careers, losing opportunities to gain experience and a foothold in the labor market can have major, long-term impacts. For example, the millennial generation, who entered the workforce during the height of the Great Recession, is estimated to have relatively low levels of home ownership, net worth and real income compared to previous generations.[6]

Unemployment trends during the pandemic have shown that upskilling and reskilling needs have already increased, and we can expect that will continue. CTE programs are instrumental in delivering high-quality education programs aligned with in-demand careers. It is projected that some—but not all—of the jobs lost during the pandemic will come back in one form or another. One study estimates approximately 60 percent of job loss will be temporary, while other studies predict about a quarter of job losses will be permanent. What is not in question is that the economy will look different on the other side of the recovery, with marginalized communities the most likely to be impacted, given Latinx Americans have been the most likely to have hours or shifts reduced and Black Americans have been the most likely to have been laid off during this crisis.[7]

CTE serves a critical role in supporting learners in their reskilling or upskilling as they look to either re-enter the economy or grow into new opportunities. Looking at data from the last recession, the vast majority of new and replacement jobs went to individuals with more than a high school diploma, including 3.1 million jobs that went to those with associate degree or postsecondary certificates. There is growing data that suggest that those who lost their jobs due to the coronavirus will pursue CTE-focused programs and degrees. About a third of adults report that, if they lose their jobs, they would need more education to replace them. Consider:

—A third of adults report they would potentially change careers.

—Two-thirds of adults interested in enrolling in postsecondary education and training in the next six months would do so to upskill or reskill.

—A majority of American workers say they prefer non-degree and skill-based education and training programs in today's economy.

This all aligns with outcomes from the last recession, with over 50 percent of displaced workers changing industries when they re-entered the workforce.[8]

Just as all education programs have been hit hard by the pandemic, so have CTE programs. This has been exacerbated by the lack of CTE-designated funding in stimulus bills. What sets CTE apart from other educational pathways is its focus on real-world skills and applied learning. High-quality CTE programs provide opportunities for direct engagement between industry and learners and instructors, often include work-based learning experiences, and enable learners to earn credentials of value. Yet what sets CTE apart is also what has presented unique challenges during the coronavirus era. CTE programs are facing many of the same dire needs as the entire education system, particularly those related to broadband and technology ac-

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[2] Congressional Research Service, Unemployment Rates During the COVID–19 Pandemic, June 2021. Retrieved from https://fas.org/sgp/crs/misc/R46554.pdf.

[3] U.S. Department of Labor, Bureau of Labor Statistics. Retrieved from https://www.bls.gov/opub/ted/2020/unemployment-rate-rises-to-record-high-14-point-7-percent-in-april-2020.htm.

[4] U.S. Department of Labor, Bureau of Labor Statistics, The Employment Situation—May 2021, June 2021. Retrieved from https://www.bls.gov/news.release/pdf/empsit.pdf.

[5] U.S Department of Labor, Bureau of Labor Statistics, Labor Force Statistics from the Current Population Survey. Retrieved from https://www.bls.gov/web/empsit/cpsee__e16.htm, based on quarterly averages.

[6] Federal Reserve Bank of St. Louis, The Demographics of Wealth, How Education, Race and Birth Year Shape Financial Outcomes, 2018. Retrieved from https://www.stlouisfed.org/~/media/files/pdfs/hfs/essays/hfs__essay__2__2018.pdf?la=en.

[7] https://www.stradaeducation.org/wp-content/uploads/2020/04/Public-Viewpoint-Report-Week-4.pdf.

[8] The White House, Addressing America's Reskilling Challenge, 2018. Retrieved from https://www.whitehouse.gov/wp-content/uploads/2018/07/Addressing-Americas-Reskilling-Challenge.pdf.

cess, digital curriculum, and teacher professional development. However, many needs in CTE are exacerbated by the applied and lab-based nature of many courses, the need for learners to meet certification requirements, and the benefits of work-based learning and other experiential programs. CTE programs stand ready to provide employers a talent pipeline, and prepare students for careers in high-skill, high-wage, or in-demand industry sectors and occupations, but need additional support. Jobs that require more than a high school diploma but less than a baccalaureate degree were growing before the pandemic, and will continue to do so now. Further, automation coupled with the unemployment rate requires nimble, proactive, and responsive CTE and workforce programs that provide specific technical as well as transferable skills. As jobseekers and employers have looked to recover from the economic impacts of the pandemic, additional funding will ensure that the CTE system is primed to support their needs.

Despite this, no stimulus package during the pandemic has included CTE-designated funding. Although Perkins V has been named as an authorized use of some of the funding under the Education Stabilization Fund in each package, there is no guarantee that money will be allocated to CTE programs.

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.[9] Additionally, students involved in CTE are far less likely to drop out of high school than other students, a difference estimated to save the economy $168 billion each year.[10] 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.[11]

The outcomes for adult learners are also significant: 84 percent of adults concentrating in CTE programs either continued their education or were employed within six months of completing their program.[12] In fact, 90 percent of Americans agree that apprenticeships and skills training programs prepare individuals for a good standard of living.[13]

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. Every dollar spent on secondary CTE students in Washington state leads to $26 in lifetime earnings and employee benefits,[14] while individuals who receive a certificate or degree from California Community Colleges almost double their earnings within three years.[15] In Wisconsin, taxpayers receive $12.20 in return for every dollar invested in the technical college system.[16] Oklahoma's economy reaps

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[9] 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 Secondary Education, Consolidated State Performance Report, 2010–11 through 2016–17.

[10] Kotamraju, P. Measuring the return on investment for CTE. Techniques: 28–31, 2011. Retrieved from https://files.eric.ed.gov/fulltext/EJ943149.pdf.

[11] 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.

[12] 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.

[13] New America, Varying Degrees 2018: Executive Summary. Retrieved from https://www.newamerica.org/education-policy/reports/varying-degrees-2018/executive-summary/.

[14] 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.

[15] Foundation for California Community Colleges, California Community Colleges, n.d. Retrieved from https://foundationccc.org/Portals/0/Documents/NewsRoom/FactSheets/ccc-facts-figures.pdf.

[16] Wisconsin Technical College System, The Technical College Effect, 2016. Retrieved from https://www.wistechcolleges.org/sites/default/files/POSTER8.5x11-2016update2__0.pdf.

a net benefit of $3.5 billion annually from graduates of the CareerTech System.[17] 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 $2.5 billion in Perkins CTE State Grants.

CTE programs are also preparing individuals with the skills that employers seek. A 2020 survey found that employers believe CTE is good for business, the economy, and public education, and the majority of those surveyed reported that those from a CTE program are better prepared with workplace, technical and real-world skills. Employers who recruit from CTE programs are also more likely to report industry growth. CTE programs have long provided unique opportunities for learners to engage with employers and participate in internships, apprenticeships, and other meaningful on-the-job experiences. Now more than ever, CTE serves a critical role in supporting learners in their reskilling or upskilling as they look to either re-enter the economy or grow into new opportunities.

CTE programs prepare students for careers in in-demand fields and provide an affordable pathway to both a family-sustaining career and financial independence. Health care 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.[18] Half of all STEM occupations, which offer students high-skilled, high-wage career opportunities, require less than a bachelor's degree.[19] 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.[20]

Additionally, the demand for workforce credentials is growing. The number of individuals earning certificates or associate degrees in CTE fields, such as manufacturing, health care, and STEM, rose 71 percent from 2002 to 2012.[21] Students can pursue these valuable credentials at community and technical colleges for a fraction of the cost of tuition at other institutions: $3,730, on average for the 2019–2020 academic year.[22] 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.[23] Meanwhile, 89 percent of executives agree there is a talent shortage in the U.S. manufacturing sector, 5 percent higher than 2015 results.[24] 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 recover from the current health pandemic and economic crisis. Already, healthcare jobs are projected to have the largest increase of any occupational sector.[25] Filling these and other positions created, as well

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[17] Snead, M. C., The Economic Contribution of CareerTech to the Oklahoma Economy: Cost-Benefit Analysis of Career Majors (FY11), 2013. Retrieved from https://www.okcareertech.org/about/costbenefit-analysis-of-career-majors/cost-benefit-analysis-of-career-majorsfy-11-pdf.

[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] Rothwell, J. The Hidden STEM Economy, Brookings Institution, 2013. Retrieved from https://www.brookings.edu/research/the-hidden-stem-economy/.

[20] 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.

[21] 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.

[22] 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.

[23] 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/.

[24] 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.

[25] U.S. Department of Labor, Bureau of Labor Statistics, Occupational Outlook Handbook, Healthcare Occupations. Retrieved from https://www.bls.gov/ooh/healthcare/home.htm.

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 May 2021, the ratio of unemployed workers to job openings is 1.2, meaning that for 9.8 million unemployed workers there are only 9.1 million jobs available.[26] As more jobs lost during the pandemic become permanent, CTE remains a critical component to the workforce pipeline for key industries that are needed to sustain a long-term economic recovery, such as healthcare, STEM, manufacturing, construction and transportation distribution and logistics. But, 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 to build, expand and support high-quality CTE programs. It is vital that Congress continues to build upon the recent increases to Perkins V to ensure we have the talent pipeline needed to fully recover from the jobs crisis caused by the pandemic.

And there's widespread support for CTE: 94 percent of parents approve of expanding access to CTE.[27] 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.[28] As the chart below demonstrates, between FY2004 and FY2020, 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).

Taking a longer view, before FY18, 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.[29] Congress recognized the need to begin to reverse this trend and from FY18 to FY21 provided an additional $217 million for CTE State Grants, bringing the total investment to $1.342 billion. While the past four 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 FY2022. And, Americans agree: 93 percent of voters support increasing the investment in skills training.[30]

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. CTE is both a proactive and responsive strategy for attending to the economic downturn—CTE programs prepare learners for lifelong success while also offering targeted skilled training for others. We applaud the commitment to growing our investment in Perkins V, and we urge the subcommittee to make CTE a top priority in the FY 2022 Labor, Health and Human Services, Education, and Related Agencies appropriations bill. Now is not the time to back away from our commitment to advancing high-quality CTE, but rather the time to double down and ensure CTE programs are available for every learner who seeks to better their own lives and opportunities

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's Senior Associate for Federal Policy Associate Meredith Hills (mhills@careertech.org).

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[26] 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.

[27] 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.

[28] 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.

[29] U.S. Bureau of Labor Statistics, CPI Inflation Calculator. Retrieved from https://data.bls.gov/cgi-bin/cpicalc.pl.

[30] 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.

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 National Institute of Health (NIH) and National Cancer Institute (NCI). ASCO is extremely grateful for the $1.25 billion increase for the NIH in fiscal year (FY) 2021. 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. ASCO appreciates this opportunity to provide the following recommendations for FY2022 funding to build on our nation's investment in biomedical research:

—National Institutes of Health (NIH): $46.111 billion
  —National Cancer Institute (NCI): $7.609 billion
    —Beau Biden Cancer Moonshot Initiative: $194 million
—Centers for Disease Control and Prevention's (CDC) Division of Cancer Prevention and Control (DCPC): $559 million
  —Cancer Registries Program: $70 million

THE NIH: A GOOD INVESTMENT

In FY2020, the NIH provided over $34 billion in extramural research to scientists in all 50 states and the District of Columbia.[1] NIH research funding also supported more than 536,000 jobs and generated over $91 billion in economic activity last year.[2]

The importance of federally funded biomedical research has been on display over the last year as scientists from all corners of the country worked to quickly develop effective COVID–19 vaccines. Researchers working towards a vaccine were not starting from scratch; years of federally funded research progress led to the discovery and identification of practical uses for messenger RNA, or mRNA, as used in the Pfizer and Moderna vaccines. Prior to COVID–19 cancer researchers were using mRNA to trigger the immune system to target specific cancer cells. Building on previous scientific advancements, coupled with collaboration across federal agencies, academic institutions, and the private sector, unprecedented flexibility, and reduction in regulatory red tape, the resulting vaccines came to market at a record pace. This remarkable achievement—a result of years of research and scientific discovery—is a testament to the need for continued investment.

Despite recent funding increases, the COVID–19 pandemic has resulted in stagnant research progress and low clinical trial accrual rates, stifling the progress of our biomedical research enterprise and weakening our clinical trials networks. The funding levels we are requesting for FY2022 would aid in recovery from these setbacks and allow meaningful growth above biomedical inflation for the first time in over a decade. They would also allow the extraordinary progress seen pre-pandemic to continue. Failure to sustain investment in research places health outcomes and the scientific leadership and economic growth of the country at risk.

THE NCI: THE NEED FOR A RENEWED COMMITMENT

This year marks the 50th anniversary of the passage of the National Cancer Act of 1971, which established the NCI in its current form. Over the last 30 years alone, the cancer death rate has fallen 31%. This includes a 2.4% decline from 2017 to 2018—a record for the largest one-year drop in the cancer death rate. However, even during a global pandemic, cancer remains the second most common cause of death in the United States. In 2021, almost 1.9 million new cancer cases will be diagnosed, and more than 600,000 people will die from cancer.[3]

The time is ripe for a renewed commitment for robust NCI funding. ASCO is grateful for funding provided to the Beau Biden Cancer Moonshot Initiative and its focus on modernizing clinical trials, establishing a direct patient engagement network, developing a national cancer data ecosystem, continuing advances in precision oncology, and developing effective immunotherapies for a broader array of cancers. However, funding for the Initiative peaked FY2019, and dropped to $195 million in FY2021; FY2023 will mark the last year of authorized Moonshot funding. ASCO urges Congress to bolster NCI funding in anticipation of the end of the Cancer Moonshot Initiative.

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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/2021/03/NIHs-Role-in-Sustaining-the-U.S.-Economy-FINAL-3.23.21.pdf.

[3] American Cancer Society; https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2021/cancer-facts-and-figures-2021.pdf.

The NCI is the largest funder of cancer research in the world, with most of its funding directly 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 growth of research grant applications as compared to other NIH Institutes or Centers. In fact, over the last five years R01 grant applications submitted to the NCI rose by 50%, while funding only grew by 20%. This means NCI is funding a smaller proportion of grant applications compared to previous years. Only 10% of viable applications received funding in 2020 compared to 28% in 1997. Even after accounting for Cancer Moonshot funding, NCI's budget has not kept up with scientific opportunity. ASCO supports the NCI's 15 by 25 initiative, in which the Institute aims to fund 15% of grant applications by 2025. Unfortunately, the President's FY2022 budget proposal of $6.733 billion for the NCI would not allow for an increase in funded applications for 2022. ASCO's request of $7.609 billion for FY2022 would allow NCI to fund 12% of grants submitted, a modest increase, but a step closer to their own goal.[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 from treatments 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 aged 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. TAPUR evaluates use of these molecularly targeted anti-cancer drugs and collects data on clinical outcomes. As of May 2021, there are over 2,130 participants enrolled in the TAPUR Study at 128 sites in 24 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 at 46 NCORP sites, which have assembled more than 1,000 affiliates across the country to conduct research. The NCORP network now covers 44 states and the District of Columbia.[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 research.

CANCER REGISTRIES & CLINICAL TRIALS: HARNESSING DATA & REDUCING DISPARITIES

We have seen tremendous progress in cancer research. Even so, with more targeted and patient-specific therapies in development, certain populations are still missing out on potentially life-threatening treatment options. ASCO was encouraged to see the CLINICAL TREATMENT Act become law at the end of 2020. This legislation will require Medicaid to cover routine care costs for clinical trials for patients with life-threatening conditions. A step forward, but barriers remain; diversity and generalizability of 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.

As a compliment to inclusive trials, cancer providers and researchers also need accessible data to understand cancer at a broader level. This data can prove especially crucial for rare and pediatric cancers, where trials are limited due to smaller patient populations. To that end, ASCO joins the cancer community in requesting $559 million for the CDC's 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 cancer surveillance, identifying trends amongst different patient cohorts, illustrating the impact of early detection, and showing the impact of treatment advances on cancer outcomes. Registries allow pro-

[4] National Cancer Institute; https://www.cancer.gov/research/annual-plan/2022-annual-plan-budget-proposal-aag.pdf.

[5] National Cancer Institute; https://ncorp.cancer.gov/news/2019-08-19.html.

viders to collect data in real time and improve cancer research, public health interventions and treatment protocols. While we work towards greater trial inclusion, registries help ensure we have data from underrepresented patient cohorts such as racial and ethnic minorities, women, children, and rural populations.

WORKING TOWARDS CURES: A NEW APPROACH

Modern cancer research delivers new treatments to patients faster than ever, thanks to continuing innovation in research and regulatory infrastructure. The continued investment Congress has made in cancer research helps make progress possible. ASCO is committed to partnering with Congress and the Administration to spur innovation and expediently get treatments to patients.

As Congress and the Administration evaluate ways to improve our national biomedical research enterprise through such efforts as the proposed Advanced Research Projects Agency-Health (ARPA–H), we urge lawmakers to leverage collaboration between the private market, biotech, health care companies, academic institutions, and government and regulatory agencies. Fostering public-private partnerships and standardization to accelerate discovery to clinically impactful products that help patients is vital. Additionally, any efforts to establish a new agency or reform the biomedical research enterprise and health innovation, should ensure sustained and dedicated funding to achieve impactful translational research with demonstration of patient benefit. It should not impact the current or future resources of existing research enterprises.

Any new agency should be transparent about its selection criteria and decision-making process for its broad strategic goals and selection of individual research projects, including clear metrics to ensure the funds are being used to advance public health meeting established deliverables. Furthermore, innovation should come from peer-reviewed science that provides evidence-based decision making for care, and the findings should be published in peer-reviewed publications. Finally, as previously discussed, all patients should have access to the clinical trials and the resulting treatments conducted with investment by the agency; insurance coverage and cost should not be a barrier to clinical trial participation and equitable care; and should implement strategies to encourage decentralization of trials and ensure diversity and equity in research.

MITIGATING THE EFFECTS OF COVID–19 AND CONTINUING THE WORK TOWARDS CURES

As with nearly every sector of society, individuals in the research community have faced loss of employment, lab closures, and loss of momentum in pre-pandemic research. Younger investigators and support staff have been especially vulnerable during the last year. Our clinical trials network has also been impacted; one study showed that clinical trial enrollment in May 2020 was 73% lower than accrual in May 2019.[6] Another study found the COVID–19 pandemic was associated with a 60% decrease in the number of launches of oncology clinical trials of drugs and biologic therapies.[7] In May 2021, NCI Director Ned Sharpless, M.D. speculated that clinical trial accrual was still just 50% of what it had been pre-pandemic.

To regain the momentum 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 FY2022.

ASCO again thanks the subcommittee for its continued support of cancer patients in the U.S. through funding for the NIH, NCI, and CDC. We look forward to working with all members of the subcommittee on an FY2022 budget that continues to advance U.S. cancer research. Please contact Kristin Stuart at Kristin.Stuart@asco.org with any questions.

[This statement was submitted by Howard Burris, MD, FASCO, Chair of the Board, Association for Clinical Oncology.]

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[6] U.S. National Institutes of Health's National Library of Medicine; https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7538012/#ref[5].

[7] The Journal of the American Medical Association https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2775637.

PREPARED STATEMENT OF THE ASSOCIATION FOR PSYCHOLOGICAL SCIENCE

APS RECOMMENDATIONS FOR FISCAL YEAR 2021 APPROPRIATIONS

—APS strongly supports the Administration's request for $51 billion for NIH in FY 2022. We are eager to see the details of the President's request. We appreciate the Administration's commitment to meaningful growth in the base budget and expanding NIH's capacity to support promising research in all scientific fields that contribute to improved health.
—APS is pleased that an NIH working group has been established to review how to integrate and realize the benefits of overall health from behavioral research at NIH, but we request Congress include report language urging that this review also address the necessary funding, authority, and organizational changes needed for the Office of Behavioral and Social Sciences Research (OBSSR) to better meet its mission. OBSSR has the mission to enhance NIH's behavioral science research enterprise across all institutes and centers. Its direct authorities to achieve its mission, however, are limited. OBSSR does not report directly to the NIH Director and has no grantmaking authority. Importantly, with a small budget of less than 1/1000 of NIH's overall budget, it has limited capacity to leverage institutes' research priorities. APS urges that these limitations be addressed in the NIH review.
—Finally, APS asks 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.

STATEMENT OF APS EXECUTIVE DIRECTOR

Chairwoman Murray, Ranking Member Blunt, and Members of the Subcommittee, thank you for the opportunity to provide testimony as you consider funding priorities for Fiscal Year (FY) 2022. I am Robert Gropp, Executive Director of the Association for Psychological Science (APS). APS is a nonprofit scientific organization dedicated to advancing the science of psychology for the benefit of science and society. APS recognizes and appreciates the Subcommittee's efforts to strengthen public health research in the United States.

FUNDING FOR THE NATIONAL INSTITUTES OF HEALTH AND POLICY ISSUES

As previously noted, APS recommends an FY 2022 funding level of $51 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. In addition to funding priorities, APS is concerned about several policy issues at HHS.

1. Inclusion of Psychologists in the Pandemic Response: Nearly 600,000 Americans have died from COVID–19. This is a tragedy that is based in human behavior, both in the human response necessary to stop the spread of the disease as well as the disproportionate impact of the disease on health disparity and racial and ethnic minority populations. Research from psychological science must be one of the inputs informing an effective public health emergency response. Psychology research teaches us how to encourage individuals to practice safe behaviors and receive vaccines, for example. But psychological scientists investigate fundamental science questions, too. For instance, improved scientific understanding of risk assessment, social motivations, and interpersonal relationships can powerfully influence the spread of infectious diseases. Psychological science helps us address consequences of social distancing such as loneliness and emerging threats to mental health. Researchers in our field have proven essential to improving our understanding and addressing COVID–19's impact. APS urges that the following report language be included in the FY 2022 Labor-HHS Report:

Behavioral Science and the COVID–19 National Strategy.—The Committee applauds the Administration's robust National Strategy for the COVID–19 Response and Pandemic Preparedness and appreciates that the strategy reflects the best advice of scientists and public health experts. However, even with effective and safe vaccinations, we must continue and expand mask-wearing, testing, and social distancing; all citizens, organizations, and communities must rally together in that common purpose. As our success in these areas depends on our

scientific understanding of human behavior, the Committee urges that the Department include psychological scientists at every level of the Department's response to COVID–19 and future public health emergencies to best and most effectively meet these common goals.

2. 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." APS is concerned by the continued low level of funding support for behavioral science research and training at NIH despite the central importance of this research to all dimensions of human health. APS is pleased that the NIH Council of Councils created a new Behavioral Sciences Working Group on Integration and Realization of the Benefits to Health from Behavioral Research at NIH to complete an assessment providing recommendations on how NIH-funded behavioral research can be better integrated with the NIH research programs to improve health. There is concern, however, that this working group may not look beyond current structures and practices. We request that the following report language be included in the FY 2022 Labor-HHS Report to direct NIH to ensure that appropriate OBSSR funding levels, authority, and organizational structure be included in this review.

Enhancements for the Office of Behavioral and Social Sciences Research.—The Committee notes that the Office of Behavioral and Social Sciences Research (OBSSR) has the mission to enhance NIH's behavioral science research enterprise across all institutes and centers. As multiple Surgeons General and the National Academy of Medicine have declared that most health problems facing the nation have significant behavioral components, the Committee strongly supports the continued strengthening of the behavioral science enterprise at NIH and urges OBSSR funding and authorities be increased to accomplish this mission. In this regard, the Committee is pleased that an NIH working group has been established to review how better to integrate and realize the benefits of overall health from behavioral research at NIH, and directs that appropriate OBSSR funding levels, authority, and organizational structure be included in this review.

UPDATING HRSA AND NATIONAL HEALTH SERVICE REGULATIONS

APS requests the Committee 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. The strong emphasis on science in PCSAS accreditation offers promise of improved prevention and treatment interventions that will strengthen HRSA and the National Health Service Corps.

PCSAS was recognized by the Council for Higher Education Accreditation (CHEA) in 2012 and now accredits 45 of the Nation's doctoral clinical science programs. CHEA is the largest higher education membership organization in the United States. It is a national body formed by 3,000 universities which reviews and screens applications from organizations to serve as accrediting bodies for the professions. CHEA is widely recognized as a primary national voice for accreditation and quality assurance. After a thorough review, CHEA approved the Psychological Clinical Science Accreditation System (PCSAS) in September 2012 to accredit schools of clinical psychology.

Prior to 2012, the American Psychological Association (APA) was the only accrediting body for clinical psychology programs. Many agency regulations are outdated and refer to the need for applicants for employment to have graduated from APA accredited programs. This historical artifact needs to be updated for HRSA and the National Health Service Corps. Doing so will help to ensure the federal government is able to recruit and hire top quality psychologists, regardless of whether they are from an APA or PCSAS accredited graduate program.

1. Updating Two HRSA Health Professions Programs Regulations is Necessary: HRSA's two psychology education training programs, called the Behavioral Health Workforce Education and Training Program (BHWET) and the Graduate Psychology Education Program (GPE), support programs that produce graduates who work in clinical psychology practice upon completion of their program. The authorizing statute in the Public Health Service Act at 756(a)(2) specifically says the Secretary may make grants for the "...training of psychology graduate students for providing behavioral and mental health services..."; however, the authorizing legislation limits eligibility to the graduates of APA-accredited programs. This excludes the graduates of PCSAS-accredited programs. FY 2021 report language is requested to open program eligibility to the graduates of PCSAS accredited programs. The language follows:

Health Workforce Eligibility Requirements.—The Committee is concerned that HRSA has not complied with the language in the Joint Explanatory Statement for Public Law 216–260 which urged HRSA to update eligibility requirements for the BHWET program and the GPE program to account for accreditation changes that have occurred since the eligibility requirements were established. The Committee notes the Council for Higher Education Accreditation, as well as the Department of Veterans Affairs, recognizes the Psychological Clinical Science Accreditation System [PCSAS]. HRSA is directed to make the necessary administrative updates to ensure that HRSA's health workforce programs continue to have access to the best qualified applicants, including those who graduate from PCSAS programs.

2. Updating National Health Service Corps Regulations is Necessary: The regulations of the National Health Service Corps also need to be updated. While this change has been agreed to, it remains pending for final approval. The language needed to urge this change follows:

Public Health Service Corps Eligibility Requirements.—The Committee is concerned that the Office of the Surgeon General has not complied with the language in the Joint Explanatory Statement for Public Law 216–260 which encouraged the Secretary to update accreditation and eligibility requirements for the Public Health Service Corps to allow access to the best qualified applicants, including those who graduate from Psychological Clinical Science Accreditation System programs. The Committee directs the Department to make these necessary the necessary changes to its eligibility requirements.

SUMMARY AND CONCLUSION

We thank the Subcommittee for its ongoing commitment to supporting scientific research that improves the human condition in the United States and around the world. 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 Robert Gropp, 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 eye and vision research community, thanks Congress, especially the House and Senate LHHS Appropriations Subcommittees, for the strong bipartisan support for the National Institutes of Health (NIH) funding increases from Fiscal Year (FY) 2016 through FY2021.

This past investment in NIH has improved our understanding of fundamental life and health sciences and prepared the nation to combat unprecedented health threats, including COVID–19. To maintain this momentum in FY2022, ARVO strongly supports $51.95 billion in NIH funding as proposed by President Biden, including no less than $46.1 billion for NIH's base program level budget (absent proposed funding for the Advanced Research Projects Agency—Health [ARPA–H]), an increase of at least $3.177 billion or 7.4%, which would allow NIH's base budget to keep pace with the Biomedical Research and Development Price Index (BRDPI) and allow for 5% growth. This increase will support promising science across all Institutes and Centers (ICs), ensure continued Innovation Account funding established through the 21st Century Cures Act for special initiatives, and support early-stage investigators.

Along with our partners and other scientific societies, ARVO also urges one-time emergency funding for federal agency "research recovery" investment to enable NIH to mitigate pandemic-related disruptions without foregoing promising new science. ARVO supports the bipartisan Research Investment to Spark the Economy (RISE) Act (H.R. 869/S. 289) which includes $10 billion for NIH.

ARVO also urges Congress to fund the NEI at $900 million, a $64.3 million or 7.7% increase over FY2021 that reflects both biomedical inflation and growth, compared to the Administration's suggested $858.4 million funding level-a $22.83 million or 2.7% increase. Despite NEI's total $160 million funding increases in the

FY2016–2021 timeframe, its enacted FY2021 budget of $835.7 million is just 19% greater than the pre-sequester FY2012 funding of $702 million. Averaged over those nine fiscal years, the 2.1% annual growth rate is still less than the average annual biomedical inflation rate of 2.7%, thereby eroding purchasing power. In fact, NEI's FY2021 purchasing power is less than that of FY2012.

The NEI currently faces an increasing burden of vision impairment and eye disease due to an aging population, the disproportionate risk/incidence of eye disease in minority populations, and the impact on vision from numerous chronic diseases, such as diabetes. NEI also faces additional challenges with the COVID–19 pandemic, as both the working-age population and students have relied almost exclusively on electronic devices and e-learning platforms, which research has shown correlates to increased rates of myopia, dry eye and eye strain.

Maintaining the momentum of eye and vision research is vital to vision health and to overall health and quality of life and would secure the U.S. as the world leader in eye and vision research and training the next generation of eye and vision scientists.

NEI-FUNDED RESEARCH SAVES SIGHT AND RESTORES VISION

Historical federal investment has led to landmark advances in the prevention of vision loss as well as the restoration of vision, including:

—*Audacious Goals Initiative:* The NEI has been at the forefront of regenerative medicine with its Audacious Goals Initiative (AGI), launched in 2013 with the goal of restoring vision. AGI-funded consortia have developed innovative ways to image the visual system such that researchers can now look at individual nerve cells in the eyes of patients to learn directly whether new treatments are successful. Another consortium has identified biological factors that allow neurons to regenerate in the retina, and current AGI proposals may result in clinical trials for therapies within the next decade.

—*Retinal Diseases:* The NEI has been at the forefront of research into retinal diseases. NEI-funded researchers helped to show that the Vascular Endothelial Growth Factor (VEGF) protein stimulates abnormal blood vessel growth that occurs in the advanced stages of the "wet" form of age-related macular degeneration (AMD) and diabetic retinopathy. Food and Drug Administration (FDA)-approved anti-VEGF drug therapies that slow the development of blood vessels in the eye delay vision loss and may improve vision for patients. NEI has funded comparison trials of anti-VEGF drugs to provide clinicians and patients with information they need to choose the best treatment options. With respect to the "dry" form of AMD, also known as geographic atrophy and is the leading cause of vision loss among individuals age 65+, since 2019 NEI has been performing a first-in-human clinical trial that tests a stem cell-based therapy from induced pluripotent stem cells (iPSC) to treat geographic atrophy. 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.

—*Genetics/Genomics:* The NEI has been at the forefront of genetics/genomics and gene therapy approaches to various eye and vision disorders-both common and rare. The causes of AMD and glaucoma remain elusive, although most cases are not inherited, genetics does play a role. While NEI-funded researchers have identified many genetic risk factors for AMD and glaucoma, further study of these genes is helping to understand disease biology and the promise for improved therapies. NEI-funded research has also made discoveries of dozens of rare eye disease genes possible, including the discovery of RPE65, which causes congenital blindness known as Leber congenital amaurosis (LCA). As of late 2017, NEI's initial efforts led to a commercialized FDA-approved gene therapy for this condition. These gene-based discoveries form the basis of new therapies that treat and may prevent the disease.

—*Front-of-Eye Research:* The NEI has launched an Anterior Segment Initiative (ASI) studying clinically significant, front-of-eye problems such as ocular pain and Dry Eye Disease (DED), especially in terms of pain and discomfort sensations and disruptions in the tearing process. Using multi-disciplinary approaches, the ASI plans to elucidate relevant anterior segment innervation pathways that contribute to normal or abnormal functioning of the neural circuits related to the ocular surface.

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]

NEI RESEARCH ADDRESSES INCREASING BURDEN OF EYE DISEASE

NEI's FY2021 enacted budget of $835.7 million is less than 0.5% of the $177 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 vison impairment by year 2050, 41% will be borne by the federal government as the "Baby Boomer" 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 $2.53 per person, per year for eye and vision research, while the cost of treating low vision and blindness is at least $6,680 per person, per year. [http://costofvision.preventblindness.org/]

Investing in vison health is an investment in overall health. In summary, ARVO requests FY2022 NIH funding of at least $51.95 billion, but urges the Subcommittee to appropriate no less that $46.1 billion for the NIH's base program level. Further, we request NEI funding of $900 million. ARVO also supports one-time emergency "research recovery" investment to mitigate the pandemic-related disruptions without foregoing promising new science.

The Association for Research in Vision and Ophthalmology (ARVO) is the largest eye and vision research organization in the world. Members include approximately 10,000 eye and vision researchers from over 75 countries.

PREPARED STATEMENT OF THE ASSOCIATION OF AMERICAN CANCER INSTITUTES

The Association of American Cancer Institutes (AACI), representing 102 premier academic and freestanding cancer centers across the United States and Canada, appreciates the opportunity to submit this statement for consideration by the subcommittee. AACI submits this request for the Department of Health and Human Services budget for the National Institutes of Health (NIH) as the subcommittee considers Fiscal Year (FY) 2022 funding. AACI requests a $3.177 billion increase for the NIH for FY 2022, bringing the recommended funding level for the NIH to $46.111 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 also requests at least $7.609 billion in FY 2022 for the National Cancer Institute (NCI).

Additionally, we look forward to seeing what comes of the $6.5 billion proposal for an Advanced Research Projects Agency-Health (ARPA–H) that was laid out in President Biden's Fiscal Year 2022 (FY22) budget. We appreciate the proposal outlining cancer as a primary initial focus of ARPA–H. We are pleased with any expenditures that include more funding for cancer research; however, our hope is that the APRA–H proposal will not be diverting any funding from base funding for the NIH or the NCI. As Congress moves into the Fiscal Year 2022 (FY22) budget process and consideration of an infrastructure package, we wanted to share our priorities related to the budget.

AACI CANCER CENTERS

AACI cancer centers are beacons of discovery, largely funded by the NIH and 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 re-

search is complex and time-intensive. The pace of discovery and translation of novel basic research to new therapies can be accelerated if researchers are able to count on an appropriate and predictable investment in federal cancer funding.

COVID–19 CHALLENGES

The COVID–19 pandemic has taken a significant toll on medical research, making increased funding more critical than ever. Clinical trials were brought to a halt and trial sites experienced challenges with safely facilitating care for enrolled patients and freezing the process of enrolling new patients.

As noted in last year's testimony, American Cancer Society data show that 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 2016—progress tied to the commitment of Congress to fund the NIH and NCI.[1] Dr. Norman E. Sharpless, NCI director, has stated that the COVID–19 pandemic will influence cancer mortality for at least the next decade, with an estimated 10,000 additional breast and colorectal cancer deaths during this time.[2] Further, the NCI reports that an increase in overall cancer mortality rates for the first time in almost 30 years is likely due to the impact of COVID–19. But the pandemic has taught us important lessons about the benefits of scientific progress to public health.

The future of cancer research relies on robust funding to the NIH and NCI. The broad portfolio of science supported by these agencies is essential for improving our basic understanding of cancer and has contributed to the health and well-being of Americans. We cannot let the challenges of the last year slow this meaningful progress.

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.

We noted last year that in FY 2020, R01 grants for established and new investigators are being funded to the 10th percentile, up from the 8th percentile in FY 2019. In FY 2021, the grants were funded to the 11th percentile.[3] We request that Congress build on progress with a FY 2022 funding increase to meet the goal of raising the NCI payline to the 15th percentile by FY 2025. AACI supports the NCI Director's Professional Judgment Budget Proposal for FY 2022 of $7.609 billion for the NCI, which will increase funding to the 12th percentile.[4]

CONCLUSION

Now is the time for Congress to invest in biomedical research—and cancer research in particular. According to the American Cancer Society, there will be an estimated 1.9 million new cancer cases diagnosed in the United States in 2021.[5] 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. We join our colleagues in the biomedical research community in recommending that the subcommittee recognize the NIH as a national priority by enacting a final FY 2022 spending package that includes $46.111 billion for the NIH and $7.609 billion for the NCI.

A robust federal investment in NCI-Designated Cancer Centers and academic cancer centers will allow the cancer research community to accelerate progress against cancer, despite challenges such as the COVID–19 pandemic.

[This statement was submitted by Jennifer W. Pegher, Executive Director, Association of American Cancer Institutes.]

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[1] https://www.cancer.org/latest-news/facts-and-figures-2020.html.
[2] https://cancerletter.com/nci-director-report/20200619__1/.
[3] https://www.cancer.gov/grants-training/nci-bottom-line-blog/2021/funding-from-congress-allows-nci-to-raise-grants-payline.
[4] https://www.cancer.gov/research/annual-plan/budget-proposal.
[5] https://www.cancer.org/research/cancer-facts-statistics/all-cancer-facts-figures/cancer-facts-figures-2021.html.

PREPARED STATEMENT OF THE ASSOCIATION OF AMERICAN EDUCATORS FELLOWS

My name is Jessica Saum and I am a special education teacher at Stagecoach Elementary School in Cabot, Arkansas. I am the current Stagecoach Elementary School and Cabot Public School Distict's Teacher of the year. I teach a self-contained classroom of students grades kindergarten through fourth grade where my students spend less than 40% of the school day out of my classroom with their typically developing peers. This time includes lunch, recess, activity classes, and for certain students instructional times such as phonics, social studies, and science.

Students with diverse needs, especially those in early childhood special education, need more time in the general education classroom learning prosocial behaviors and having more exposure to grade level curriculum. In order to provide this, schools need additional funding to ensure staffing of trained paraprofessional support for students with moderate to severe learning disabilities as well as to fund inclusion co-taught classroom supporting those with specific learning disabilities and deficits in specific content areas.

When learning happens in an inclusive classroom, general education teachers and special education teachers work together and are able to meet the needs of all students. Carl A. Cohn, EdD, the executive director of the California Collaborative for Educational Excellence, said, "It's important ... to realize that special education students are first and foremost general education students." This is often not how students with special needs are treated.

Inclusive classes look different in how they are arranged and how they operate. Some use co-teaching with a collaborative team model having is a special education teacher in the room all day. In other inclusive classrooms, there is a special education teacher that "pushes in" to the class during specific times during the day to teach. This allows students to minimize transitions that can be very overwhelming, and is used in place of pulling kids out of class to a separate room. In both of these situations, teachers are available to teach and help all students.

This type of learning is beneficial for all students, not just for those who are receiving special education services, having both positive short-term and long-term effects. Studies have shown that students with special education needs who are in inclusive classes are absent less often and develop stronger skills in reading and math. Additionally they also more likely to have jobs and pursue education after high school. The same research shows that their peers benefit, too. The typically developing students are more comfortable with and more tolerant of differences. I have seen this in my own children as they have formed meaningful relationships with students I teach and are advocates even at a young age and friends to exceptional learners.

Most students than ever with special needs are expected to take the same high stakes assessments as students without special needs. Eleven of the thirteen students in my special class setting took the same district and state assessments as their grade level peers in the 2020–2021 school year. They deserve the opportunity to learn alongside typical peers, having access to the same curriculum, with the support from special educators to navigate appropriate prosocial behaviors and receive modifications and accommodations to ensure success.

What we must directly address is how we can spend this much-needed federal money. It is important to determine whom it goes to when investing more into this often overlooked population, where the needed training comes from, and for whom is it used for. General education teachers need additional training provided at the state level through professional development at their district or coop, specifically on High Leverage Practices for Inclusion to support this data proven practice being implement in their classrooms. There needs to be increased funding, specifically designated for districts to hire additional paraprofessionals and special education teachers to work with students in the general education classroom, ensuring students are being educated in their least restrictive environment as required through the Individuals with Disabilities Act (IDEA). Furthermore, there needs to be an increased emphasis nationally at the collegiate level in teacher preparation programs on educating diverse learners in the general education setting. Teachers are not adequately prepared to meet the needs of exceptional learners when they enter the teaching profession and the lack of training to ensure this has led to many students being educated in settings more restrictive than necessary.

Teachers can and will do more when supported appropriately and when they are properly trained. I have witnessed this first hand as a special education teacher. When my students have general education teachers trained to support them and confident in their abilities to meet their unique needs, they have more growth academically, are more socially competent, and lead happier and more successful lives at home and in their communities. It is critical to note that lasting effects of inclu-

sive practices in schools extend far beyond the school setting making children a part of their community, helping them develop a sense of belonging and becoming better prepared for life.

Providing children with the resources to attend schools which are committed to and prepared for inclusive practices, demonstrates the shared commitment to having all children feel appreciated and accepted throughout life. All children deserve to attend age appropriate regular classrooms to the maximum extent possible receiving curriculum relevant to their needs that will provide for their educational success. All children benefit from cooperation, collaboration among home, among school, among community.

Thank you for your time and consideration.

[This statement was submitted by Jessica Saum, Special Education Teacher, Association of American Educators Advocacy Fellow.]

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 health through medical education, health care, medical research, and community collaborations. Its members are all 155 accredited U.S. and 17 accredited Canadian medical schools; more than 400 teaching hospitals and health systems, including Department of Veterans Affairs medical centers; and more than 70 academic societies. Through these institutions and organizations, the AAMC?leads and serves America's medical schools and teaching hospitals and their more than 179,000 full-time faculty members, 92,000 medical students, 140,000 resident physicians, and 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, with a strong commitment to community collaborations, is essential to ensure a resilient health care infrastructure prepared to respond to both novel and existing threats. For FY 2022, the AAMC recommends the following for federal priorities essential in assisting medical schools and teaching hospitals to fulfill their missions that benefit patients, communities and the nation: at least $46.1 billion for the National Institutes of Health (NIH); $500 million for the Agency for Healthcare Research and Quality (AHRQ); $1.51 billion for the Health Resources and Services Administration (HRSA) Title VII health professions and Title VIII nursing workforce development programs, and $485 million for the Children's Hospitals Graduate Medical Education (CHGME) program; and at least $10 billion for the Centers for Disease Control and Prevention (CDC). The AAMC appreciates the Subcommittee's longstanding, bipartisan efforts to strengthen these programs. Additionally, to enable the necessary support for the broad range of critical federal priorities, the AAMC urges Congress 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, highlighted by the central role medical research has played in combatting COVID–19. As illustrated over the last year, 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 together to improve the lives of Americans through research. This partnership is a unique and highly productive relationship 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 $42.9 billion for medical research conducted and supported by the NIH in the FY 2021 omnibus spending bill. Additionally, the AAMC thanks the Subcommittee for recognizing the importance of retaining the salary cap at Executive Level II of the federal pay scale in FY 2021, and for the emergency resources that have advanced COVID–19 research.

In FY 2022, the AAMC joins nearly 400 partners in supporting the Ad Hoc Group for Medical Research recommendation that Congress provide at least $46.1 billion in program level funding for the NIH, including funds provided through the 21st Century Cures Act for targeted initiatives. This funding level for the foundational work at the core of NIH's mission would continue the momentum of recent years by enabling meaningful growth of 5% in the NIH's base budget over biomedical in-

flation to help ensure stability in the nation's research capacity long term. Securing a reliable, robust budget trajectory is key in positioning the agency—and the patients who rely on the research it funds—to capitalize on the full range of research in the biomedical, behavioral, social, and population-based sciences. We must continue to strengthen our nation's research capacity, solidify our global leadership in medical research, ensure a 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.

In addition to our strong support for a robust increase in NIH's base funding, we look forward to working with lawmakers and the administration to fulfill the goals of the proposed Advanced Research Projects Agency for Health (ARPA–H) within NIH as part of the administration's $52 billion request for the NIH to "drive transformational health research innovation and speed medical breakthroughs by tackling ambitious challenges requiring large-scale, sustained, and cross-sector coordination." The nation's medical schools and teaching hospitals are hubs of innovation in research and care delivery, and the AAMC looks forward to engaging with lawmakers and the administration on opportunities to advance a bold and productive medical research agenda in harnessing our shared commitment to innovation and scientific discovery.

We also wish to highlight the challenges that the pandemic has imposed on the medical research workforce and the broader research enterprise. We continue to be concerned that, without supplemental resources, the disruptions imposed by COVID–19 will undermine NIH's ability to support previous investments in the existing research workforce and new investments in life-saving research. In his recent testimony before the subcommittee, NIH Director Francis Collins, MD, PhD, cited the $16 billion impact of the coronavirus pandemic on medical research progress in all disease areas, and especially on the research workforce. We urge support for emergency funding for NIH as outlined in the bipartisan Research Investment to Spark the Economy (RISE) Act (H.R. 869/S.289).

Agency for Healthcare Research and Quality. Complementing the medical research supported by NIH, AHRQ sponsors health services research designed to improve the quality of health care, decrease health care costs, and provide access to essential health care services by translating research into measurable improvements in the health care system. The AAMC joins the Friends of AHRQ in recommending $500 million in funding for AHRQ in FY 2022.

Health Professions Funding. The Health Resources and Services Administration (HRSA) Title VII and Title VIII programs have helped the country combat COVID–19, despite the challenges the pandemic posed for grantees. Many grantees adapted their curricula to educate our health workforce during this public health challenge. They also dealt with the unexpected costs of providing personal protective equipment for in-person clinical training and switching from in-person to virtual learning. The pandemic has underscored the need to increase and continuously reshape our health workforce. The programs have proven successful in recruiting, training, and supporting public health practitioners, nurses, geriatricians, mental health providers, and other front-line health care workers critical to addressing COVID–19. Additionally, in coordination with HRSA, grantees have used innovative models of care, such as telehealth, to improve patients' access to care during the pandemic.

The COVID–19 pandemic has also highlighted the pervasive health inequities facing minority communities and gaps in care for our most vulnerable patients, including an aging population that requires more health care services. The HRSA Title VII and Title VIII programs educate current and future providers to serve these ever-growing needs, while preparing providers for the health care demands of tomorrow. A diverse health care workforce improves access to care, patient satisfaction, and health professionals' learning environments. Studies show that HRSA Title VII and Title VIII programs increase the number of underrepresented students enrolled in health professions schools, heighten awareness of factors contributing to health disparities, and attract health professionals more likely to treat underserved patients. The AAMC joins the Health Professions and Nursing Education Coalition (HPNEC) in recommending $1.51 million for these critical workforce programs in FY 2022.

In addition to 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 train the future primary care and specialty care workforce for our nation's children. We support $485 million for the CHGME program in FY 2022. We also encourage Congress to provide robust funding to HRSA's Rural Residency Programs, which provides funding to develop new rural residency programs or separately accredited rural training track programs, to expand training opportunities in rural areas.

The AAMC encourages Congress to provide long-term sustained funding for the National Health Service Corps (NHSC), through its mandatory and discretionary mechanisms. We were appreciative of the $800 million in supplemental funding for the NHSC in the American Rescue Plan (H.R. 117–2), and we support an appropriation for the NHSC that would fulfill the needs for current Health Professions Shortage Areas.

Centers for Disease Control and Prevention. The AAMC joins the CDC Coalition in a recommendation of at least $10 billion for the CDC in FY 2022. In addition to ensuring a strong public health infrastructure and protecting Americans from public health threats and emergencies, CDC programs are crucial to reducing health care costs and improving health. Within the CDC total, the AAMC supports $102.5 million for the Racial and Ethnic Approaches to Community Health (REACH) program and $25 million to support gun safety research.

Additional Programs. The AAMC also supports at least $474 million for the Hospital Preparedness Program within the Office of the Assistant Secretary for Preparedness and Response (ASPR), in addition to $40 million to continue the regional preparedness programs created to address Ebola and other special pathogens, including funding for regional treatment centers, frontline providers, and the National Emerging Pathogen Training and Education Center (NETEC).

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 FY 2022 spending bill.

PREPARED STATEMENT OF THE ASSOCIATION OF FARMWORKER OPPORTUNITY PROGRAMS

Chair Murray and Ranking Minority Member Blunt:

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 2022 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, well-trained, skilled workers. Administered by DOL, NFJP provides funding through a competitive grant process to 54 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 2019 alone, NFJP service organizations provided more than 17,300 agricultural workers with services, according to DOL. These NFJP providers have served more than an estimated 170,000 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, such as those needed to rebuild the nation's infrastructure. 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 supports appropriations for OSHA's 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 220 trainers in 30 states trains agricultural workers on how to protect against pesticide poisoning. 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 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 $46.1 billion in fiscal year (FY) 2022. AIRI also commends Congress for continuing to reject harmful policies such as reducing support for facilities and administrative (F&A) costs or investigator salary support on NIH grants. In addition, AIRI looks forward

to working with the Subcommittee and the Biden Administration to explore how the proposed Advanced Research Project Agency for Health (ARPA–H) can support high-risk, high-reward research to quickly develop new cures. AIRI urges the Subcommittee to ensure that this proposed effort complements, and does not negatively impact, NIH's funding for fundamental biomedical research that is critical for understanding and addressing the public health challenges facing the United States.

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 ten percent of NIH's peer-reviewed, competitively awarded extramural grants.

AIRI thanks the Subcommittee for providing an increase of $1.25 billion for NIH in the FY 2021 Consolidated Appropriations Act. 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 cancer, Alzheimer's Disease, emerging infectious diseases, and the opioid crisis, among others. In addition, NIH's instrumental role in developing new vaccines to combat the COVID–19 pandemic reminds us that now is not the time to pull back 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 and ensuring that we are prepared for the next public health crisis. To ensure cutting-edge research at independent research institutes is not disrupted, AIRI strongly supports a topline of $46.1 billion for NIH in FY 2021.

AIRI thanks the Subcommittee and Congress for providing critically needed supplemental funding in 2020 to combat the COVID–19 pandemic. NIH investments were critical in the record-breaking development of multiple vaccines and improved treatments and therapeutics for COVID–19. Independent research institutions are, by design, structurally nimble and responsive to emerging research issues. In part because of this, AIRI members have made significant contributions to COVID–19 research. Selected examples include:

—The Fred Hutchison Cancer Research Center's and RTI International's role in the Accelerating COVID–19 Therapeutic Interventions and Vaccines (ACTIV) program essential for the development of treatments and vaccines.

—Fred Hutch's work in modeling the spread and evolution of COVID–19 and as the coordination center for the NIH-funded COVID–19 Prevention Network.

—La Jolla Institute of Immunology's pioneering work to understand T cell responses to the infection.

—Jackson Lab's work in developing a line of ACE2 mice for preclinical studies.

Not only is NIH research essential to advancing health, it also plays a key economic role in communities nationwide. In FY 2020, NIH invested $34.65 billion, or almost 80 percent of its budget, in the biomedical research community. This investment supported more than 536,338 jobs nationwide and generated nearly $91.35 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 independent research institutes, medical centers, and universities 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 member institutes' flexibility and research-only missions provide an environment particularly conducive to creativity and innovation. Independent research in-

[1] NIH's funding information and economic impact data comes from United for Medical Research's 2021 State-By-State Update, https://www.unitedformedicalresearch.org/wp-content/uploads/2021/03/NIHs-Role-in-Sustaining-the-U.S.-Economy-FINAL-3.23.21.pdf.

stitutes 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 looks forward to working with Congress and the Biden Administration to examine how the proposed establishment of an ARPA–H can push the research enterprise to take on high-risk, high-reward research efforts. If successful, an ARPA–H has the potential to convene researchers to take on grand challenges in public health that were previously thought to be impossible to solve. However, we still do not fully understand many of the basic mechanisms underlying diseases and public health challenges facing the nation today, such as cancer, Alzheimer's, and addiction, among others. Funding for fundamental research is still crucial to address these issues, and AIRI urges the Subcommittee to ensure that new proposals do not negatively impact these important ongoing efforts.

The U.S. has the most robust medical research enterprise in the world, but our leadership in biomedical research is being challenged by the investments being made in the research capacity of other nations, such as China. While the most recent funding increases to the NIH budget will greatly help sustain biomedical research in the U.S., it is important to continue providing stable funding to uphold our biomedical excellence.

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 $46.1 billion in FY 2021 and reaffirming support for NIH's current F&A and investigator salary policies to strengthen our nation's investment in life-saving medical research.

PREPARED STATEMENT OF THE ASSOCIATION OF MINORITY HEALTH PROFESSIONS SCHOOLS

SUMMARY OF FISCAL YEAR 2022 RECOMMENDATIONS

Health Resources and Services Administration:

—$1.51 billion for the Health Resources and Services Administration (HRSA) Title VII health professions and Title VIII nursing workforce development programs.
—$47.42 million for HRSA's Minority Centers of Excellence
—$47.95 million for HRSA's Health Careers Opportunity Program.
—$2 million for HRSA's Minority Faculty Loan Repayment Program.
—$67 million for HRSA's Scholarships for Disadvantaged Students (SDS).
—$67 million for HRSA's Area Health Education Center (AHEC) Program

Centers for Disease Control and Prevention:

—$74 million for the Racial and Ethnic Approaches to Community Health (REACH) Program

National Institutes of Health:

—$46.1 billion for the National Institutes of Health
—1 billion for the National Institute on Minority Health and Health Disparities (NIMHD).
—$300 million for the Research Centers at Minority Institutions (RCMI)
—$200 million in new, annual research funding dedicated specifically targeted at enabling historically black health professions schools to support research that reverses health status disparities among minority Americans.
—$100 million for NIH's Extramural Research Facilities program
—$100 million to reinvigorate the NIMHD's Research Endowment Program (REP)

Office of the Secretary:

—$72 million for the Office of Minority Health at the Department of Health and Human Services.
—$5 billion in new funding designated for Historically Black Health Professions Institutions for the improvement and development of health care infrastructure.

Department of Education:

—$100 million for the Strengthening Historically Black Graduate Institutions (HBGI) Program.

Chairwoman Murray, Ranking Member Blunt, and distinguished members of the subcommittee, thank you for the opportunity to submit testimony and thank you for your leadership in addressing challenges facing the health workforce, health disparities, and medically underserved communities. I am Dr. Kathleen Kennedy, Malcolm Ellington Professor of Health Disparities Research and Dean, College of Pharmacy Xavier University of Louisiana and the Chair of the Association of Minority Health Professions Schools (AMHPS), which was established in 1976 to promote a national minority health agenda by addressing the needs of the health workforce and improving health status in medically-underserved communities. Speaking to you today against the backdrop of the continued COVID–19 pandemic with hope on the horizon, we have learned valuable lessons over the past year and a half, but we know that there is more work to be done. The pandemic has pulled back the curtain on what many of AMHPS institutions know and work towards everyday: the pitfalls and shortcomings of minority health. Given the recent deluge of media coverage surrounding this disheartening topic, the country is primed and ready to act in a meaningful way. Our funding recommendations are robust and we realize ambitious, however there have rightfully been discussion concerning the devastating effect of the pandemic on people of color and the need to address this effect for any future pandemic. To be as clear we can be, there must be more robust investment on minority health and disparities. To achieve this we know that it will require the steadfast leadership of health equity champions. We stand ready to work with you and your colleagues to facilitate these efforts.

AMHPS is comprised of the twelve historically black medical, dental, pharmacy, and veterinary schools in the United States. The members are two schools of dentistry at Howard University and Meharry Medical College; four schools of medicine, at Charles R. Drew University, Howard University, Meharry Medical College, and Morehouse School of Medicine; five schools of pharmacy, at Florida A&M University, Howard University, Texas Southern University, Hampton University, and Xavier University; and one school of veterinary medicine, at Tuskegee University. Today, the association assists its member institutions in the expansion and enhancement of educational opportunities in the health professions for minorities and disadvantaged students and disadvantaged people. AMHPS continuously adheres to is founding call and honors its threefold mission to improve the health status of blacks and other minorities; improve the representation of blacks and other minorities in the health professions; strengthen our institutions and programs and to strengthen other programs throughout the nation, which in turn will improve the role of minorities in the provision of health care.

Health disparities across racial and ethnic groups in the U. S. have been well documented over the last several decades and have remained remarkably persistent in spite of the changes in many facets of the society over that period. Moreover, the benefits of increasing diversity in the health professions to reduce such disparities have been studied at length, are based on empirical data, and are well understood by the medical community. Examples of these benefits include:

—Minority physicians are more likely to practice in medically underserved areas and care for patients regardless of their ability to pay.

—Minority physicians are more likely to choose primary care practices.

—Evidence suggests that improving cross-cultural communication between doctors and patients and providing patients with access to a diverse group of doctors improve adherence, satisfaction and health outcomes.

—There is evidence that the intellectual, cultural sensitivity, competency, and civic development of students is enhanced by learning in a diverse educational environment.

—A diverse health workforce encourages a greater number of minorities to enroll in clinical trials designed to alleviate health disparities.

There is little left to discover or dispute with respect to the benefits of achieving greater racial and ethnic diversity of the nation's health professionals—the attention has once again shifted to identifying the most effective and sustainable methods to do so. While there are many national campaigns underway to increase diversity in all medical and health professions schools particularly during this period of enrollment growth, it is imperative that we further recognize and leverage the public value of Historically Black Health Professions Schools.

The daunting news that Blacks Americans in the US are disproportionately suffering and dying from the novel coronavirus (COVID–19) unfortunately was not a

tremendous surprise to those of us who regularly monitor and understand health status disparities in this nation. There are well-known health status challenges faced daily by Black Americans and minority health care providers, it also represents a surrogate for the glaring lack of health infrastructure in medically underserved communities. At AMHPS institutions, we have long been and remain committed to addressing these very same disparities in whatever way that we can, with an eye first and foremost towards the communities with the greatest need across our country.

Ironically, as a result of their mission focus the financial models of historically black health professions schools are uniquely disadvantaged compared to most of their peer institutions. Unlike subspecialty-oriented, research-intensive institutions—with higher margin clinical services, an integrated hospital system, substantial research enterprises, sizeable endowments, and a critical mass of wealthy donors—these institutions are faced with an unprecedented set of adverse factors that challenge their financial viability. Consequently, they are disproportionately dependent on the various federal programs that support their core purpose.

Specifically, these programs include: the Title VII Health Professions Training Programs administered by the Health Resources and Services Administration (HRSA) of the Department of Health and Human Services (HHS); the Research Centers at Minority Institutions (RCMI), the Extramural Research Facilities; the Research Endowment; and Centers of Excellence programs administered the National Institutes of Health's National Institute on Minority Health and Health Disparities; and the Historically Black Graduate Institution (HBGI) program administered by the Office of Postsecondary Education of the U.S. Department of Education (DOE).

Madam Chair, unfortunately, over the past several years funding for diversity-focused programs has deteriorated in varying degrees. Absent a monumental overall investment the financial position and academic viability of historically black health professions schools will deteriorate rapidly. The front loaded investment in health professions training programs, graduate programs in biomedical sciences and public, and safety net providers is more cost effective than absorbing uncompensated care originating from minority and underserved communities. Now is the time for targeted investments in historically black health professions schools to ensure a steady pipeline of minority healthcare providers, biomedical scientists, and other health practitioners prepared to support and advance the delivery of high quality, culturally appropriate, evidence based health care. Thank you all again for the opportunity to share the priorities of the Association of Minority Health Professions Schools.

[This statement was submitted by Kathleen B. Kennedy, Pharm.D., Chair, Association of Minority Health Professions Schools, Inc. and Malcolm Ellington, Professor, Health Disparities Research and Dean, College of Pharmacy Xavier University of Louisiana.]

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 FY22 appropriations for the U.S. Department of Health and Human Services (HHS). ASTHO is requesting $10 billion for the Centers for Disease Control and Prevention (CDC), $824 million for the Public Health Emergency Preparedness Cooperative Agreement (PHEP), $149 million for the CDC Preparedness and Response, All Other CDC Preparedness line, $170 million for the Preventive Health and Health Services Block Grant (Prevent Block Grant), and $250 million for the data modernization effort at the CDC. Under the Assistant Secretary for Preparedness and Response (ASPR), ASTHO is requesting $474 million for the Hospital Preparedness Program (HPP) and not less than $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 $9.2 billion in discretionary funding for the Health Resources and Services Administration (HRSA).

You are probably wondering, "Why is governmental public health at the table requesting more funding? Didn't Congress just provide billions of dollars in emergency funding for you all?" The answers are yes and thank you. We all must recognize the sheer amount of emergency funding required to boost our public health system and respond to the COVID–19 pandemic. We must also acknowledge that huge sums of this emergency funding could have been avoided with ongoing, predictable funding that meets the needs of state, territorial, and local public health departments. The emergency supplemental funding is narrow, specific, and time limited.

All too often, after emergency supplemental funding expires, health officials are forced to shut down programs, allow software licenses to expire, furlough staff, and move on. While there are billions of emergency supplemental dollars in the system right now—that we are immensely grateful for—we anticipate that, without a change of course, there will be an enormous funding cliff in two to three years. Meanwhile, we all know that communities of color are disproportionately impacted by underinvestment on all public health fronts, whether we are discussing maternal morbidity and mortality, infant mortality, the prevalence of chronic diseases, substance use and misuse, behavioral and mental health, the HIV epidemic, and most strikingly, overall life expectancy. We have an opportunity to make things better for the American people, especially for those who need it most. This committee and Congress can ensure we have sustained, predictable, and increased funding for all of public health, which translates into better lives for those we serve.

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. Our members' mission is to provide the leadership, expertise, information, and tools to assure conditions in which all residents can be healthy. In short: Keeping people safe.

America's state and territorial public health departments work in strong partnership with CDC toward this goal. For this essential task, we request $10 billion in overall funding for CDC. CDC plays a vital role in supporting communities to expand the capacity of our nation's front line of public health defense: Our country's state, tribal, territorial, and local public health departments. Through this partnership with CDC, state and territorial health agencies work across the country to prevent avoidable diseases, promote healthy communities, protect the public's health, and ensure the vibrance and security of our economy. These resources also support disease-neutral infrastructure such as data and information technology systems, workforce development, community partnership building, and administrative preparedness. We continue to learn how far behind we are as a country when it comes to our ability to accurately track diseases or even transmit data efficiently and accurately to a central location. ASTHO is thankful for the current investment in our public health systems, but dependable and appropriate financing is essential to keep our country ahead of the curve.

Public health preparedness requires support at the federal level and implementation by state, territorial, and local jurisdictions. Recognizing this, ASTHO requests $824 million for PHEP at CDC. America's public health preparedness outlays have operated in a punctuated equilibrium. We make leaps forward after emergencies such as September 11, Ebola, Zika, and measles outbreaks, and then are lulled into periods of stasis for far too long. PHEP requires ongoing and increased funding to ensure that lessons and improvements from the COVID–19 response are not lost. In close partnership with the PHEP is the Hospital Preparedness Program (HPP) at ASPR, for which ASTHO requests $474 million. 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. Now more than ever, we clearly understand the importance of public health and healthcare preparedness programs working collaboratively and with proper resources. We are also requesting that Congress provide no less than $49.5 million to sustain the National Emerging Special Pathogen Training and Education Center and the 10 existing regional Ebola and other special pathogen treatment centers under ASPR. The investment made in this system over five years ago has proven its importance in providing specialty treatment, training, and national-level expertise during the COVID–19 response. This network is a valuable front-line tool in protecting our country.

Preventing disease in the first place is the most economical use of our public funds when it comes to health spending. ASTHO's members strive to implement locally tailored, innovative programs that not only prevent disease and disability but support wellness as we work toward national health priorities. 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. 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.

ASTHO appreciates this committee's ongoing support of CDC's data modernization initiative. Public health is singlehandedly keeping the fax industry alive, and

we must leap forward. We applaud Congress's investment and down payment to date ($600 million through FY21 and FY21 funding and the CARES Act) and the inclusion of language authorizing activities to improve the public health data systems at CDC in the Consolidated Appropriations Act for FY21. We respectfully request the Subcommittee continue to provide sustained annual funding of at least $250 million for the public health Data Modernization Initiative at CDC.

ASTHO is also encouraged by the Administration's plan to end the HIV epidemic and address social determinants of 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, community-based organizations, and healthcare partners must have the resources necessary to enhance and deliver these evidence-based public health interventions.

While the pandemic is at the forefront of our minds, we have never fully addressed the ongoing crisis in our country caused by substance misuse, addiction, and drug overdoses. ASTHO is appreciative of previous investments in public health to address this crisis. We respectfully request Congress to sustain activities and continue the response to the opioid epidemic and substance abuse and misuse disorders more broadly.

CDC is not the only federal agency that strives to improve the public's health in states and territories. ASTHO is requesting $9.2 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.

As you look to the FY22 discretionary appropriations bills, we strongly urge you to build a base funding for public health—through CDC, ASPR, and HRSA—that is sustainable and predictable. Thank you so much for your time and consideration of our request. We stand ready to continue working toward optimal health for all.

[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 the Association of University Programs in Occupational Health and Safety (AUPOHS), we respectfully request that the Fiscal Year 2022 Labor, Health, and Human Services Appropriations bill include no less than $375,300,000 for the National Institute for Occupational Safety and Health (NIOSH), including no less than $34,000,000 for the Education and Research Centers (ERCs), $30,500,000 for the Agriculture, Forestry, and Fishing (AgFF) Program, and a $4,000,000 increase over the FY21 level for the Total Worker Health(r) (TWH) Program.

As you have no doubt heard from other testimonies, far too many Americans still lose their lives on the job. In 2019, a worker died every 99 minutes from injuries they got on the job (BLS 2020). This includes our first responders, who can be struck and killed by drivers while helping victims of a roadside traffic accident; our construction workers, who may fall from an inadequately marked or guarded roof edge; and our shop owners and employees who may be asked to work late nights without proper security and become victims of violence. Although it is harder to measure, we also estimate that an additional 145 people die every day in America from work-related disease—developing cancers from hazardous chemicals that we encounter at work, or heart disease from our chronically stressful work environments. In addition to work-related deaths, we also have a high burden of non-fatal workplace injury and illness. Leading up to the pandemic, 2.8 million workers were seriously injured on the job every year and one-third of those injured workers required time off to recover before they could return to work. This not only costs the nation's businesses more than $1.1 billion a week on serious, nonfatal workplace injuries (Liberty Mutual 2020) but also causes great harm to workers and their families if their workers' compensation systems fail to provide adequate care or wage replacement.

The pandemic has amplified all of these issues for the American workforce. More than 3,600 of our health care workers died from COVID–19 in the first year of the pandemic, and we know that many of these deaths are attributable to the extreme shortage of protective gear encountered in medical settings (Lost on the Frontline 2021). That is to say, these deaths were preventable. In just the first months of the pandemic, 16,233 workers in meat and poultry processing facilities were infected with COVID–19 (CDC 2020); these were also workers who sacrificed their health and wellbeing in order to keep essential goods and services moving. We owe an immense debt to all of our essential workers, and as such, we have an opportunity to

better serve these workers moving forward. By designing safer workplaces that reduce the risk of exposure to future variants, answering workers' questions about vaccines and making them accessible, and by researching, designing, and preparing programs to bolster workers' mental health as we come to terms with what we have experienced this past year, we can serve our essential workers.

NIOSH is the primary federal agency responsible for conducting research that leads to actions and policies that prevent work-related illness and injury by promoting safe work practices and work environments as well as worker health and well-being. NIOSH is also the federal agency 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 viruses. During this pandemic, NIOSH has accelerated the approval process for establishing the safety and quality of new masks and other PPE. NIOSH continues to fund and promote critical research for a changing workforce and work practices, an important service for employers and employees in the face of the current pandemic and other disasters. NIOSH has, for example, deployed teams across the country in response to industry requests for assistance, including more than 15 meatpacking plants that experienced outbreaks. NIOSH has contributed key leadership and expertise, providing federal guidance and decision tools for industries including construction, manufacturing, food and agriculture, mass transit, transportation and trucking, restaurants and bars, childcare facilities, schools, among others, including recent guidance for businesses to safely return to work and/or expand operations.

The NIOSH-supported extramural Centers, including the Education and Research Centers (ERCs), Centers in the Agriculture, Forestry, and Fishing (AgFF) Program, and the Total Worker Health(r) (TWH) Centers of Excellence, have responded rigorously to the pandemic and supported NIOSH to rapidly respond to the needs and safety of the nation's workforce. These Centers have been proactive in providing resources, employer assistance, over 100,000 hours of outreach training, and research that are helping to drive improvements in our rapid response to emerging occupational safety and health issues. The work the Centers have undertaken during this pandemic underscores the need for increased funding for NIOSH and the Centers. As workplaces rapidly evolve, changes continue to present new health and safety risks to workers, which need to be addressed promptly through occupational health and safety research and training.

The 18 university based ERCs provide local, regional, and national resources for all those in need of occupational health and safety assistance. Collectively, the ERCs provide graduate- and post-graduate level education and research training in the occupational health and safety disciplines. The ERCs prepare a workforce of occupational safety and health professionals to every Federal Region in the U.S who are trained to identify and mitigate vulnerabilities from all sources, including increased readiness to respond to chemical, biological, radiological, or nuclear attacks. Occupational health and safety professionals work with emergency response teams to minimize disaster losses, as exemplified by their lead role in minimizing hazards among workers involved in clean-up and restoration 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 ERCs responded rapidly to provide employers across the country with accessible, concise information on the workplace implications of COVID–19 and are now providing local and national online and telephonic advising programs for businesses as they seek to reopen safely.

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 AgFF were established by Congress in 1990 (PL 101–517) in response to evidence that agricultural, forestry, and fishing workers suffer substantially higher rates of occupational injury and illness than other nation's workers. Agricultural workers are more than six times more likely to die on the job than the average worker, averaging 540 fatalities per year, and more than 1 in 100 workers incur nonfatal injuries resulting in lost workdays each year. Our food security depends on a healthy and safe agricultural workforce—an essential sector that has been hit particularly hard during the pandemic. Today, the NIOSH AgFF initiative includes ten regional Agricultural Centers and one national Children's Farm Safety and Health Center. The AgFF program is the only substantive federal effort to ensure safe working conditions in these vital production sectors. The program also conducts research and outreach to ensure the safety of our nation's 86,000 workers in forestry and logging, an industry with a fatality rate more than 30 times higher than that of all our nation's workers. The AgFF Centers have had a significant impact on protecting safety and health of agricultural workers. For example, the developed of rollover protective structures (ROPS or roll bars) and seatbelts on tractors were shown to prevent 99%

of overturn-related deaths. Partnering with fishing communities, the AgFFs developed comfortable lifejackets to wear at work, which have increased chances of survival in the event of a fall overboard. The lifesaving, cost-effective work of the AgFF program is not replicated by any other agency. USDA's National Institute of Food and Agriculture interacts with experts at NIOSH to learn about cutting-edge research and new directions in this area. In addition, state and federal OSHA personnel rely on NIOSH research to develop evidence-based standards for protecting agricultural workers and would not be able to fulfill their mission without the AgFF program.

NIOSH also supports six TWH Centers of Excellence that conduct multidisciplinary research and test practical solutions to emerging challenges that impact the safety, health, well-being, and productivity of the American workforce. The TWH Centers conduct solutions-focused research in partnership with employers and employees and partner with government, business, labor, and community to improve the health and productivity of the workforce. 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. These Centers have been heavily relied upon by employers and employees to address the impact of the current pandemic not only from an infectious disease perspective but also to address the impact on mental health, stress, burnout, and resiliency of essential workers, workers abruptly working remotely, and those furloughed or laid off. The TWH Centers are an investment in the American economy, helping valued employees return home safe and healthy at the end of a productive workday.

We urge you to recognize the critical contribution of NIOSH, including the ERCs, the AgFF Program, and the TWH Program to the health and productivity of our nation's workforce. Thank you for the opportunity to submit testimony.

PREPARED STATEMENT OF KATHERINE BENNETT, MD FACP

As the Assistant Director for Education of the Northwest Geriatrics Workforce Enhancement Center (NW GWEC) at the University of Washington (UW), immediate past president of the National Association for Geriatric Education (NAGE), and a current Geriatrics Academic Career Award recipient, I am pleased to submit this statement for the record on behalf of myself, the NW GWEC, and NAGE recommending appropriations of at least $105.7 million in Fiscal Year 2022 to support geriatrics workforce training under the Geriatrics Workforce Enhancement Program (GWEP) and the Geriatrics Academic Career Award (GACA) program. Administered by the Health Resources and Services Administration (HRSA), both programs reach rural and underserved populations and address health inequities. We thank you for your past extensive support of these programs. An appropriation at this level will build upon these programs that are vital to the health and well-being of our nation's older adults and those who provide care for them.

We all know that there are many older people in our homes, communities, and states who need the care of well-trained health professionals. It turns out that we have much of the know-how, expertise, curricula, and teachers to offer this training! What we need from you is the funding to support the dissemination of this expertise to more health care providers and systems who treat older patients. The GWEP and the GACA programs are the only federally funded programs designed to increase the number of health professionals with the skills and training to provide high quality, patient-centered, equitable, cost-saving care for older adults. This training is critical to addressing the suboptimal care that is so frequent and widespread, and something I see the devastating impacts of each day—older adults who are prescribed dozens of medications that are contributing to falls and cognitive impairment; advanced dementia that has gone undiagnosed for years; and life-altering injuries from falls that could have been prevented.

Suboptimal healthcare occurs not because primary care teams do not care but because most providers in practice have received insufficient and more often no training whatsoever in the core principles of high-quality care for older adults. In a just society, we aspire to provide adequate health care at every age and stage of life. The care of older adults is a unique skill set, largely due to age-related changes to the entire body, the simultaneous presence of multiple chronic diseases, and conditions that are unique to older adults—this care really cannot be done well without specific training. The GWEP and the GACA programs seek to change the present reality through quality improvement and education initiatives conducted in partnership with primary care practices and community agencies, and by training future leaders in geriatrics care transformation.

There are currently 48 GWEPs, located in 35 states and 2 territories, that are working to rapidly transform and expand the health care of older adults. The current appropriation level makes it impossible to have at least one GWEP in every state or for current GWEPs to have adequate funds to do an expanding body of work. This increased funding is urgently needed so that these vital programs can equitably reach all areas of the country and effectively respond to the rapid growth in number and increasing health complexity of older adults. These programs are integral to the training, support, and expansion of the eldercare workforce and long-term services and supports infrastructure.

The 48 current GWEPs have tremendous impact on their regions. During 2019–2020, 56,603 health professions trainees participated in GWEP-led education activities, and 290,161 faculty and providers attended 2,069 different continuing education events, which included 906 events focused on Alzheimer's disease and other dementias. GWEPs partner with health systems (including federally qualified health centers and Veteran's Affairs Medical Centers) and community-based organizations to have the greatest impact and optimize the community/health care linkages that are essential to older adults and their caregivers. Every GWEP is focused on meeting the needs of rural and/or underserved populations, and GWEPs play an integral role in reducing health inequities. For example, a GWEP based on the South Side of Chicago addressed health disparities for African Americans with dementia by partnering with faith-based community leaders, and another GWEP partnered with FQHCs to create and distribute multilingual COVID–19 education materials and increase behavioral health capacity.

Over the past two years, GWEPs have joined forces with the Institute for Healthcare Improvement and The John A. Hartford Foundation to drive spread of the Age-Friendly Health System initiative. This initiative aims to align healthcare with an older adult's goals by eliciting what matters most to them, ensuring that medications regimens minimize the risk of harm, optimizing mood and cognition, and guiding them to move safely and prevent falls. This type of evidence-based care not only improves outcomes but reduces healthcare costs. To date, GWEPs are partnering on this initiative with 302 health care delivery sites, 42% of which are in medically underserved communities and 45% designated as primary care. Nearly 6,000 different activities focused on Age-Friendly Health System transformation have reached 205,322 individuals.

The COVID–19 pandemic highlighted the fragility of the network of supports that help keep older adults healthy and thriving in the community. The GWEPs quickly pivoted to redirect the training of the healthcare workforce in the face of the obstacles resulting from the pandemic while continuing to meet the needs of older adults and their caregivers. For example, our GWEP partnered with Area Agencies on Aging to provide electronic tablets (along with training and support) and telehealth stations to keep older adults connected online to essential primary care services. We also quickly shifted our training to an entirely virtual format and focused on what interprofessional teams need to optimally care for older adults during the pandemic. Training sessions covered COVID–19 in older adults, assessing cognition via telehealth, addressing goals of care during the pandemic, and screening for falls via telehealth.

Around the country, GWEPs have done nothing short of amazing work during COVID–19 by partnering with primary care and community agencies to meet the medical, behavioral health, social, and basic needs of older adults and their caregivers. GWEPs addressed social isolation via virtual connection and phone outreach, trained teams of healthcare providers in age-friendly telehealth, provided virtual trainings on key care principles for older adults, delivered virtual caregiver support, and partnered on rapid vaccine rollout to the most vulnerable in the community, to name just a few examples. Taken together, the GWEPs delivered 400 unique training sessions that addressed COVID–19 related issues and reached over 54,000 individuals. The pandemic demonstrated the tremendous ability of GWEPs to adapt to unforeseen circumstances and remain focused on transforming the care of older adults to be age-friendly and preparing the healthcare workforce to meet the most pressing needs of older adults and their caregivers.

The Northwest Geriatrics Workforce Enhancement Center (NW GWEC), UW's GWEP, was established in 2015 and provides training and programs that enhance the lives of older adults and their caregivers in Washington and throughout the region. Our programs include Project ECHO-Geriatrics, a Primary Care Liaison Program based at the Area Agencies on Aging (AAA), a AAA Practicum for health professions trainees, and the Geriatrics Healthcare Lecture Series. Here are some examples of our reach.

—*Project ECHO-Geriatrics:* NW GWEC's Project ECHO—Geriatrics, or the Extension for Community Healthcare Outcomes, which is based on the evidence-based

ECHO model that trains and mentors current and future primary care providers to provide specialty care to their own patients and reduce health disparities. Sessions involve virtual mentoring sessions with teaching and consultations with an interprofessional geriatrics specialist panel. Since 2016, we have held over 60 monthly sessions with over 1,000 unique participants. Sessions focus on key primary care topics such as dementia, fall prevention, and depression. Dr. Braun, a faculty member at the Providence St. Peter Family Medicine Residency Program with sites in Olympia and Chehalis, WA said, "The program not only helps achieve our hours of required geriatrics training but has transformed the care I see provided by our residents in clinic and across healthcare settings."

—*Primary Care Liaison Program:* Our GWEP partnered with several Area Agencies on Aging in WA to create a Primary Care Liaison (PCL) program to connect primary care clinics to AAAs through outreach, engagement, and education as well as facilitating referrals. This program has increased primary care referrals to participating AAAs by over 4-fold.

The GACA program aims to train the next generation of leaders in geriatrics. There are currently 26 GACA awardees across 16 states representing a range of health professions disciplines (e.g., physicians, social workers, dentists, physical therapists). GACA awards support career development of future educators, leaders, and innovators in geriatrics and awardees also train interprofessional teams to provide age-friendly care. For example, as a current GACA awardee, I partnered with my local Area Agency on Aging (AAA) to create a new Project ECHO specifically to train AAA case managers in age-friendly care. The curriculum covers dementia, fall prevention, depression, and medication safety, and each ECHO session includes consultation on complex patients. GACA awardees throughout the country are reshaping the care of older adults through innovative projects such as redesigning airports to be age-friendly, reducing unsafe opioid prescribing in nursing homes, and integrating (oft neglected) oral health into routine primary care.

Although GWEPs are preparing the healthcare workforce to meet the needs of older adults and their caregivers, not all states are benefiting: Only 35 states and two territories have a GWEP, and only 16 states have a GACA recipient. Moreover, since renewal of the GWEP program in 2019, annual funding per GWEP has been reduced by $100,000 compared to the initial award period (2015–2019). An increase in appropriation is essential to ensure that every state has at least one GWEP and that GWEP sites can expand their work. Additionally, increased appropriations can ensure that there are more GACA awardees to meet the nation's current and future needs for transformative leaders in geriatric medicine.

In summary, GWEPs and GACAs are essential to ensure that the healthcare workforce in this country can meet the needs of older adults. Through our GWEPs, we have developed the knowledge and expertise to train interprofessional health care teams. Through our many partnerships and training activities, we have proved integral to the training and care delivery of the healthcare workforce including those in the long-term services and supports infrastructure as well as eldercare workforce infrastructure. I thank you for your consideration of this request for appropriations and am deeply grateful for your past support of these programs that are revolutionizing healthcare of older adults and their caregivers to be age-friendly, high-quality, equitable, cost-saving, and aligned with their personal goals and preferences.

PREPARED STATEMENT OF THE BEYOND AIDS FOUNDATION

Dear Committee Members,

I am writing in support of a FY 2022 budget request for Department of Health and Human Services (DHHS) to develop a national strategy and implementation plan for the prevention, control and treatment of Herpes Simplex Virus, Types 1 and 2 infections.

It is critical for public health and disease control to address Herpes Simplex Virus (HSV), a lifetime infection that impacts nearly half of Black women in our country, disproportionately impacts LGBTQ populations, and is an important driver of the HIV epidemic. Approximately 40% of new cases of HIV infection have been attributed to chronic HSV infection. HSV also kills approximately 1,000 infants annually as a result of neonatal herpes and injures thousands more. Despite this largely preventable mortality and morbidity, neonatal herpes is currently not even a national reportable condition. Additionally, there is a growing body of research indicating that HSV may be a contributing factor to Alzheimer's Disease, Encephalitis, Bell's palsy, among other neurodegenerative diseases.

There is currently no organized national strategy to address HSV. It is often not tracked nor routinely tested for during clinical and screening visits. And the majority of spread is via asymptomatic carriers who are in most cases unaware of their infection status. It is estimated that over 60 million Americans have genital infections with either HSV–2 or HSV–1, making it among the most prevalent STIs in the US. We can and should be doing more to stop the spread and provide better treatment to the nearly 1 in 3 Americans with this chronic condition.

For the past two decades, I have served as the volunteer Medical Advisor for the largest in-person herpes support (HELP) groups in the country (Los Angeles and Orange Counties, San Diego), and since the COVID–19 pandemic, the online SoCal HELP group. I have been privy to observe the negative outcome of having non-existent federal HSV policies and programs. They include severe genital pain syndromes as well as bouts of depression, anxiety, shame, and loss of self esteem accompanying these infections. As the former Director of the largest domestic STD Program (Los Angeles County) in the US for over a decade, I was and am currently acutely aware of the shortcomings of our HSV policies, planning and services, and the great need to change our approach and address this problem.

If we prioritize women's and maternal health, the health of Black, Hispanic, LGBTQ, indigenous and other at-risk communities, we must prioritize Herpes Simplex Virus treatment and prevention. If we prioritize mental health, biomedical research for incurable diseases such as Alzheimer's or HIV, and dismantling systemic racism in healthcare, we must also prioritize Herpes Simplex Virus control. Addressing HSV addresses all of these national priorities and can improve the health and quality of life, and reduce the economic burden for millions of Americans.

Sincerely.

[This statement was submitted by Gary A. Richwald, MD, MPH, President, Beyond AIDS Foundation.]

PREPARED STATEMENT OF THE BIG CITIES HEALTH COALITION

On behalf of the Big Cities Health Coalition (BCHC), we respectfully request that the Subcommittee provide the highest possible funding for the U.S. Centers for Disease Control and Prevention (CDC), central to protecting the public's health, for Fiscal Year 2022. Key CDC programmatic priorities of the Coalition and our member health departments include violence prevention, immunization, public health preparedness, epidemiology and laboratory capacity, opioid overdose prevention, and the public health data modernization initiative.

BCHC is comprised of health officials leading 30 of the nation's largest metropolitan health departments, who together serve nearly 62 million—or one in five—Americans. Our members work every day to keep their communities as healthy and safe as possible. We thank you for your continued leadership and support for our nation's public health workforce and systems during the ongoing COVID–19 pandemic.

As the Subcommittee members recognize, federal funding for CDC and the programs that support local and state public health departments have remained largely stagnant. Additional investments through sustained annual funding is necessary to build public health capacity for the next pandemic, as well as the everyday population health programs.

NATIONAL CENTER FOR IMMUNIZATION AND RESPIRATORY DISEASES

National Immunization Program

We respectfully request $1.1 billion in FY2022 for the National Immunization Program. The CDC Immunization Program funds 50 states, six large, BCHC member cities (Chicago, Houston, New York City, Philadelphia, San Antonio, and Washington, D.C.), and eight territories for vaccine purchase and immunization program operations. In addition to the challenges of the COVID–19 pandemic and continuing disease outbreaks, recent growth of electronic health records and compliance with associated regulations, new vaccines and school requirements have increased the complexity of vaccine management. Additional base funding is needed for each grantee to sustain improvements supported by emergency funding and maintain sound and efficient immunization infrastructure. We also ask that the Committee encourage CDC to be as flexible as possible in coordinating funding and guidance across immunization program streams as we do COVID vaccinations while still also carrying out routine immunizations.

NATIONAL CENTER FOR EMERGING AND ZOONOTIC INFECTIOUS DISEASE

Epidemiology and Lab Capacity

We respectfully request $500 million in FY2022 for the Epidemiology and Lab Capacity (ELC) program, which is a single vehicle for multiple programmatic initiatives that go to 50 state health departments, six large, BCHC member cities (Chicago, Houston, Los Angeles County, New York City, Philadelphia, and Washington, D.C.), Puerto Rico, and the Republic of Palau. ELC grants strengthen local and state capacity to contain infectious disease threats by detecting, tracking and responding in a timely manner, as well as maintaining core capacity as the nation's public health eyes and ears on the ground. Increased funding will help build the epidemiology workforce, allowing state and local health departments to begin to move towards establishing a minimum epidemiology workforce; to promote and offer training for state and local epidemiologists; and to monitor needs in state- and/or local-based epidemiology capacity. ELC dollars sent to the states should be tracked through existing CDC reporting structures and shared publicly to ensure funds are also supporting big city epidemiology activities.

PUBLIC HEALTH SCIENTIFIC SERVICES

Public Health Data Modernization Initiative (DMI)

We respectfully request $250 million in FY2022 for the DMI that is working to create modern, interoperable, and real-time public health data and surveillance systems at the state, local, Tribal, and territorial levels. These efforts will ensure our public health officials on the ground are prepared to address any emerging threat to public health-whether it be COVID–19, measles, a foodborne outbreak like E. coli, or another crisis. COVID–19 exposed the gaps in our public health data systems and since then Congress has provided funding for DMI through the CARES Act and American Rescue Plan Act. These investments have been critical, but the public health surveillance systems must live beyond COVID–19 and be ready for any and all future threats. This requires long-term, sustained investment that is not just to build capacity at the federal and state level, but also at health departments in cities and counties across the country.

PUBLIC HEALTH WORKFORCE

We respectfully request $160 million in FY2022 for the public health workforce and career development programs as proposed in the President's budget. The public health workforce is the backbone of our nation's governmental public health system at the county, city, state, and tribal levels. Investments must be made to build back the public health workforce, as well as attract and retain diverse candidates with diverse skill sets. These funds support CDC's fellowship and training programs including the Public Health Associate Program and the Epidemic Intelligence Service that extend the capacity of health departments and key partners at all levels of government.

CROSS-CUTTING ACTIVITIES AND PROGRAM SUPPORT

Public Health Infrastructure and Capacity

We respectfully request $400 million in FY2022 for a new Public Health Infrastructure and Capacity investment as proposed in the President's budget request. The pandemic exposed the deadly consequences of chronic underfunding of basic public health capacity. Because public health is largely funded by disease or condition, there has been little investment in cross-cutting capabilities that are critical for effective public health. These capabilities include: public health assessment; preparedness and response; policy development and support; communications; community partnership development; organizational competencies; accountability; and equity. Governmental public health infrastructure requires sustained investments over time and we believe this is an important start. This investment is critical to ensuring that our governmental public health system is prepared for the next pandemic as well as to strengthen the health of our communities every day.

NATIONAL CENTER FOR INJURY PREVENTION AND CONTROL

Opioid Overdose Prevention and Surveillance

We respectfully request $713 million in FY2022 for Opioid Overdose Prevention and Surveillance in line with the President's request. Many health departments were forced to curtail opioid and other substance use disorder services during the pandemic. Unfortunately, overdose numbers are increasing in many communities, erasing progress of recent years. Previously, programs that connected with people

in hospital emergency departments after an overdose had seen successful outcomes in steering people toward syringe services programs and treatment programs. However, these programs rely on in person interactions that have been scaled back during the pandemic. Funding is needed in local communities to ensure that substance use disorder prevention continues to stem the tide of overdose and death. We also encourage the Committee to include directive language to insure these dollars reach the local level in those communities that are not directly funded, as well as have CDC and the Office of the Assistant Secretary of Health at the Department of Health and Human Services better track and share publicly state expenditures.

Gun Violence Prevention Research

We respectfully request $25 million in FY2022 for Gun Violence Prevention Research and the same as the President's budget request. Firearm violence is a serious public health problem in the United States that impacts the health and safety of all Americans. Despite initial funding in FY 2021 to research key issues around firearm violence, significant gaps remain in our knowledge about the problem and ways to prevent it; we need to continue and expand the research. Addressing these gaps is an important step toward keeping individuals, families, schools, and communities safe from firearm violence and its consequences. The public health approach to violence prevention includes working to define the problem, identifying risk and protective factors, developing and testing prevention strategies, and then, assuring widespread adoption of effective, targeted programs. Additional funds would be used to provide grants to conduct research into the root causes and prevention of gun violence focusing on those questions with the greatest potential for public health impact. The goal of this research is to stem the continued rise of firearm violence across the country to make our communities safer.

Community Based Violence Intervention Initiative

We respectfully request $100 million in FY2022 for a new Community Violence Intervention initiative as proposed in the President's budget request to implement evidence-based community violence interventions locally. BCHC whole-heartedly supports such an investment. Violence, like many public health challenges, is preventable. Yet, the majority of public investments are used to address the aftermath of violence, too often through systems that can cause further harm. Communities can be made safer when we understand the events that have led to present conditions and act on this knowledge by implementing policies and practices that address the root causes of violence. By making investments in public health strategies within communities that are most impacted by violence, cities can work across sectors to shift from an overreliance on the criminal justice system and move from reimagining to realizing community safety.

CENTER FOR PREPAREDNESS AND RESPONSE

Public Health Emergency Preparedness Cooperative Agreements

We respectfully request $1 billion in FY2022 for the public health emergency preparedness (PHEP) grant program. PHEP provides funding to strengthen local and state public health departments' capacity and capability to effectively respond to public health emergencies, including terrorist threats, infectious disease outbreaks, natural disasters, and biological, chemical, nuclear, and radiological emergencies. PHEP funding has been cut by over 30% in the last decade. Recent events, such as the response to the COVID–19 pandemic, demonstrate the need to invest in these programs to rebuild and bolster our country's public health preparedness and response capabilities. America's public health preparedness systems are stretched to the brink and will need increased and stable base funding for years to rebuild and improve. We also encourage the committee to include directive language to insure these dollars reach the local level in those communities that are not directly funded, as well as have CDC and the Office of the Assistant Secretary of Health at the Department of Health and Human Services better track and share publicly state expenditures.

NATIONAL CENTER FOR CHRONIC DISEASE PREVENTION AND HEALTH PROMOTION

Social Determinants of Health

We respectfully request $153 million in FY2022 for the Social Determinants of Health (SDOH) program in line with the President's request. CDC's SDOH program was initially funded in FY2021 to coordinate CDC's activities and to begin to provide tools and resources to public health departments, academic institutions, and nonprofit organizations to address the social determinants of health in their communities. Local and state health and community agencies lack funding and tools to

support these cross-sector efforts and are limited in doing so by disease-specific federal funding. Given appropriate funding and technical assistance, more communities could engage in opportunities to address social determinants of health that contribute to high health care costs and preventable inequities in health outcomes.

Office of Smoking and Health (OSH)

We respectfully request $310 million in FY2022 for the Office of Smoking and Health (OSH). Tobacco use has long been the leading preventable cause of death in the United States. Each year, it kills more than 480,000 Americans and is responsible for approximately $170 billion in health care costs. OSH has a vital role to play in addressing this serious public health problem. It provides grants to states and territories to support tobacco prevention and cessation, runs a highly successful national media campaign, conducts research and surveillance on tobacco use, and develops best practices for reducing it. Additional resources will allow OSH to address the alarmingly high rates of youth e-cigarette in addition to other forms of tobacco.

PREPARED STATEMENT OF THE CAMPAIGN FOR TOBACCO-FREE KIDS

I am Matthew Myers, President of the Campaign for Tobacco-Free Kids. I am submitting this written testimony for the record to urge the subcommittee to increase funding by $72.5 million for the Office on Smoking and Health (OSH) at the Centers for Disease Control and Prevention (CDC). By providing OSH with a fiscal year 2022 funding level of $310 million, CDC will be able to more effectively address high levels of youth e-cigarette use, expand its highly effective Tips from Former Smokers public education campaign, and aggressively address the role that tobacco use plays in health disparities by increasing its efforts to assist populations and regions of the country with disproportionately high rates of tobacco use and tobacco-related disease and premature death. Helping tobacco users to quit is of particular importance at this time given that cigarette smoking increases the risk of severe illness from COVID–19.[1]

Tobacco use remains the leading cause of preventable disease and death in the United States. More than 480,000 Americans die from tobacco use each year, and over 16 million Americans are currently living with a tobacco-caused disease.[2] Thirty-two percent of heart disease deaths, 30 percent of all cancer deaths, 87 percent of lung cancer deaths, and nearly 80 percent of all chronic obstructive pulmonary disease (COPD) deaths stem from tobacco use.[3] Smoking shortens the life of a smoker by more than a decade.[4]

Funding for CDC's Office on Smoking and Health remains modest when compared to the estimated $226 billion in annual health care costs attributable to tobacco use.[5] Even with the funding increases it has received over the past two years, the Office on Smoking and Health's resources remain stretched too thin. OSH needs additional resources to address an epidemic in youth use of e-cigarettes while continuing to reduce other forms of tobacco use, especially among populations disproportionately harmed by tobacco products.

High levels of youth e-cigarette use is threatening to undermine decades of progress in reducing youth tobacco use. E-cigarettes have been the most popular tobacco product used by kids since 2014.[6] These products come in a wide array of fla-

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[1] CDC, "People with Certain Medical Conditions," accessed April 28, 2021, https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html.

[2] U.S. Department of Health and Human Services (HHS), The Health Consequences of Smoking—50 Years of Progress: A Report of the Surgeon General, 2014, http://www.surgeongeneral.gov/library/reports/50-years-ofprogress/.

[3] HHS, The Health Consequences of Smoking—50 Years of Progress: A Report of the Surgeon General, 2014; "Centers for Disease Control and Prevention (CDC) Vital Signs, Cancer and Tobacco Use, Tobacco Use Causes Many Cancers," November 2016. https://www.cdc.gov/vitalsigns/pdf/2016-11-vitalsigns.pdf.

[4] HHS, The Health Consequences of Smoking—50 Years of Progress: A Report of the Surgeon General, 2014.

[5] Xu, X et al., "Annual Healthcare Spending Attributable to Cigarette Smoking in 2014," American Journal of Preventive Medicine, 2021.

[6] Wang, TW, et al., "E-cigarette Use Among Middle and High School Students—United States, 2020," MMWR, Volume 69, September 9, 2020, https://www.cdc.gov/mmwr/volumes/69/wr/pdfs/mm6937e1-H.pdf; Gentzke, A., et al., "Vital Signs: Tobacco Product Use Among Middle and High School Students—United States, 2011–2018, MMWR, Vol. 68, No. 6, February 2019. https://www.cdc.gov/mmwr/volumes/68/wr/pdfs/mm6806e1-H.pdf.

vors that attract youth and often deliver high levels of nicotine.[7] In 2020, 3.6 million youth were current users of e-cigarettes, including nearly 1 in 5 high school students.[8] Alarmingly, 38.9 percent of all high school e-cigarette users used e-cigarettes for 20 days or more a month, an indicator of addiction.[9] In addition to exposing users to nicotine and other harmful and potentially harmful substances, research shows that e-cigarette use increases the risk of smoking cigarettes.[10]

The CDC's Office on Smoking and Health has a critical role to play in addressing the youth e-cigarette epidemic. The agency has extensive experience working with state and local health departments and the capacity to identify and implement effective prevention strategies designed specifically towards youth. An increase in funds would allow CDC to provide more resources to state and local health departments; educate students, parents and their communities about the risks of youth e-cigarette use; and develop and implement other strategies to protect kids.

In addition to the youth e-cigarette epidemic, there remains a great need to help adult tobacco users who want to quit. The vast majority of adult smokers started as youth, want to quit and wish they had never started.[11] The CDC's national media campaign, Tips from Former Smokers (Tips), has proven to be highly successful at helping smokers quit. The campaign features former smokers discussing the harsh realities of living with a disease caused by smoking and how current smokers can access evidence-based resources to assist them in quitting. Between 2012 and 2018, the campaign motivated over 16.4 million smokers to make a quit attempt and helped over one million smokers to successfully quit for good.[12] A recent cost-effectiveness analysis found that over the same timeframe, Tips helped prevent 129,100 smoking-related deaths and saved an estimated $7.3 billion in smoking-related health care costs.[13]

The Tips campaign has been enormously successful despite being on air for only part of the year. In 2020, the campaign ran for 28 weeks. The 2014 Surgeon General's Report, The Health Consequences of Smoking-50 Years of Progress, said that media campaigns like Tips would ideally run 12 months a year.[14] With additional funding, the CDC could extend the number of weeks the campaign is on the air as well as the frequency with which the ads are run. Research has demonstrated that increased exposure to Tips ads leads to increases in intentions to quit and quit attempts.[15]

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[7] Office of the Surgeon General, "Surgeon General's Advisory on E-Cigarette Use Among Youth," December 18, 2018, https://e-cigarettes.surgeongeneral.gov/documents/surgeon-generals-advisory-on-e-cigarette-use-among-youth-2018.pdf.

[8] Wang, TW, et al., "E-cigarette Use Among Middle and High School Students—United States, 2020," MMWR, Volume 69, September 9, 2020, https://www.cdc.gov/mmwr/volumes/69/wr/pdfs/mm6937e1-H.pdf.

[9] Wang, TW, et al., "E-cigarette Use Among Middle and High School Students—United States, 2020," MMWR, Volume 69, September 9, 2020, https://www.cdc.gov/mmwr/volumes/69/wr/pdfs/mm6937e1-H.pdf.

[10] HHS, E-Cigarette Use Among Youth and Young Adults. A Report of the Surgeon General. Atlanta, GA: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Office on Smoking and Health, 2016; Barrington-Trimis, JL, et al., "E-Cigarettes and Future Cigarette Use," Pediatrics, 138(1), published online July 2016; National Academies of Sciences, Engineering, and Medicine. 2018. Public health consequences of e-cigarettes. Washington, DC: The National Academies Press. http://nationalacademies.org/hmd/Reports/2018/public-health-consequences-of-e-cigarettes.aspx. Berry, KM, et al., "Association of Electronic Cigarette Use with Subsequent Initiation of Tobacco Cigarettes in US Youths," JAMA Network Open, 2(2), published online February 1, 2019;.

[11] U.S. Department of Health and Human Services (HHS), The Health Consequences of Smoking—50 Years of Progress: A Report of the Surgeon General, 2014; Babb, S., et al., "Quitting Smoking Among Adults—United States, 2000–2015," MMWR 65(52), January 6, 2017;Nayak, P., et al., "Regretting Ever Starting to Smoke: Results from a 2014 National Survey," International Journal of Environmental Research and Public Health, 2017; O'Connor, Richard J., et al., "Exploring relationships among experience of regret, delay discounting, and worries about future effects of smoking among current smokers." Substance Use & Misuse 51, no. 9 (2016).

[12] Murphy-Hoefer R, Davis KC, King BA, Beistle D, Rodes R, Graffunder C. Association between the Tips From Former Smokers Campaign and Smoking Cessation Among Adults, United States, 2012–2018. Preventing Chronic Disease, 2020.

[13] Shrestha SS, est al., "Cost Effectiveness of the Tips From Former Smokers Campaign—US, 2012–2018. American Journal of Preventive Medicine, December 2020.

[14] U.S. Department of Health and Human Services (HHS), The Health Consequences of Smoking—50 Years of Progress: A Report of the Surgeon General, 2014, http://www.surgeongeneral.gov/library/reports/50-years-ofprogress/.

[15] Davis, Kevin C., et al. "Association Between Media Doses of the Tips From Former Smokers Campaign and Cessation Behaviors and Intentions to Quit Among Cigarette Smokers, 2012–2015." Health Education & Behavior (2017).

Tobacco use plays a significant role in health disparities. Despite the progress that has been made in reducing tobacco use, certain populations and regions of the country face disproportionately high rates of tobacco use and tobacco-related disease and premature death. For example, Americans with lower levels of education and income, American Indians and Alaska Natives, lesbian, gay and bisexual adults, and adults with a mental illness all smoke at significantly higher rates than other Americans.[16] Despite initiating smoking later in life than whites, Black Americans suffer from significantly higher rates of diseases and death caused by smoking.[17]

With additional funding, CDC could provide targeted assistance to groups disproportionately harmed by tobacco use. By collaborating with state and local health departments and community organizations, CDC could implement prevention and cessation programs tailored to resonate with and serve specific groups.

We urge the subcommittee to increase funding for CDC's Office on Smoking and Health from the $237.5 million it received in fiscal year 2021 to $310 million in fiscal year 2022. An additional $72.5 million would provide CDC with the resources it needs to increase funding to states and take other steps to address the epidemic of youth e-cigarette use, expand the highly successful Tips from Former Smokers media campaign, and provide targeted assistance to groups disproportionately harmed by tobacco use.

We appreciate the opportunity to highlight the important work of CDC's Office on Smoking and Health and the need to increase its funding to $310 million in fiscal year 2022.

[This statement was submitted by Matthew L. Myers, President, Campaign for Tobacco-Free Kids.]

PREPARED STATEMENT OF THE CAREGIVER ACTION NETWORK

On behalf of Caregiver Action Network (CAN), I am testifying in support of the Care Corps program funded through HHS' Administration for Community Living (ACL). We request doubling the appropriation for Care Corps from $4 million in FY 2021 to $8 million in FY 2022.

Care Corps is an innovative Federally funded grant program that was created in FY 2019 with a $5 million appropriation, subsequently receiving $4 million in FY 2021. In August 2019, the U.S. Administration for Community Living (ACL) awarded a five-year cooperative agreement to implement the new Care Corps program to a team of four organizations comprised of Oasis Institute, Caregiver Action Network, the National Association for Area Agencies on Aging, and Altarum. The four organizations named the new program the Community Care Corps.

Community Care Corps fosters innovative local models to provide volunteer nonmedical assistance to family caregivers, older adults, and adults with disabilities. Community Care Corps is an opportunity for community organizations to use volunteers to address some of the gaps in existing basic supports for family caregivers, older adults, and people with disabilities. The program, intended as a demonstration program over 5 years, will also evaluate the effectiveness of local models in different communities nationally.

For tens of millions of Americans who are older, frail, or functionally disabled, timely access to reliable assistance with simple household tasks and meaningful companionship can make an enormous difference in the quality of their lives and their ability to sustain meaningful, ongoing connections to the community in which they live.

Today, 80% of the care for those over age 65 is provided by family caregivers. Yet in the future there will be fewer caregivers. According to AARP, in 2010, there were more than 7 potential caregivers for every person over age 80. By 2030, the care-

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[16] Cornelius ME, Wang TW, Jamal A, Loretan CG, Neff LJ. Tobacco Product Use Among Adults—United States, 2019. MMWR Morb Mortal Wkly Rep 2020;69:1736–1742. DOI: http://dx.doi.org/10.15585/mmwr.mm6946a4; Substance Abuse and Mental Health Services Administration (SAMHSA), HHS, Results from the 2019 National Survey on Drug Use and Health, NSDUH: Detailed Tables, 2019, https://www.samhsa.gov/data/report/2019-nsduh-detailed-tables.

[17] Roberts, ME, et al., "Understanding tobacco use onset among African Americans," Nicotine & Tobacco Research, 18(S1): S49–S56, 2016; Alexander, LA, et al., "Why we must continue to investigate menthol's role in the African American smoking paradox," Nicotine & Tobacco Research, 18(S1): S91–S101, 2016; CDC, "Quitting Smoking Among Adults-United States, 2000–2015," MMWR, 65(52): 1457–1464, January 6, 2017, https://www.cdc.gov/mmwr/volumes/65/wr/pdfs/mm6552a1.pdf; HHS, "Tobacco Use Among US Racial/Ethnic Minority Groups-African Americans, American Indians and Alaskan Natives, Asian Americans and Pacific Islanders, and Hispanics: A Report of the Surgeon General," 1998, http://www.cdc.gov/tobacco/data__statistics/sgr/1998/complete__report/pdfs/complete__report.pdf.

giver ratio will drop to 4 to 1; and by 2050, the ratio drops to less than 3 to 1. During this same period, the number of individuals over the age of 84 is set to rise by 350%.

Given the rapidly shrinking ratio of family caregivers to the number of older Americans who need assistance, volunteers aged 18 and older can help ameliorate the coming "caregiving cliff" brought on by the nation's demographic changes. In support of the Care Corps program, the Report accompanying the House Labor-HHS Appropriations bill last year "recognize[d] the growing demand for services and supports to help seniors and individuals with disabilities live independently in their homes, and the need to support family caregivers who facilitate that independence."

Interest in the new Community Care Corps program across the country has been tremendous. Community Care Corps issued its first RFP in 2020 and received 183 applications from 45 states plus DC and Puerto Rico. The application process was very competitive, with the 183 applications totaling $23 million in funding requests. Clearly, not all applications received funding (we were only able to fund 10% of the grant requests); and those that did, did not receive the full amount requested.

We selected 23 grantees from 20 states from this competitive pool of applications. The award amounts range in size from $30,000—$250,000. The 23 grantees' local model volunteer programs are community-based and provide a wide range of non-medical volunteer services. Community Care Corps volunteer programs do not replace the important services that the home care workforce and other paid professionals provide to help individuals live independently in the community.

Our 2020 grantees represent a diverse cross section of the nation, representing urban, rural, Frontier and Tribal communities. The grantees comprise numerous types of organizations including community-based organizations, university-based clinics, area agencies on aging, neighborhood villages, government agencies, coalitions, hospitals, and social service organizations. The size of the organizations also varies considerably—from very large such as Maryland's St. Agnes Hospital, a member of Ascension Health, the largest non-profit health care organization in the nation, to North Carolina's Carova Beach Volunteer Fire and Rescue Auxiliary with a volunteer staff of one serving a small ocean front community that can only be accessed by four-wheel-drive. Grantees provide services to individuals of a variety of races and ethnicities including Hispanic, Native American, White, Black, Asian, and Native Alaskan. Two grantees specifically serve new Americans.

We particularly search for local grantees with innovative ways to use volunteers to provide non-medical assistance in their community. For example, in Alaska volunteers assisted the target population with fishing and hunting to supplement food sources. The grantee in Michigan leveraged face-to-face video calls to participants even prior to the COVID crisis. In Connecticut, the grantee exercised flexibility by using their Trusted Ride Transportation program to pivot and provide COVID vaccine appointments and transportation for older adults in need of the vaccine.

In the first six months—even with time needed to adapt their original plans to the then-emerging Covid pandemic that required changes in how they deliver volunteer services—the grantees have already served 2,744 people. That included:

—2,273 older adults

—162 adults with disabilities

—309 family caregivers

Also, during the first six months, more than a thousand volunteers provided non-medical services and 191 training sessions were held for these volunteers.

Over the five years of the Community Care Corps program, local models with the most promising results, most effective and efficient outputs and outcomes, and greatest positive ROI will be assessed as ideal candidates for broader dissemination. Several outcomes and outputs are measured on a quarterly basis.

We are now about to begin the second grant cycle. The Senate Appropriations Labor/HHS Subcommittee included $4 million for Community Care Corps in FY 2021 and that was the level that was enacted for FY 2021. With the $4 million appropriated, we are able to fund additional grants and look forward to getting applications for innovative volunteer models from local communities across the country. The RFP for new applications has just been released and applications will be accepted through July 9. In addition, current grantees can apply for second-year funds. One of the key enhancements to our 2021 RFP is an intensified focus on diversity of volunteers, communities served, and caregivers in both the application and review process.

Caregiver Action Network (CAN) is the nation's leading non-profit family caregiver organization providing education, peer support, and resources to family caregivers across the country free of charge. One of the many things CAN does for Community Care Corps is to provide a wide range of communication and outreach support. CAN works with the grantees to capture videos of the experiences of care re-

cipients, family caregivers, and volunteers to amplify their collective voices through stories. These videos provide a true and authentic voice that increases awareness about the impact of grantee local models on their communities. As of this reporting period, grantees have generated more than 30 videos of volunteers, care recipients, family caregivers, and staff that have been shared on social media, with local media outlets, and with elected officials.

The first grant cycle of the Community Care Corps has been extremely successful. With the tremendous interest in the program and the large number of worthy applications from communities across the country, we request doubling the appropriation for Care Corps to $8 million in FY 2022 from the $4 million level in FY 2021 (and the $5 million level in FY 2019). This will allow the program to fund more local volunteer services and make up for the gap in funding that occurred in FY 2020. Thank you.

[This statement was submitted by John Schall, Chief Executive Officer, Caregiver Action Network.]

PREPARED STATEMENT OF THE CDC COALITION

The CDC Coalition is a nonpartisan coalition of 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. We urge a funding level of at least $10 billion for CDC's programs in FY 2022 to help ensure the agency has adequate resources for its many important programs to improve the public's health. We appreciate the increases provided for CDC in FY 2021 and we are grateful for the emergency supplemental funding provided for CDC to address COVID–19. We urge Congress to continue efforts to build upon these investments to strengthen all of CDC's programs. We strongly support the increases for important CDC programs outlined in President Biden's FY 2022 budget request and urge the committee to support these and other needed funding increases for CDC 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 public health emergency preparedness and response programs and must receive sustained support for these critical programs. 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 also urge you to provide adequate funding for CDC's infectious disease, laboratory and disease detection capabilities 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. Additionally, your continued support for CDC's public health Data Modernization Initiative is critical to ensuring we have both the world-class data workforce and data systems that are ready for the next public health emergency.

We strongly support the president's budget request for $400 million in new funding to bolster core public health infrastructure and capacity at the federal, state, territorial and local levels. This flexible funding is critical to addressing the gaps in core public health infrastructure and capacity at all levels as well as ensuring our nation's health departments are able to attract and retain experienced leaders and respond to future public health emergencies and disease outbreaks. Sustained, flexible funding is critical to rebuilding and strengthening the nation's public health system.

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 2019, opioids killed nearly 50,000 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 2019, there were over 39,707 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 support the president's request to double this funding in FY 2022. All programs within the National Center for Injury Prevention and Control must be adequately funded to conduct research, prevent injuries, and help save lives.

In 2019, 659,041 people in the U.S. died from heart disease, the nation's number one cause of death, accounting for about 23% of all U.S. deaths. More males than females died of heart disease in 2019, 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 2019, 150,005 people died of stroke, accounting for about one of every 19 deaths. Annually, heart disease and stroke cost the U.S. an estimated $363.4 billion in health care and lost productivity. CDC's Heart Disease and Stroke Prevention Program; WISEWOMAN; and Million Hearts improve cardiovascular health and we urge you to provide adequate funding for these important lifesaving programs.

More than 1.9 million new cancer cases and over 600,000 deaths from cancer are expected in 2021. The amount spent on cancer related healthcare is expected to grow from $183 billion in 2015 to $246 billion in 2030—an increase of 34%. 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 improves screening rates among targeted, low-income populations aged 50–75 years in targeted states and territories through evidence-based interventions. CDC funds all 50 states, DC, 7 tribes and tribal organizations and 7 U.S. territories and Pacific Island jurisdictions to develop comprehensive cancer control plans to address each state's particular needs. We urge Congress to adequately support these critical programs.

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 nearly one million individuals quit smoking and millions more to make a serious quit attempt. Congress must continue to support these and other 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. Diabetes is the leading cause of kidney failure, nontraumatic lower-limb amputations, and new cases of blindness among adults in the U.S. and the total direct and indirect costs associated with diabetes were $327 billion in 2017. We urge you to provide adequate resources for CDC's Division of Diabetes Translation and the National Diabetes Prevention Program which fund critical diabetes prevention, surveillance and control programs.

Obesity prevalence in the U.S. remains high. More than 42% of adults are obese and 19.3% 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.

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 1.2 million Americans are living with HIV with 14% 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 26 million new infections occurred in 2018. STDs, including HIV, cost the U.S. healthcare system almost $16 billion annually in direct lifetime medical costs.

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.

We thank the committee for its initial investment in CDC's Social Determinants of Health program and urge you to build upon this investment by increasing fund-

ing for the program to ensure that public health departments, academic institutions and nonprofit organizations are supported to address the social determinants of health in their communities that contribute to high health care costs and preventable inequities in health outcomes. We urge you to support the president's request of $153 million for this important program.

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 and reduce, monitor and track exposure to lead and other environmental health hazards. Increased funding for all NCEH programs is critical to protecting the public from environmental health hazards and reducing illness, disease, injury and even death.

To meet the many ongoing public health challenges facing the nation, including those outlined above, we urge you to provide at least $10 billion for CDC's programs in FY 2022.

[This statement was submitted by Don Hoppert, Director of Government Relations, American Public Health Association.]

PREPARED STATEMENT OF THE CENTERS FOR DISEASE CONTROL AND PREVENTION

Chairwoman Murray, Ranking Member Blunt, and distinguished members of the Committee, it is an honor to appear before you today to discuss how investments in the Centers for Disease Control and Prevention (CDC) are protecting American's health, now and in the future. I am grateful for this opportunity to address this committee, as well as for your long-standing and consistent leadership on issues of critical importance to the health of Americans, and the world.

It is my privilege to represent CDC at this hearing. CDC is America's health protection agency. For 75 years, CDC has been trusted to carry out its mission to protect America's safety, health, and security. Even during the unprecedented circumstances of the past year, CDC's scientific expertise, determination, selflessness, and innovation has helped the agency continue to advance its mission. We work 24/7 to prevent illness, save lives, and protect America from threats to our health, safety, and security. Addressing infectious diseases and pandemics, like COVID–19, is central to our mission. CDC's expertise lies in our ability to study emerging pathogens like SARS–CoV–2, to understand how they are transmitted, and to translate that knowledge into timely action to protect the public's health. CDC identifies and mitigates other causes of morbidity and mortality beyond infectious diseases, such as environmental and workplace hazards and intentional and unintentional injuries (such as those from falls, violence, or overdose). CDC promotes healthy behaviors, such as exercise and nutrition, to prevent chronic diseases such as diabetes and heart disease, and to prevent outcomes such as stroke. We promote healthy communities by increasing access to nutritious food and safe walking and green space. By deploying experts on the ground to support our state, Tribal, local, territorial and global partners, we translate science into implementing guidance that protects individuals, communities, and populations. In our work with other Federal agencies we ensure the safe and appropriate use of medical countermeasures, including vaccines, and collaborate with the academic and private sector to further our understanding of new diseases and problems that affect health.

The COVID–19 pandemic threw the United States and the world into a health, economic, and humanitarian crisis. As the crisis unfolded, it put a spotlight on preexisting weaknesses and gaps that threaten the health of Americans. It brought into stark light the great disparities in health outcomes by race and ethnicity. We must acknowledge the long-standing and too often unstated impact that racism has on public health. The pandemic has also highlighted our frail public health infrastruc-

ture, and the way that frailty impacted our ability to respond at the necessary scale and speed.

Experts had warned for years that a pandemic of this scale was coming. Today, we know to expect additional novel and currently rare diseases to emerge and gain footing as a result of our changing climate, closer interaction with animals, and globalization. Over the last 12 years, the United States has faced four significant emerging infectious disease threats—the H1N1 influenza pandemic, Ebola, Zika, and COVID–19. These experiences show that public health emergencies and, specifically, infectious disease threats, are here to stay. While urgency demanded rapid and unique responses to each of these threats, none resulted in the sustained improvements needed in our nation's public health infrastructure. This lack of robust public health infrastructure continues to present significant challenges in our ongoing fight against COVID–19. In fact, emergencies have resulted in the rapid build-up of infrastructure needed to address the emergency, then dissolution of that infrastructure, often leaving no sustainable infrastructure in place to address the next threat. This lack of robust public health infrastructure continues to present significant challenges in our ongoing fight to tackle COVID–19.

World-wide, billions of people do not and will not have immediate access to COVID–19 vaccines. Cases will continue to increase, and variant COVID–19 strains are likely to emerge, persist, and cause outbreaks. As this becomes more common, our public health system at home and abroad must be ready with highly sophisticated detection and sequencing, combined with a rapid response at the source. The unprecedented investments provided to CDC through COVID–19 supplemental appropriations have helped our efforts to control COVID–19, and will also go a long way toward addressing deficits in the core components of the public health infrastructure that has long been ignored. Our ability to respond to the next public health crisis will depend on whether we invest in a public health system that is highly functional on a day-to-day basis and pivots to meet new threats, rather than continue our partial defense, which ramps up in response to an urgent and often short-term event.

A resilient public health system can be realized with careful planning that builds on the gains made with COVID–19 emergency supplementals and incorporates lessons learned as a result of this crisis, including reliable, flexible funding. The FY 2022 Discretionary Budget Request for CDC and ATSDR includes a total funding request of $8.7 billion, an increase of $1.6 billion over FY 2021 Enacted. This is the largest increase in budget authority for CDC in nearly two decades and defends Americans' health in four ways: (1) building public health infrastructure, (2) reducing health disparities, (3) using public health approaches to reduce violence, and (4) defeating other diseases and epidemics.

First, building the public health infrastructure. CDC's FY 2022 request prioritizes foundational funding to rebuild the public health infrastructure needed to safeguard the Nation's health and economic security. Drawing on lessons learned, as well as the latest information and technologies, CDC will begin to address long-standing vulnerabilities in the U.S. public health network by training a larger cadre of experts who can deploy and support public health efforts, and building capacity to detect and respond to emerging global biological threats.

Public health action is driven by data. Earlier improvements in our systems for collecting information after other public health emergencies, including Ebola and EVALI, facilitated exchange of health information, linking local, state, and federal public health systems with healthcare systems and the public. With investments in public health data modernization in the FYs 2020 and 2021 appropriations and the COVID–19 supplementals, CDC increased the scale and speed of these systems during the COVID–19 response to protect people who are at risk for severe illness (such as older Americans), those with chronic medical conditions, and those from racial and ethnic minorities. These advancements must be applied across the public health system and at all levels of government. The funds requested in FY 2022 will be used to continue building a modern disease surveillance system at CDC, which will catalyze a multi-sectoral, comprehensive, and cohesive approach to documenting evidence, using state-of-the-art technology and analytical tools. CDC will continue working diligently to ensure its research and data are of the highest quality and are disseminated nationally to inform decision-making throughout the public health system, while supporting advances in data systems at all levels.

The COVID–19 pandemic made clear the role that CDC labs and public health labs across the nation play in conducting critical surveillance and responding to outbreaks and emerging threats. CDC and state laboratories were required to flex and surge during peak periods of illness, far beyond routine clinical testing. In FY 2019, CDC was only able to meet 50% of state and local health departments' stated needs for epidemiology and laboratory capacity funding, with personnel support being the

biggest unfunded need, followed by equipment and supplies. The FY 2022 request will foster innovation, collaboration with the clinical system, and a commitment to quality. Improving technologies at the state and local levels would enable public health labs to quickly utilize and scale up essential laboratory analyses. In a post-COVID–19 world, investments to maintain and improve laboratories will help prevent the failures we experienced while trying to address COVID–19.

The U.S. needs a workforce of qualified public health professionals who will prepare for, respond to, and prevent public health crises. Physicians working for states often earn less than $150,000 per year. This is after having taken on medical school debt of $200,000 on average. The FY 2022 request includes an increase to build a diverse and culturally competent workforce who can rapidly develop innovative approaches in surveillance and detection, risk communications, laboratory science, data systems, and disease containment. With this funding, CDC will support critical training programs for public health professionals that develop strategic and systems thinking, data science, communication, and policy evaluation. Existing cooperative agreement mechanisms will be leveraged to support public health jobs that meet current needs and attract new personnel to work in underserved and rural areas.

Addressing gaps in capacity across levels of government to detect and respond to outbreaks while maintaining and surging in other problem areas requires investments to be disease-agnostic and flexible. With FY 2022 funding, CDC will provide support to health departments to meet national quality standards, conduct performance improvement activities, increase communication and collaboration across the public health system, and reshape health departments to meet changing conditions and needs. Funding will help health departments strengthen their abilities to effectively respond to a range of public health threats, such as COVID–19, and build capacities that do not currently exist.

COVID–19 is a sobering reminder that a disease threat anywhere is a disease threat everywhere. Or as stated by WHO: no one is safe unless everyone is safe. We cannot adequately protect American lives and the U.S. economy without addressing global disease threats wherever they may arise. CDC's strategic investments in global health security are critical to U.S. health security by building sustainable global capacity to prevent, detect, and respond to emerging infectious disease threats. CDC works in more than 60 countries on more than 150 projects and is a key implementing agency for the U.S. Government's leadership role in the Global Health Security Agenda. With additional resources requested in FY 2022, CDC will build on existing partnerships with Ministries of Health, public health agencies, infectious disease research institutions, and international organizations to strengthen global laboratory capacity for early disease detection, enhance disease surveillance for accurate data to drive decision making, and foster effective regional and global coordination.

Next, I'd like to talk about reducing health disparities. The disparities seen over the past year among communities of color were not a result of COVID–19. In fact, the pandemic illuminated inequities that have existed for generations and revealed a known, unaddressed, and serious public health threat: racism. The well-being of our entire nation will be compromised as long as we fail to address this.

Racism is not just discrimination against one group based on the color of their skin or their race or ethnicity, but the structural barriers that impact racial and ethnic groups differently to influence where a person lives, where they work, where their children play, and where they worship and gather in community. The social determinants of health (SDOH)-such as high-quality education, stable and fulfilling employment opportunities, safe and affordable housing, access to healthful foods, commercial tobacco-free policies, and safe green spaces for physical activity-are critical drivers of health inequities in this country. CDC is building the evidence-base for collaborative approaches to SDOH through community accelerator planning and expanding a network of community health workers to develop a sustainable infrastructure to improve health equity. CDC's FY 2022 budget request includes an increase of $150 million to use a social determinants of health approach to improve health equity and health disparities in racial and ethnic minority communities and other disproportionately affected communities around the country.

This budget directly responds to health disparities recorded in our public health data. For example, about 700 women die each year in the U.S. as a result of pregnancy or delivery complications, and American Indian, Alaska Native, and Black women are two to three times more likely to die than White women. Data show that about 2/3 of these deaths may be preventable. Children from lower-income and racial and ethnic minority households experience a disparate, increased risk for lead exposure.

Achieving health equity is central to addressing the HIV epidemic. The U.S. Government spends $20 billion per year in direct health expenditures for HIV care and

treatment. An estimated 1.2 million persons have HIV and approximately 15% are unaware they have it. With recent advancements in antiretroviral therapy and biomedical advancements in HIV prevention, such as pre-exposure prophylaxis (PrEP), along with effective care and treatment, we have the tools to end the HIV epidemic. An increased investment requested in FY 2022 for the Ending the HIV Epidemic (EHE) initiative will enable CDC to advance the four key strategies needed to end the epidemic in the 57 EHE focus jurisdictions. In addition, CDC will address health equity in the entire HIV prevention portfolio, test innovation in service delivery models to increase access to prevention services, use syndemic approaches to broaden reach to key populations and create efficiencies, and strengthen engagement of grassroots community-based organizations in implementing EHE initiative.

Third, the budget request also addresses the public health epidemic of violence. We know too well how this epidemic permanently alters the lives of its victims and their families and puts enormous strain on our communities and local economies. Increases in CDC's FY 2022 budget request will help address violence through public health approaches, which include improving reporting systems that provide the data needed to understand and address violent deaths and injuries in the United States.

And fourth, we must defeat other diseases and epidemics. Just as racism underlies a number of public health issues, climate issues underlie a number of infectious diseases and have significant health impacts. Climate changes are associated with changes in the geographical range of mosquitos, ticks, and other disease vectors. Climate-related events impact a wide range of health outcomes. Some of the most significant climate-related events-such as heat waves, floods, droughts, and extreme storms-affect everyone. These climate events compromise our access to clean air, clean water, and a reliable food supply. In addition, climate events can impact the presence of allergens and vectors, like ticks and mosquitoes, and the subsequent health outcomes that can result from these changes in exposures. We know that a changing climate can intensify existing public health threats, and that new health threats will emerge: unequally distributed risks (age, economic resources, location), increased respiratory and cardiovascular disease, injuries and premature deaths related to extreme weather events, changing prevalence and geography of foodborne and waterborne illnesses and other infectious diseases, and threats to mental health as people feel less safe.

CDC works with states, cities, and tribes to apply the best climate science available, predicting health impacts, and preparing public health programs to protect their communities. To do this, CDC developed the Building Resilience Against Climate Effects (BRACE) framework to help communities prepare for the health effects of climate change by anticipating climate impacts, assessing vulnerabilities, projecting disease burden, assessing public health interventions, developing adaptation plans, and evaluating the impact and quality of activities. With the requested increase in FY 2022, we can further expand the Climate and Health Program by providing a larger number of health departments with technical assistance and funding and finding innovative ways to protect health via climate adaptations. As with every other public health threat, we will inform our effort by building and examining systems that collect data on conditions related to climate, including asthma and vector-borne diseases, and coordinate programs and communication that improve health outcomes.

The opioid epidemic has shattered families, claimed lives, and ravaged communities across the Nation-and the COVID–19 pandemic has only deepened this crisis. Addressing the current overdose epidemic remains a priority for CDC. The Administration's strategy brings together surveillance, prevention, treatment, recovery, law enforcement, interdiction, and source-country efforts to address the continuum of challenges facing this country due to drug use. CDC's role is to prevent drug-related harms and overdose deaths.

The additional funding requested in FY 2022 to address the opioid epidemic will enable CDC to provide more funding to all States, Territories, and select cities/counties. CDC will prioritize support to collect and report real-time, robust overdose mortality data and to move from data to action, building upon the work of the Overdose Data to Action (OD2A) program. To do so, CDC will partner with funded jurisdictions to implement surveillance strategies that include contextual information alongside data, as well as increase surveillance capabilities for polysubstance use and emerging substance threats such as stimulants. The additional resources requested will enable CDC to support investments in prevention efforts for people put at highest risk, for example, supporting risk reduction and access to medications for opioid use disorder for people transitioning from alternate residence (jail/prison, treatment facility, homeless shelter). CDC will also address infectious disease consequences, such as viral hepatitis, of the opioid epidemic.

I look forward to working together to address both the immediate challenges ahead in our fight against COVID–19, as well as the weaknesses in the public health infrastructure that left our country vulnerable to this pandemic. We at CDC are grateful for your support. We will continue to work tirelessly to ensure the health of this nation and the world. Together, we can build a sustainable and resilient public health system that can respond effectively to emerging threats and also to ongoing public health needs of every American.

[This statement was submitted by Rochelle P. Walensky, M.D., M.P.H., Director, and Anne Schuchat, M.D.,Principal Deputy Director, Centers for Disease Control and Prevention.]

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 the 1 in 50 individuals living with paralysis in the United States, 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 19 years, competing in a rigorous, competitive bidding process every three years for renewal of this grant. For fiscal year 2022, 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 FY21. The Reeve Foundation was also pleased to see that the President's Budget for FY22 requests a 5% increase for the Paralysis Resource Center.

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 of 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 needed a centralized place to call for resources and expertise.

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. Our 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 directly 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.

A. The PRC's Core Programs

(1) *Information Specialists.* One of the PRC's most essential functions is the team of certified, trained Information Specialists (IS) who provide personalized support to individuals, families, and caregivers 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. 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 and the PRC team would hold my hand the entire way. It is also important to note how critically their services have been educating and supporting the paralysis community during the pandemic.

To date, the PRC Information Specialists have provided direct counseling to over 106,000 people. We have distributed 220,000 copies of our Paralysis Resource Guide, which is a staple in hospitals and rehabilitation facilities across the country.

(2) *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 450 peer mentors have been trained and certified in 43 states and Washington, DC. These individuals have mentored over 17,000 peers.

(3) *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, the District of Columbia and the U.S. territories. Since 1999, the Quality-of-Life Grants Program has directed over $33 million dollars to assist over 3,300 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. In 2020, the PRC created a new Quality of Life (QOL) grants program specifically aimed at addressing social isolation during the COVID–19 pandemic, with the goal of enhancing connectedness of people living with paralysis and their caregivers to their communities and preventing adverse health outcomes.

(4) *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 racial and ethnic minorities, older adults, low-income earners, and LGBTQ individuals.

(5) *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 as part of the PRC, which attracts close to three million visitors per year, and Reeve Connect, our online forum, has allowed over 8,000 individuals to connect with experts, chat with one another and share the experiences that matter to them in a secure, private space.

B. 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.

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.

PREPARED STATEMENT OF THE COALITION FOR CLINICAL AND TRANSLATIONAL SCIENCE

FISCAL YEAR 2022 APPROPRIATIONS RECOMMENDATIONS

—CCTS joins the broader medical research community in asking Congress to provide the National Institutes of Health (NIH) with at least a $3.2 billion funding increase for FY22, to bring total agency funding up to a minimum of $46.1billion annually.

—Please provide the Clinical and Translational Science Awards (CTSA) program at the National Center for Advancing Translational Sciences (NCATS)

with at least a $32 million increase in dedicated line-item funding for FY22 to bring annual support for the program up to a minimum of $620 million.
—Please provide the Cures Acceleration Network (CAN) at NCATS with $100 million in dedicated funding for FY22.
—Please provide the Institutional Development Awards (IDeA) program and the Research Centers in Minority Institutions (RCMI) program at NIH with meaningful proportional funding increases for FY22.
—CCTS joins the broader public health community in requesting $500 million for the Agency for Healthcare Research and Quality (AHRQ).
—CCTS joins the broader public health community in requesting $10 billion for the Centers for Disease Control and Prevention (CDC).

Chairwoman Murray, Ranking Member Blunt, and distinguished members of the Subcommittee, thank you for considering the views of the clinical and translational research community as work on FY 2022 appropriations. The community deeply appreciates the ongoing investment in medical research, including FY21 NIH funding and overall support for the COVID–19 response. Moreover, CCTS commends you for continuing to protect line-item funding for the CTSA program, which provides critical research infrastructure support to meritorious institutions across the country and serves as a major catalyst for advancing the full spectrum of medical research at NIH. The value, importance, and impact of the CTSA program as well as full-spectrum research at NIH was best highlighted by our ability to quickly develop treatments, vaccines, diagnostic tools, and health information to quickly respond to the ongoing COVID–19 pandemic. As you consider FY 2022 funding, CCTS and the broader community would like to highlight recent progress, emerging opportunities, and the importance of sustained investment.

ABOUT THE COALITION FOR CLINICAL AND TRANSLATIONAL SCIENCE

The Association for Clinical and Translational Science, 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.

Most crucially, the appropriations committees have included detailed 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 advancing full spectrum research and team science as well as maintaining the integrity of the CTSA line-item will be provided for FY 2022.

RECENT CTSA ACTIVITY

Yale Center for Clinical Investigation (YCCI)

YCCI initiated double-blind randomized outpatient covid treatment trials involving the experimental drug apilimod dimesylate (LAM–002A), a first in class, highly selective PIKfyve kinase inhibitor from Connecticut Biotech firm AI therapeutics, which prevents SARS–CoV–2 viral entry into cells. Similarly, a randomized, double blind outpatient repurposing trial of camostat mesylate, which inhibits SARS–CoV–2 infection by blocking the virus-activating host cell protease TMPRSS2, was simultaneously initiated. YCCI also supported participation in multi-institutional randomized placebo controlled trials including Pfizer-sponsored vaccine trials and a randomized, placebo controlled cooperative inpatient trial of convalescent plasma by a consortium of CTSA institutions. Innovative pandemic monitoring approaches were developed including the measuring of SARS–CoV–2 RNA concentrations in primary municipal sewage sludgeas a leading indicator of COVID–19 outbreak dynamics.

The YCCI's Cultural Ambassador program, initiated eleven years ago, has been a critical component in the response to the pandemic. This bi-directional partnership influences Yale research priorities and drives research that meets the needs of the surrounding community. The Cultural Ambassadors, appointed by the community, collaborate with Yale researchers on trial design, recruitment, and reducing access barriers for the community and engage in advocacy and education efforts in the community, driving awareness of the importance of clinical research. The program builds trust-based relationships, increases health system engagement and contributes to improved overall health. This has been the lynchpin for community-based clinical trials that has resulted in participation in clinical trials by underrepresented minorities of 31% in the last academic year.

University of Washington

Limiting Opioid Abuse.—Over the last several years, our CTSA has organized dozens of rural clinics into a network. This network initiated an observational study of best practices in the management of patients who are on long-term opioid therapy for chronic pain, which evolved into a prescribing program. Rigorous testing of the developed intervention at 20 rural practice sites demonstrated a 19% reduction in high dose opioid prescribing.

COVID Clinical Trials in Rural Communities.—The UW CTSA, through the development of the rural clinic network, was able to push clinical trials from the UW to rural Washington rapidly. Providence Health in Spokane, WA, one of our Network partners, was 1 of the first 10 US sites to open the ACTIV–1 trial and enrolled their first participant 5 days after receiving the protocol. Inclusion of rural serving clinical sites was critical to our regional communities as COVID–19 infections were increasing dramatically in migrant farm worker populations.

Vanderbilt

The Vanderbilt Institute for Clinical and Translational research was well positioned to respond to the pandemic in large part because of the CTSA-supported infrastructure. First, the local ecosystem was mobilized to organize and coordinate the local response. From this, we identified the need to harmonize various trial activities across the country, and NCATS supported initiatives for harmonizing COVID–19 trial oversight and data pooling. At the same time, we were positioned to conduct clinical trials with efficient contracting and regulatory approvals, launching PassItOn—a trial of convalescent plasma—with seed funding from Dolly Parton. NCATS supported the rest of the trial, which has almost reached its enrollment target of 1000 patients. We were also identified as the science unit for NHLBI's network of networks, providing guidance to the agent selection, design, and analysis of trials of the host-tissue response to SARS-CoV–2 infection, building on the success of our drug repurposing program and biostatistics programs. Continuing to springboard of these foundations, we are now leading ACTIV4D–RAAS and serving

as the DCC for ACTIV6, this latter with funding through NCATS. Lastly, our CTSA-supported learning health system has completed the only known large, randomized controlled of prone positioning in moderately sick inpatients, with results in the process of being disseminated.

University of Texas Health Science Center at San Antonio

Resources, facilities, and personnel from the Institute for Integration of Medicine & Science, home to the UTHSCSA CTSA grant, enabled a rapid, collaborative, and comprehensive response to the COVID–19 crisis. Within weeks of the pandemic onset, UTHSCA established a unique virtual clinic for newly diagnosed patients. Research teams are characterizing health disparities and COVID–19 symptoms in this majority (84%) Hispanic population. As part of the NIH Community Engagement Alliance Against COVID–19 Disparities, CTSA specialists partner with regional health professionals and local organizations in underserved regions across South Texas to provide expert community engagement, community based-participatory research, and dissemination of best practices for COVID–19 care. As a result of the extensive preparation of CTSA hub and network research infrastructure, UTHSCA was among the top enrolling sites for major national studies including the NIH Accelerating COVID–19 Therapeutic Interventions and Vaccines (ACTIV) trials. CTSA support was also instrumental in launching a pioneering study of immunological resilience in 522 Veterans with COVID–19, which has yielded new biomarkers and new insights into the relative vulnerability of males to serious illness.

[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 81 national health organizations representing more than 100 million patients and consumers, health providers, professionals and researchers—appreciates the opportunity to submit testimony for the record about the importance of health funding. Together, our members speak with one voice in support of federally funded health programs with a shared goal of improved health and well-being for all. While each member organization has its own funding priorities within the Department of Health and Human Services (HHS), our coalition is united in support of increased and sustained funding for all federal agencies and programs across the public health continuum—from bench to bedside—to ensure that all Americans lead long, healthy, productive lives.

Today, we have an unprecedented opportunity to shape the future of this country's public health infrastructure. The COVID–19 pandemic critically strained health, social, and economic systems around the world, and highlighted the importance of sustained and predictable health funding. Supplemental funding to address the urgent needs of the pandemic was, and continues to be, essential, but it alone is not the solution to respond to future pandemics. For too long, Congress neglected critical pieces of our public health infrastructure and health research pipeline, which hindered our ability to respond quickly and effectively when disaster struck. Now is the time to take corrective action and make sustained investment in public health. We learned many lessons during the pandemic, including that biomedical research and a robust public health workforce are indispensable and require sustained investment. A significant fiscal year (FY) 2022 allocation for public health funding will allow our health systems to emerge stronger and better equipped to improve health outcomes.

The Coalition urges Congress to seize the opportunity FY 2022 presents as the first appropriations cycle in a decade not governed by the spending caps of the Budget Control Act of 2011 (BCA). Without the BCA imposed budget caps, Congress should provide funding increases across the HHS accounts commensurate with the need for non-defense discretionary programs that support public health, medical and scientific research, infrastructure, education, public safety, and more. Congress should follow the increase set forth in President Biden's FY 2022 Discretionary Budget request and increase the HHS budget by at least 23.5 percent or $25 billion above FY 2021 levels. Increased funding will not only support future economic growth, but will strengthen the health, safety, and security of all Americans.

HHS agencies play a key role in addressing our nation's public health needs and work in partnership with state and local governments to protect and promote health in our communities. While each agency within HHS has a unique mission to respond to our nation's health demands, they are all interconnected. For example, the COVID–19 pandemic has shown that investment in medical research at the National Institutes of Health (NIH) is important, but on its own will not improve

health. You need the Food and Drug Administration to approve new treatments. You need the Centers for Disease Control and Prevention, Health Resources and Services Administration, Substance Abuse and Mental Health Services Administration, and Indian Health Service to ensure we have qualified health professionals who can translate research into health care and public health delivery, support Americans while they're awaiting new cures, and prevent them from getting sick in the first place. You also need the Agency for Healthcare Research and Quality to provide clinical evidence on what treatments work best, for whom, and in what circumstances. And you need the Administration for Community Living to support those who are aging and those who have disabilities—as well as their caregivers—so that they can live their best life, every day. Without robust funding for all agencies and programs of the interdependent public health continuum, we're falling short on the promise to protect and improve the health and well-being of all Americans. Shortchanging public health and health research programs—or cutting health programs—leaves Americans vulnerable to health threats and will not prevent public health crises from arising in the first place as we witnessed over the last year.

As COVID–19 cases begin to decline and life starts to look more like it did before the pandemic, it is important to recognize that the pandemic's effects go far beyond the virus itself and will have long-lasting impacts on Americans. Research is just one of the many areas impacted by the pandemic that requires additional investment to get back on track. Every agency within HHS conducts research that is important to strengthening our public health system. Congress has a responsibility to ensure that all agencies within HHS receive equitable funding for efforts to regain some of the ground that has been lost due to necessary pauses in and increased costs of research as well as ensure the pandemic does not wipe out a whole generation of investigators who were forced to choose other career paths because of the disruption.

Another well-established impact of the pandemic has been the toll it has taken on mental health and substance abuse. Four in ten adults report symptoms of anxiety or a depressive disorder, up from one in ten adults in June 2019. Substance abuse and misuse, including alcohol, has increased by 12 percent.[1] Gains made in the fight against the opioid epidemic-another dire public health crisis-were diminished as an estimated 87,000 Americans lost their lives due to overdose from September 2019 to September 2020, a 29 percent increase over the previous year.[2] Adequate funding for preventive, supportive, and rehabilitative services will be critical to address and reduce these concerning trends.

The detection and management of chronic diseases is another area of public health that was set back as a result of the pandemic. An estimated six in ten American adults have a chronic disease, with four in ten having two or more.[3] Restrictions on elective procedures and non-urgent health care visits, coupled with concerns about the virus and obstacles to connecting virtually with providers during the pandemic caused many Americans to postpone routine care and skip necessary screenings, which in some cases has negatively impacted patients' ability to manage their disease.[4] Additionally, the millions of Americans now living with post-acute sequelae of COVID–19-often referred to as "long-haulers" because they experience lingering symptoms that last from weeks to months-could further increase the number of people in the U.S. living with a chronic disease, like diabetes or heart disease, and adds new complexities to our chronic disease management efforts. As a result, there is a significant need for increased funding for public health programs that reduce barriers to care and help patients detect and manage their conditions.

Research, mental health, substance use disorders, and chronic disease are just some of the areas of public health that have been impacted by the pandemic and require increased investments. Despite the funding included in the emergency appropriations packages, we have seen setbacks in most, if not all, areas of public

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[1] Nirmita Panchal, R. K., & 2021, F. (2021, April 14). The Implications of COVID–19 for Mental Health and Substance Use. KFF. https://www.kff.org/coronavirus-covid-19/issue-brief/the-implications-of-covid-19-for-mental-health-and-substance-use/.

[2] Centers for Disease Control and Prevention. (2021, May 12). Products—Vital Statistics Rapid Release—Provisional Drug Overdose Data. Centers for Disease Control and Prevention. https://www.cdc.gov/nchs/nvss/vsrr/drug-overdose-data.htm.

[3] Centers for Disease Control and Prevention. (2021, January 12). Chronic Diseases in America. Centers for Disease Control and Prevention. https://www.cdc.gov/chronicdisease/resources/infographic/chronic-diseases.htm.

[4] Kendzerska, T., Zhu, D. T., Gershon, A. S., Edwards, J. D., Peixoto, C., Robillard, R., & Kendall, C. E. (2021, February 15). The Effects of the Health System Response to the COVID–19 Pandemic on Chronic Disease Management: A Narrative Review. Risk management and healthcare policy. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7894869/#:~:text=Obese%20patients%20with%20chronic%20diseases,during%20in%2Dperson%20medical%20visits.

health. The only way to remedy this situation is through robust and sustained funding. As the country continues to work to build back, Congress has a responsibility to make robust, sustained, investments in our public health system. Health security is national security; Congress would not hesitate, rightfully so, to make increased investments in defense or national security after a crisis. Now is our chance to act boldly and make investments in public health that will benefit all Americans. The goal for our nation's public health system should not be to return to normal, but rather to build a paradigm that makes the U.S. a healthier country by addressing health disparities and ensures that when the next public health crisis comes, we are prepared.

The Coalition for Health Funding strongly supports at least a 23.5 percent increase for the Department of Health and Human Services above FY 2021 levels. We look forward to working with Congress to support the health of all Americans and we hope that you will view us and our member organizations as a resource.

[This statement was submitted by Erin Morton, MA, Executive Director, Coalition for Health Funding.]

PREPARED STATEMENT OF THE COALITION FOR SERVICE LEARNING

On behalf of the Coalition for Service Learning and the 160+ organizations we represent, we respectfully request that you include a $250 million annual appropriation for the Learn and Serve America program and related National Service Trust payments authorized by Subtitle B of the Edward M. Kennedy Serve America Act in the FY22 Labor, Health and Human Services, Education and Related Agencies Appropriations bill for the Corporation for National and Community Service (CNCS) dba AmeriCorps.

Additionally, we request that accompanying report language include the following:

"Within the total, the Committee provides funds for Summer of Service programs, Semester of Service programs, and Innovative and Community-Based Service-Learning programs in public schools and institutions of higher education. Additionally, fifty-percent of the funds are to be directed to economically disadvantaged communities and at least five-percent to be set aside for payments to Indian tribes and territories. Grants to disadvantaged communities are exempt from match requirements. There shall be a two-percent set-aside of the total appropriation for training and technical assistance contracts and program evaluation."

Lastly, since the AmeriCorps agency will need to increase their capacity in order to administer these new programs, we request that such sums as may be necessary shall be appropriated for agency salaries and expenses under Subtitle K of the Serve America Act and such sums as may be necessary for education awards for Summer of Service participants in the National Service Trust.

The COVID–19 pandemic has amplified existing inequities in education, isolated individuals, and put students' educational outcomes at risk. Students are struggling academically but also socially and emotionally, especially those in underserved areas. Engaging students through service-learning is a proven way to instill a sense of community, belonging, and responsibility and is a proven strategy to help address the academic and emotional learning loss that has occurred.

The congressionally-appointed bipartisan National Commission on Military, National, and Public Service completed a report in March of 2020 in which it set a goal of all K–12 students receiving service-learning experiences by 2031. It highlighted the opportunity to give young people the problem-solving and academic achievement skills they will need to be successful in school, work, and life. In the Commission's vision, every American would be exposed to service opportunities throughout their lifetime, beginning with young people experiencing robust civic education and service-learning during elementary, middle, and high school.

In order to achieve this vision, the Commission recommended that Congress provide a $250 million annual appropriation to CNCS to award competitive grants to SEAs, LEAs, IHEs, State Service Commissions, and nonprofits to develop and implement service-learning programs for K–12 and postsecondary students across the country, including:

—$100 million for Summer of Service programs for students who will be enrolled in grades 6–12 at the end of the summer;

—$100 million for Semester of Service programs for students in grades 9–12; and

—$50 million for service-learning programs in public schools and institutions of higher education.

Dedicated resources for educators and districts are essential for the success of service-learning programs. Funding would enable school districts to provide teachers with the training and support needed to develop their service-learning skills and to

build service-learning activities into their curricula. Funding for Learn and Serve America would help lower financial barriers and incentivize schools and educators to actively promote and incorporate service-learning into classrooms across the nation.

Service-learning is a critical program strategy at the intersection of education, national service, and civic health, with positive impacts on increasing academic engagement and 21st Century skill development, meeting community needs while building a recruitment pipeline for AmeriCorps programs, and improving civic education and participation.

We are hopeful that Congress recognizes the importance of reestablishing a program that will help address academic and emotional learning loss, re-engage students through service-learning activities, and instill a sense of community. We urge Congress to provide $250 million for Learn and Serve America and are grateful for your consideration of this request.

Best regards,

- Amy Cohen, Executive Director, The George Washington University Honey W. Nashman Center for Civic Engagement and Public Service, and Former Director of Learn and Serve America
- Susan Stroud, Senior Fellow, The George Washington University Honey W. Nashman Center for Civic Engagement and Public Service, and Founding Director of Learn and Serve America
- Emily Samose, Founder, ECS Consulting, and Former Staff, Learn and Serve America
- Brad Lewis, Former Staff, Learn and Serve America
- Amy Meuers, CEO, National Youth Leadership Council
- Aaron Dworkin, CEO, National Summer Learning Association
- Ally Talcott, Step Up Advocacy for the National Summer Learning Association
- Kate Cumbo, Executive Director, PeaceJam Foundation
- Kaira Esgate, CEO, States for Service and America's Service Commissions
- Susan Abravanel, President, Susan Abravanel Consulting
- Michael Minks, Vice President of Operations, Youth Service America
- Steven A. Culbertson, President & CEO, Youth Service America

Coalition Members—National Organizations

- Erik Peterson, Senior Vice President of Policy, Afterschool Alliance
- Gary Kosman, CEO, America Learns
- Dr. Ariel King, President, Ariel Foundation International
- Abby Robinson, Acting CEO, Atlas Corps
- Sage Learn, National Director of Government Relations, Boys & Girls Clubs of America
- Shawna Rosenzweig, Chief Strategy Officer, Camp Fire National Headquarters
- Andrew Seligsohn, President, Campus Compact
- Kei Kawashima-Ginsberg, Director, The Center for Information & Research on Civic Learning & Engagement, Jonathan M. Tisch College at Tufts University
- John Bridgeland, Founder &CEO, Civic
- Robert Hackett, President, Corella & Bertram F. Bonner Foundation
- Sanjli Gidwaney, Director, Design for Change USA
- Marly Leighton, Chief of Staff, DoSomething.org
- Vince Meldrum, President/CEO, Earth Force
- Tamara Roske, Executive Director, Earth Guardians
- Donna Ritter, Executive Director, Educators Consortium for Service Learning
- Adam Fletcher, Director, Freechild Institute
- Amanda Antico, Founder, EvolvED Global
- Stefonie Sebastian, Senior Service Engagement Specialist, National FFA Organization
- Donna Butts, Executive Director, Generations United
- Linda Staheli, Founding Director, Global Collaboration Lab Network
- Rick Lathrop, Founder/Executive Director, Global Service Corps
- Sam Fankuchen, Founder & CEO, Golden
- Patricia Hall, Founder, H2O for Life
- Nichole Cirillo, Executive Director, IAVE
- Serita Cox, CEO, iFoster
- Doug Bolton, CEO, Cincinnati Cares, Inspiring Service
- Bradley Hill, Director of Growth and Strategic Partnership, Junior State of America
- Betsy Peterson, Executive Director, Learning to Give
- Robert Jackson, Sr. Director of Development, Martin Luther King Jr. Center for Nonviolent Social Change

- Abbie Evans, Senior Director, Government Relations, MENTOR
- Sarah Fanslau, VP, Youth Programs, Multiplying Good
- Gina Warner, President & CEO, National Afterschool Association
- Kuna Tavalin, Consultant, National Center for Families Learning
- Lawrence Paska, Executive Director, National Council for the Social Studies
- McClellan Hall, Founder, CEO, National Indian Youth Leadership Project
- Stephanie Grove, President, National Senior Corps Association (NSCA)
- Fish Stark, Global Director of Programs, Peace First
- Moran Banai, Managing Director, Policy and Government Relations, Service Year Alliance
- Lee Arbetman, Executive Director, Street Law
- Derek Summerville, Director of Youth Engagement, YMCA of the USA
- Adam Fletcher, Vice-President, Youth and Educators Succeeding
- David Battey, President and Founder, Youth Volunteer Corps

Coalition Members—State & Local Organizations (listed alphabetically by State)

- Kids 1st Awareness Community Center (AL)
- Blue Crew (CA)
- California Campus Compact (CA)
- CBK Associates (CA)
- Cooline Team of East Palo Alto (CA)
- Norte Vista High School (CA)
- Playable Agency (CA)
- S.C.R.A.P. Gallery (CA)
- 1 Sacred Place (CO)
- Billig Consulting (CO)
- Goldey (DE)
- American University Center for Community Engagement & Service (DC)
- Center for Social Justice Research Teaching & Service (DC)
- Griffin Legacy & Associates (DC)
- LearnServe International (DC)
- Raising A Village Foundation (DC)
- Beyond Before Community Development Corporation (FL)
- Florida Atlantic University (FL)
- FSU Center for Leadership and Social Change (FL)
- Jacksonville University (FL)
- Chautauqua Learn and Serve Charter School (FL)
- Intentional Icon Inc (FL)
- Miami Dade College Institute for Civic Engagement and Democracy (FL)
- AFRD Georgia (GA)
- Favor House (GA)
- John & JeJuan Stewart Jr. Foundation (GA)
- KIPP South Fulton Academy Beta Club (GA)
- The Bridge Foundation (GA)
- Making Dreams Come True Valley of Rainbows (HI)
- Hawaii Pacific Islands Campus Compact (HI)
- University of Hawaii Office of Civic and Community Engagement (HI)
- Serve Illinois Commission (IL)
- ProAct Indy (IN)
- Serve Indiana Commission (IN)
- Volunteer Center of Story County (IA)
- Bluebird Experience (KY)
- Kentucky Campus Compact (KY)
- LSU AgCenter 4 (LA)
- 3Levels.org (ME)
- Bates College (ME)
- Harkins Consulting (ME)
- Maine Campus Compact (ME)
- Saint Joseph's College of Maine (ME)
- Loyola University Maryland Center for Community (MD)
- The Giving Square (MD)
- University of Maryland College Park (MD)
- Campus Compact Mid (MD)
- No Struggle No Success (MD)
- Notre Dame of Maryland University (MD)
- The WordSmith (MD)
- UMBC The Shriver Center (MD)
- Wicomico County Public Schools MD (MD)
- Jonathan M. Tisch College of Civic Life at Tufts University (MA)
- Action 2 Achieve (MA)
- Brandeis Center for Youth and Communities University (MA)
- LEAP Arlington (MA)
- Michigan Community Service Commission (MI)
- West Michigan Consulting Services (MI)
- Peacebunny Islands Inc/Peacebunny Foundation (MN)
- Youthprise (MN)
- Black Girls Rock of MS (MS)
- CryOut Teen Organization (MS)
- Missouri Community Service Commission (MO)
- Center of Effort LLC (MO)
- Montana Education Partnership (MT)
- Boulder Elementary School (MT)
- New Generation for a New World (NJ)
- New Jersey Campus Compact (NJ)
- Operation Grow Inc. (NJ)
- Rider University (NJ)
- Campus Compact of NY & PA (NY)
- Grandma's Love Inc. (NY)
- Hobart and William Smith Colleges/ Geneva 2030 (NY)
- Wagner College (NY)

- GenerationNation (NC)
- Ladies of Purpose Social Group Inc. (NC)
- North Carolina Campus Compact (NC)
- North Carolina Service Learning Coalition (NC)
- Northern Marianas College (MP)
- John Carroll University Center for Service & Social Action (OH)
- Ohio Campus Compact (OH)
- The Hero Within You Network (OH)
- Oklahoma AmeriCorps (OK)
- Camp Fire Central Oregon (OR)
- Campus Compact of Oregon (OR)
- Ecumenical Ministries of Oregon: Northeast Emergency Food Program (OR)
- Drexel University School Improvement Project (OR)
- Drexel University Lindy Center for Civic Engagement (OR)
- My New Journeys (PA)
- University of Pennsylvania Netter Center for Community Partnerships (PA)
- Blackstone Academy (RI)
- Carter County Drug Prevention (TN)
- Carter County Drug Prevention/Keep Carter County Beautiful (TN)
- Volunteer Tennessee (TN)
- CAVALRY (TX)
- City of Houston Volunteer Initiative Programs Office (TX)
- El Paso Community College (TX)
- Student Advocacy Coalition (TX)
- The Leaders Readers Network (TX)
- Sunrise High School (UT)
- FYR is LIT (VI)
- EDGE Consulting Partners (VA)
- Independent Consultant K (VA)
- OccupyFaith (WA)
- Washington Campus Compact (WA)
- Volunteer Center of Racine County (WI)

PREPARED STATEMENT OF COLLEGE ON PROBLEMS OF DRUG DEPENDENCE

Thank you for the opportunity to submit testimony in support of the National Institute on Drug Abuse (NIDA). 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 related to substance use disorders. CPDD serves as an interface among government, industry and academic communities maintaining liaisons with regulatory and research agencies as well as education, treatment, and prevention facilities in the substance use disorder field.

In the Fiscal Year 2022 Labor, Health and Human Services Appropriations bill we request that the subcommittee include the President's requested level of $51 billion for the National Institutes of Health (NIH), including no less than $46.1 billion for NIH's base program level budget. In addition, we greatly appreciate the President Budget's recognition of the need to significantly increase our nation's investment in the National Institute on Drug Abuse (NIDA) and its response to the opioid epidemic. The President's Fiscal 2022 Budget recommends a $372.2 million increase in NIDA's budget, a 25 percent increase. We strongly encourage the Subcommittee to include the President's recommended funding level of $1.852 billion for NIDA in the Senate version of the Fiscal Year 2022 Labor, Health and Human Services Appropriations bill.

We also respectfully request the inclusion of the following NIDA specific report language.

Opioid Initiative. The Committee continues to be concerned about the opioid overdose epidemic and appreciates the important role that research plays in the various federal initiatives aimed at this crisis. The Committee is also aware of the most recent data from the Centers for Disease Control and Prevention that shows opioid overdose fatalities increasing from 2018 to 2019, with the primary driver being the increased overdose deaths involving synthetic opioids, primarily illicitly manufactured fentanyls. To combat this crisis the Committee has provided within NIDA's budget no less than $270,295,000 for the Institute's share of the HEAL Initiative and in response to rising rates of stimulant use and overdose, the Committee has included language expanding the allowable use of these funds to include research related to stimulant use and addiction.

Methamphetamine and Other Stimulants. The Committee is concerned that, according to data released by the Centers for Disease Control and Prevention, 32,000 overdose deaths involved drugs in the drug categories that include methamphetamine and cocaine in 2019, an increase of over 700%. The sharp increase has led 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. Methamphetamine is highly addictive and there are no FDA-approved treatments for methamphetamine and other stimulant use disorders. 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 which effectively limits 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 and antidotes for their harmful effects, we should be lowering regulatory and other barriers to conducting this research. The Committee appreciates NIDA's completion of a 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 to sources of marijuana including dispensary products.

COVID Pandemic and Impact on Substance Use Disorders. The Committee is acutely aware of the risks that the ongoing COVID–19 pandemic poses to individuals with substance use disorders. According to the Centers for Disease Control and Prevention, drug overdose deaths accelerated during the pandemic which saw over 81,000 drug overdose deaths in the United States in the 12 months ending in May 2020, the highest number of overdose deaths ever recorded in a 12-month period. Moreover, research supported by the National Institute on Drug Abuse found that individuals with substance use disorders are at increased risk for COVID–19 and its more adverse outcomes. The Committee commends NIDA for conducting research on the adverse impact of the pandemic on SUDs and encourages the Institute to expand its research on these issues.

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 area, 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. The Committee recommends that NIDA increase its support for the education of scientists and practitioners to find improved prevention and treatments for substance use disorders as the Institute has done for the COVID–19 pandemic.

Marijuana Research. The Committee is concerned that marijuana policies on the federal level and 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 continue to fund research on the use and consequences of these devices.

In addition, we request the following report language within the Office of the Director account:

> *The HEALthy Brain and Child Development (HBCD) 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 abuse, mental disorders, and other behavioral and developmental problems. The Committee recognizes that the HBCD Study is supported in part by the NIH HEAL Initiative, and NIH Institutes, Centers, and Offices (ICOs), including OBSSR, ORWH, NIMHD, NIBIB, NIMHD, NIEHS, NICHD, NINDS, NIAAA, NIMH, and NIDA, and encourages other NIH ICOs to support this important study.

Substance use disorders (SUD) are 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 SUD as a chronic, often-relapsing brain disease -this new knowledge has helped to correctly emphasize the fact that SUD 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 fatalities due to heroin and synthetic fentanyl, as well as continued illicit use of prescription opioids. Our knowledge of how drugs work in the brain, their health consequences, how to treat people with SUDs, and what constitutes effective prevention strategies has increased dramatically due to research. However, because 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 FY2022 budget cycle will involve setting priorities and accepting compromise, however, in the current climate we believe a focus on substance use disorders 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 Chair Murray and Ranking Member Blunt,

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 (FY) 2022 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 FY2021 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 (P.L. 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 (FY) 2022, COSSA urges the Committee to appropriate:

—$46.1 billion for the National Institutes of Health;
—$10 billion for the Centers for Disease Control and Prevention, including $200 million for the National Center for Health Statistics;
—$500 million for the Agency for Healthcare Research and Quality;

—$800 million for the Bureau of Labor Statistics;
—At least $700 million for the Institute of Education Sciences; and
—$151.4 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. As you know, the need for increased investment in science has become even more pronounced by the disruptions caused over the past year by the COVID–19 pandemic.

NATIONAL INSTITUTES OF HEALTH

COSSA joins more than 360 organizations in support of $46.1 billion for the National Institutes of Health (NIH) in FY 2022. 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.

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 the Senate to emphasize support for OBSSR and encourage NIH to increase the Office's budget in FY 2022.

CENTERS FOR DISEASE CONTROL AND PREVENTION

COSSA urges the Subcommittee to appropriate $10 billion for the Centers for Disease Control and Prevention (CDC), including $200 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 its 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. One needs only to look at the varied responses across different communities to COVID–19 guidance and policies surrounding social distancing, mask-wearing, and vaccination to understand the critical role understanding the social aspects of public health plays in keeping Americans safe and healthy. As the Department of Health and Human Services' principal statistical agency, NCHS produces data on all aspects of our health care system, including opioid and prescription drug use, maternal and infant mortality, chronic disease prevalence, health care 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 health care 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 $500 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 health care challenges. AHRQ funds research on improving the quality, safety, efficiency, and effectiveness of America's health care system. It is the only agency in the federal government with the expertise and explicit mission to fund research on improving health care 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 ro-

bust support, especially given the critical role hospitals and group care settings have played in the COVID–19 pandemic.

BUREAU OF LABOR STATISTICS

COSSA urges the Subcommittee to appropriate $800 million for the Bureau of Labor Statistics (BLS) for its core programs. 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, 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 at least $700 million for the Institute of Education Sciences (IES) in FY 2022. 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 $151.4 million ($134.3 million for Title VI and $17.1 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 Submitted by Wendy Naus, Executive Director, Consortium of Social Science Associations.]

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, and research scientists. We urge the Committee to appropriate (1) at least $125 million for the HRSA Primary Care Training and Enhancement (PCTE) program and (2) at least $500 million for AHRQ, specifically funding $5 million to AHRQ's Center for Primary Care Research.

More than 44,000 primary care physicians will be needed by 2035; however, current primary care production rates will not meet demand, according to the authors of Annals of Family Medicine (Petterson, et al Mar/Apr 2015). The PTCE programs and AHRQ research enhance our nation's workforce and health infrastructure, creating better health outcomes and lower costs.

Primary Care Training and Enhancement—Title VII

The PCTE 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.

We are concerned that the President's FY2022 Budget did not include additional funding for the Primary Care Training and Enhancement program. Additional funding for the PCTE program can help address many of the failings and flaws of the current primary health care and public health infrastructure that have been identified in the COVID–19 pandemic. For example, additional funding is needed for both residencies and departments to help address faculty retention, public health competencies, recruit and retain students into primary care, develop new, innovative curriculum related to the pandemic and to address segmented primary care workforce to reduce delivery system division and increase full scope primary care providers.

A 2021 report by The National Academy of Science, Engineering and Medicine (NASEM) on Implementing High-Quality Primary Care: Rebuilding the Foundation of Health Care, identified the problems with under-funding Title VII programs finding that despite the demonstrably better patient outcomes that have resulted from Title VII investments, Title VII funding remains only a tiny fraction of the total GME funding; reduced to less than 10% since the 1960s. Primary care training grants under Title VII are vital to the continued development of a workforce designed to care for the most vulnerable populations, including concerns related to health equity.

We urge your continued support for this program and an increase in funding levels to $125 million in FY 2022 to allow for a robust competitive funding cycle to fund new initiatives to help address issues related to the COVID–19 pandemic, and a shortage of primary care providers. An example of the type of program supported by the PCTE program was the Danbury and Griffin Hospital programs in Connecticut who used it to develop innovative programs and curricula related to interdisciplinary training.

Agency for Health Care Research and Quality (AHRQ)

Primary care clinical research (PCR) is a core function of AHRQ. Primary care research includes: translating science into patient care, better organizing health care to meet patient and population needs, evaluating innovations to provide the best health care 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. Important primary care research initiatives have been unfunded in recent years such as research for patients with Multiple Chronic Conditions (MCC) and the statutorily authorized Center for PCR.

AHRQ is in a unique position to further PCR 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, above FY2021 levels, is needed to accomplish these goals. For this reason, we are supporting additional overall funding increases for FY 2022 to $500 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, while expanding their ability to address health inequities, and (6) how health extension systems serve as connectors of research institutions with practices and communities.

President's FY2022 Budget Request for AHRQ

The recently released Fiscal Year 2022 Budget request includes a major, new primary care initiative at AHRQ totaling $10 million. The Congressional Justification (CJ) for AHRQ, reminds Congress that "AHRQ is the only PHS agency that supports clinical, primary care research which includes translating science into patient care and better organizing health care to meet patient and population needs."

We support the CJ's assertion that "primary care research is critical to AHRQ's mission to make health care safer, higher quality, more accessible, equitable, and affordable." We are also pleased that the primary care initiative discussed in the CJ would support the work of practice-based research networks (PBRNs.) In order to fulfill the promise of this initiative, we recommend a related initiative—that at least $5 million of the amount Congress provides to AHRQ be directed to the statutorily authorized Center for Primary Care Research within the Agency. This would support the needed coordination and prioritization of primary care research investments within AHRQ, as two recent national studies have recommended.

Two Recent National Studies Support this Funding Request

In 2020, the RAND Corporation published a report appropriated by Congress and commissioned by AHRQ that assessed federally funded PCR since 2012 regarding gaps and to recommend improvements. The report emphasized the significant role AHRQ plays in PCR. RAND made several recommendations, including to provide targeted funds to create a proper hub for federal PCR. This is important because PCR is a distinct science that differs from health services research. With $5 million in dedicated funds for PCR, AHRQ could prioritize and coordinate investments in PCR directly improving the health and wellbeing of Americans. In 2021, The NASEM report on High Quality Primary Care concurs with RAND's assessment on the importance of targeted funding for PCR and recommends prioritization of funding for AHRQ's Center for Primary Care Research.

A real-world example of successful AHRQ work supporting primary care practice and patient safety is funding to the Oregon Health & Science University, the Rural Practice-based Research Network helped lead Healthy Hearts Northwest by recruiting 100 primary care practices to develop team-based quality improvement infrastructure improvements in small to medium-size practices. The Evidence Now Initiative operated as health extension agents in Oregon's frontier communities. In another example, AHRQ funding has allowed the University of Missouri to build infrastructure for patient-centered outcomes research in three arenas. The first study evaluated the advantages and disadvantages of endovascular vs. open surgery for legs with inadequate blood flow. The second project focused on improved discharge plans from skilled nursing facilities through improved primary care connections. Missouri partnered with the AAFP to create a national research network to improve chronic pain for the third project.

In conclusion, we support increased funding for AHRQ at the level of $500 million for FY 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 enhance our nation's primary care workforce and infrastructure.

Prepared Statement of the Covenant House International

Dear Chairwoman Murray and Ranking Member Blunt:

Covenant House is the largest charitable organization in North and Central America housing and serving children and youth facing homelessness including survivors of human trafficking. Every year, we reach tens of thousands of young people in 33 cities in six countries: The United States, Guatemala, Honduras, Mexico, Nicaragua, and Canada. Since our founding, we have reached more than 1.5 million children and youth. Our high-quality programs are designed to empower young people to overcome adversity, today and in the future.

Covenant House strongly supports the Runaway and Homeless Youth and Trafficking Prevention Act (RHYTPA) administered by HHS's ACF and McKinney-Vento Act's Education for Homeless Youth program (ECHY) administered by Department of Education, which have both proven to be effective in addressing child and youth homelessness. Covenant House is requesting significant investment increases in these main federal programs reaching children and youth facing homelessness.

Across our 23 U.S. communities which currently benefit from these programs, in FY20:

—9,300 youth were served through street outreach programs. 7,400 youth were served in residential programs and 6,400 youth were reached in drop-in centers and non-residential programs.

—49 percent of youth served by Covenant House across the United States reported a mental health diagnosis, nearly 50 percent had not yet completed high school, and 33 percent have a history of foster care.

—Over 80% of youth served were of young people of color, including Black/African American and Latino. And based on our groundbreaking research reported out in 2018:
—1 in 5 of youth interviewed reported being survivors of trafficking, and
—22% of youth interviewed were offered money for sex on their first night experiencing homelessness.

In addition to meeting basic needs, RHYTPA provides youth with housing stability and the necessary supports of mental health counseling, employment and training, education, and physical health services-needed to ensure youth remain stable, health and connected to caring adults. EHCY grants provide school stability and support to proactively mitigate the risk of homelessness—more critical than ever as schools recover from COVID. Covenant House also supports the Runaway and Homeless Youth's Street Outreach program to outreach and engage youth who are in unsafe living conditions.

Covenant House has received $4.8 million in RHYTPA grants since 2017 in regular grants and $861,000 from the CARES Act emergency funding. While this funding has been critical to our network maintaining services, the overall annual Runaway and Homeless Youth program does not have nearly enough resources to meet the demand in the field. Last year, there were 545 applications to the program but only 179 awards granted (less than 33 percent). The vast majority of these applications scored at the highest level and were worthy of funding if resources were available. As a result of this unmet demand, RHYA programs often turn away thousands of youth each year due to lack of available beds, leaving these children vulnerable without safe and stable housing and increasing their risk of predation and harm.

As for EHCY, even prior to the COVID–19 pandemic, the U.S. Department of Education reported record numbers of youth homelessness in the 2018–2019 academic year, with more than 1.4 million youth experiencing homelessness. The COVID–19 pandemic has only exacerbated this issue. With only a quarter of school districts receiving support through the EHCY program in a given year, it is clear that homeless children and youth are still under-identified and face significant barriers to school enrollment and education continuity.

The President's FY22 budget requested $145 million for RHYTPA consolidated programs, including the Street Outreach Program.

—Covenant House is joining with our coalition partners in requesting $300 million for RHYTPA to meet the basic safety and housing needs of youth experiencing or at risk of homelessness.

The President's FY22 budget requested level funding at $106 million for the McKinney-Vento Education for Homeless Children and Youth Act program.

—Covenant House is joining with our coalition partners in requesting $300 million for EHCY.

For additional information please contact Lori Maloney, SVP of Advocacy at Covenant House, at lmaloney@covenanthouse.org or Sally Schaeffer, consultant, at sally@uncorkedadvocates.com.

[This statement was submitted by Kevin Ryan, President and CEO, Covenant House International.]

PREPARED STATEMENT OF THE CREUTZFELDT-JAKOB DISEASE FOUNDATION

Chairwoman Murray, Ranking Member Blunt, and Members of the Subcommittee:

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). We request Congressional support in increasing the Prion Disease Surveillance appropriation through the CDC, Emerging and Zoonotic Infectious Diseases, by $1 million, for a total of $7.5 million.

Overview

Creutzfeldt-Jakob Disease (CJD), is a rare,100% fatal, degenerative brain disease that causes rapidly progressive dementia. CJD is transmissible and presently has no treatment or cure. Approximately 1 in 6,200 individuals will die from this disease in their lifetime; however, the unreported and undiagnosed number of cases remains unclear.

CJD is caused by the presence of an abnormal "prion" protein in the brain and is known as a prion disease. CJD/prion disease surveillance receives modest support through the Centers for Disease Control and Prevention (CDC). We need your sup-

port to strengthen and continue the coordination of CJD and other prion disease surveillance activities and to assure the safety of the American public.

Variant CJD (vCJD), and Bovine Spongiform Encephalopathy (BSE)

One form of this disease in humans, variant CJD (vCJD), is known to be caused by ingesting tissues in beef contaminated with Bovine Spongiform Encephalopathy (BSE), 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 disease surveillance and awareness to prevent further dissemination of vCJD. The two most recent cases of vCJD in Europe are believed to be due to occupational exposure and several cases of vCJD have been transmitted between individuals via blood transfusions. Hence, vCJD risk is not confined to eating contaminated food.

Chronic Wasting Disease (CWD)

Emerging laboratory data show that Chronic Wasting Disease (CWD), a naturally occurring prion disease of deer and elk, 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 the disease transmits by contact and through contaminated environment, including soil and plants, in free ranging animals. Additionally, multiple lines of experimental evidence indicate that sheep and cows are susceptible to CWD. Since CWD has been proven to cross several 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. Continued prion disease surveillance, particularly through examination of human brain tissue, is imperative to evaluate whether CWD has or can spread to humans.

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.

Prion disease surveillance is funded at $6.5 million/year. That figure has increased by just $500,000 over the past six years, despite increasing costs of surveillance. Expenses have since risen for the resources required to perform adequate surveillance such as increasing number of cases as expected by the aging American population, increasing autopsy costs over time, screening for COVID19, and taking extra precautions necessary for COVID19. Without an increase in funding commensurate with these increased expenses, surveillance will be compromised.

Request:

We ask for Congressional support in increasing prion disease surveillance's appropriation by $1 million, for a total of $7.5 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 prion surveillance. Reduction of funding or maintaining static 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 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 CWD among deer and elk, and explore whether CWD could spread to humans. Additionally, increasing prion disease surveillance in the U.S. increases surveillance at the national (CDC) and state (state public health departments) levels, which has been severely affected by competing concerns within the CDC division (e.g., COVID19).

Background:

The NPDPSC is funded entirely by the CDC from funds allocated by Congress. The CDC traditionally keeps approximately half of the appropriation for national surveillance projects and funding prion disease surveillance at the state level.

Increasing the appropriation from $6.5M to $7.5M will allow the NPDPSC to persist and continue to develop more efficient detection methods while providing an acceptable level of prion disease surveillance. Acceptable national surveillance is not possible at a lower level of funding. The requested $1M addition to the appropriation (total of $7.5M) would enable the NPDPSC to maintain appropriate 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 to public health (e.g., transmission risks from human to human).

The National Prion Disease Pathology Surveillance Center is the only laboratory based 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 require costly replacement of contaminated surgical equipment.

The NPDPSC also plays a decisive role in resolving suspected cases or clusters of cases of food-acquired and medically transmitted prion disease that are often magnified by the media, stirring intense public alarm. To date, the NPDPSC has examined over 7,500 suspected incidents of suspected prion diseases and has definitely confirmed presence and type of prion disease in more than 4,600 cases.

The NPDPSC is 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 UK, the European Union, and Japan, does not have a sufficiently robust animal prion disease surveillance system.

The NPDPSC offers assurances, to countries that import (or are considering importing) meat from the United States, that the U.S. is free of indigenous human cases of "mad cow" disease. In the past, 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.

Since its inception in 1997, the NPDPSC has collected and stored over 7,500 brains and many more samples of cerebrospinal fluid from cases of suspected prion disease, making it the largest prion disease biobank in the world. Increased funding is required to continue to preserve these precious specimens for future international research efforts as well as to serve as reference materials to evaluate potential emerging prion diseases (e.g., chronic wasting disease).

Thank you for the opportunity to submit this testimony.

[This statement was submitted by Deborah R. Yobs, President/Executive Director, Creutzfeldt-Jakob Disease Foundation.]

PREPARED STATEMENT OF AMANDA PEEL CROWLEY

Madam Chairwoman,

It is an honor to provide testimony to the Subcommittee on behalf of the thousands of children across the country who have had their lives turned upside down by Childhood Post-Infectious Neuroimmune Disorders, or CPINDs. These medical conditions develop after illnesses and are thought to reflect a misguided immune system and inflammatory response to infection.

I ask that the Committee consider providing language in the Committee's fiscal year 2022 report under the Department of Health and Human Services, Office of the Director, Multi-Institute Research Issues account, directing the National Institutes of Health (NIH) to identify research priorities for CPINDs, including PANDAS and PANS, and to investigate these disorders across disciplines, including neurobiology, neurology, immunology, rheumatology, infectious disease, and mental health. We are also asking that NIH report to the Committee on the incidence, causes, diagnostic criteria, and treatment of these conditions, especially including ways to advance understanding and improve clinical care. This year, there is an urgent need to better understand post-infectious conditions because of COVID–19 and for NIH to prioritize and fund CPINDs' research.

In 2020, the world woke up to the notion of post-infectious complications as we witnessed the impact of COVID–19 in daily reports of patients with chronic and delayed-onset symptoms. Growing research data has confirmed the association of debilitating psychiatric and neurological symptoms with the SARS–CoV–2 virus in

both adults and children. A significant number of children have developed neurological symptoms with COVID–19 infection, including altered mental status. New research describing late-developing psychiatric changes, including anxiety, OCD, and aggression, in children following COVID–19 infection concludes that SARS–CoV–2 should in fact be considered in the differential diagnosis of a CPIND known as Pediatric Acute-onset Neuropsychiatric Syndrome (PANS). The time has come to connect the dots—it is more than clear that infections lead to neurological and psychiatric symptoms. Robust research is under way, and we ask for CPINDs to be included. We firmly believe that investigations into the mechanism of CPINDs will have a far-reaching impact.

Children with CPINDs experience the onset of debilitating neuropsychiatric and behavioral disorders following illness such as influenza, "strep throat," and COVID–19. Studies indicate that misdirected antibodies and immune cells assault structures in a region of the brain involved in emotion, cognition, and movement. It is not surprising that, as in well-described types of autoimmune encephalitis, the symptoms signal dysfunction is this same brain region.

Two neuroimmune conditions, Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) and Pediatric Acute-onset Neuropsychiatric Syndrome (PANS), were described in 1998 and 2010, respectively. PANDAS is believed to be a variation of rheumatic fever. Rheumatic fever can develop if streptococcal infections are not treated properly, setting off an immune response where antibodies and immune cells attack the heart, kidneys, joints, or brain. The term PANS was developed as a broader diagnosis than PANDAS, with the same symptoms arising from infections other than strep. These disorders are often misdiagnosed as purely psychiatric, and early opportunities to treat medically, by targeting the underlying infections, inflammation, and immune dysfunction, are missed or delayed leading to escalating severity and associated costs.

Families like mine are blindsided when children's personalities completely change, and our kids are suddenly overcome by crippling fears, obsessive thinking, compulsive behaviors and tragically, suicidal thoughts. Some children are unable to separate from parents and many cannot attend school, or even leave the house. When children are unable to participate in school, they often experience learning impairments and significant academic declines. Previously successful students now need special education services, including aides to support their learning and behavior. Children who previously wrote legibly have such serious declines that they are no longer able to hold a pencil. Some children are beset by severe motor and vocal tics leading to further educational and social challenges. There is no part of life that escapes unscathed.

There are other serious physical consequences to illness in these children. Some, as young as four or five, suddenly appear anorexic, restricting their eating to near starvation because of worries about contaminated food or fear of choking. In extreme cases, children have to be placed on feeding tubes.

Children experience massive mood swings and fly into aggressive rages, full of irrational explosive anger. Even seven- or eight-year-old children can become suicidal, with an obsessive feeling that they have to die. Several children have ended their lives, and many others have been hospitalized when their symptoms become serious or life-threatening.

All three of my children have PANDAS, and our family's journey is, sadly, typical. Their stories illustrate the need for standardized clinical care and for accurate early diagnosis and education concerning risks to children and the many burdens on families, schools, and health care systems.

My two older children acquired multiple misdiagnoses as their behaviors and symptoms worsened over years. We finally arrived at the true cause of their illness: an undiagnosed, untreated strep infection, the same bacteria that causes a sore throat. When they received medical treatment, they showed improvements far beyond traditional psychiatric therapies.

My children also exemplify the contrast between early diagnosis and misdiagnosis. My youngest child was treated successfully when her symptoms were new, but my oldest children have suffered more serious complications and required more extensive treatment. They have lost critical time between the onset of their symptoms and medical intervention that they cannot completely regain.

With delays in diagnosis and care, children are at risk for further decline and potential long-term disability as their brain inflammation remains untreated. As symptoms escalate, the burden on families, healthcare systems, and schools grows exponentially. Caregivers endure significant lost work time and out-of-pocket medical costs. Insurers pay for emergency room visits and inpatient treatment, as well as ongoing pharmacological and behavioral treatment to manage unlivable symptoms. Educational systems face an enormous financial burden when putting special

education services into place for children who need increased academic and behavioral support.

There is a significant lack of NIH funding to support research into these disorders and to understand their true cost and prevalence. To date, the avenues for identifying, treating, and tracking post-infectious neuroimmune patients are minimally developed. Only through targeted research can we determine why some children develop psychiatric symptoms after infection, find diagnostic biomarkers, and demonstrate which treatments are most effective. We cannot achieve this alone. Action needs to be taken by NIH to increase funding for research into the causes and treatments of these conditions.

This year my family faced not only the ongoing trauma of PANDAS, but the horrors of COVID–19, first-hand. My father, who was in good health, was diagnosed last August and just weeks later was fighting for his life. He continues his long road to recovery, 10 months later. Like my children, the lasting damage was not done by the infection itself, but by the immune response. If we knew how to recognize and treat this complication early, we would have vastly different outcomes, not just for COVID–19 patients but for the thousands of children not in the spotlight who have CPINDs.

I want my family's experience with these devastating post-infectious conditions to help other families who are suffering. SARS–CoV–2 highlights both a pressing need and an opportunity for collaborative research across disciplines to better understand how neuropsychiatric complications develop and to find tools and treatments for early diagnosis and treatment. The world has rallied medicine and science in an unprecedented way this year. Let us also widen the scope to continue work on CPINDs, including PANDAS and PANS. The time to act is now—funding research will be a vital next step for the health of our country and the future of our children. Parents are doing all we can to support our children. Won't you please join with us to help solve this nationwide health crisis?

[This statement was submitted by Amanda Peel Crowley, Founding Member, Massachusetts Coalition for Pans/Pandas Legislation.]

PREPARED STATEMENT OF THE CURE ALZHEIMER'S FUND

Chairwoman Murry, Ranking Member Blunt, and members of the Senate Labor, Health & Human Services, Education, and Related Agencies (LHHSE) 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 $289 million in Fiscal Year 2022 above the final enacted amount for Fiscal Year 2021 for Alzheimer's disease research at the NIH. Additionally, Cure Alzheimer's Fund respectfully requests at least $560 million in total appropriations for the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative. The BRAIN Initiative is playing an increasingly 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 more than 15 years ago, Cure Alzheimer's Fund has invested more than $126 million in research through 530 grants in twenty-one states.

With the sustained commitment this Subcommittee has shown to Alzheimer's disease research at NIH, targeted investments into basic research made by private organizations such as Cure Alzheimer's Fund, have been leveraged into larger-scale research projects at NIH. An analysis by Cure Alzheimer's Fund found that the close to $17 million it invested in research in 2018, led to an additional investment of close to $121 million by NIH in the next two years. This shows the importance of continued and sustained investment for the Alzheimer's disease research portfolio at NIH because discoveries happening today will need to be funded in the future.

https://curealz.org/wp-content/uploads/2020/11/PV__Cure__Leverage__Annual AppealInsert__R5V1.pdf

Without the ongoing commitment demonstrated by this Subcommittee, investments made by private organizations, and the discoveries spurred by these investments, would not be able to be further explored, examined, and validated. The public-private partnership between groups like Cure Alzheimer's Fund and NIH is vital to Alzheimer's disease research because Cure Alzheimer's Fund can target investment in novel research ideas, allow researchers to collect initial data and strengthen

their hypothesis, and then "hand-off" the project to NIH for larger-scale investment and research that is beyond the scope of Cure Alzheimer's Fund. The robust research portfolio at NIH allows this continuum of research to continue and thrive.

Two concrete examples of this are the brain lymphatic system and the role of the innate immune system in the development of Alzheimer's disease. As I described in my written testimony last year, as far back as 2010, Cure Alzheimer's Fund has supported research into the beta-amyloid protein and its role in fighting infection. This was a novel research concept that was not receiving federal support. However, because of the investment made by Cure Alzheimer's Fund, the role of the innate immune system and infection are now NIH research targets.

As Dr. Francis Collins, Director of the NIH, mentioned at a 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.

NIH 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

In the past, I have also highlighted the work of Dr. Jonathan Kipnis and the role of the brain lymphatic system, and I want to again highlight this research as an example of the importance of basic research supported by Cure Alzheimer's Fund becoming a larger research project at NIH.

In 2016, Cure Alzheimer's Fund supported research by Dr. Kipnis and the role of Meningeal Lymphatics in cleansing the brain.

https://curealz.org/research/foundational-genetics/the-role-of-meningeal-lymphatics-in-cleansing-the-brain-implications-for-alzheimers-disease/

Cure Alzheimer's Fund's commitment to this research has continued while the research has also been supported by NIH. NIH recently highlighted this research in a press release at the end of April. Or five years after Cure Alzheimer's Fund made its initial investment.

https://www.nia.nih.gov/news/brains-waste-removal-system-may-offer-path-better-outcomes-alzheimers-therapy

Without Cure Alzheimer's Fund's first investment in 2016, and NIH's larger-scale investment after that, this research would not have been able to have been pursued so thoroughly. And this would not have been possible without the sustained and continued commitment to Alzheimer's disease research funding at NIH demonstrated by this Subcommittee.

As Cure Alzheimer's Fund continues to invest in research into novel research targets, there are more opportunities for NIH to be able to provide larger-scale research funding to help us better understand the pathology of Alzheimer's disease.

Cure Alzheimer's Fund has supported research by Dr. Caleb Finch into the role pollution and particulate matter play in the development of Alzheimer's disease. The first investment Cure Alzheimer's Fund made into this research was in 2014.

https://curealz.org/research/translational-research/air-pollution-and-app-processing/

Last year, the National Academies of Sciences, Engineering, and Medicine had a day-long symposium on Advancing the Understanding of Chemical Exposures Impact Brain Health and Disease. Dr. Finch was a presenter during this symposium.

https://www.nap.edu/read/25937/chapter/1

NIH is now supporting this research and it is becoming increasingly important to not only Alzheimer's disease research, but environmental justice research as well. We know that disadvantaged communities experience higher rates of Alzheimer's disease; research like Dr. Finch's is helping to identify environmental drivers like air-borne pollutants.

Cure Alzheimer's Fund is supporting research into vascular contributors to the development of Alzheimer's disease; African Americans have higher risk of neurovascular issues that are risk factors for Alzheimer's Disease as well as medical conditions of concern in and of themselves.

https://curealz.org/research/amyloid/the-role-of-picalm-in-vascular-clearance-of-amyloid-b-and-neuronal-injury/

https://curealz.org/research/foundational-genetics/neurobiological-basis-of-cognitive-impairment-in-african-americans-deep-phenotyping-of-older-african-americans-at-risk-of-dementia/

This is important research for both the understanding of Alzheimer's disease and reducing health disparities for disadvantaged communities. With sustained and continued support from this Subcommittee, Cure Alzheimer's Fund will be able to continue to invest in basic research knowing that NIH will have the necessary resources to be able to provide larger-scale investment into these important research topics.

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 $289 million above the final enacted level in Fiscal Year 2021 for Fiscal Year 2022 for Alzheimer's disease research at NIH, and at least $560 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.

Respectfully Submitted June 24, 2021.

[This statement was submitted by Timothy Armour, President and CEO, Cure Alzheimer's Fund.]

PREPARED STATEMENT OF DAVE PURCHASE PROJECT, THE NORTH AMERICAN SYRINGE EXCHANGE NETWORK, TACOMA NEEDLE EXCHANGE, AND COALITION PARTNERS

Chairwoman Murray, Ranking Member Blunt, and members of the Subcommittee, my name is Dr. Paul LaKosky and I serve as the Executive Director of Dave Purchase Project, the North American Syringe Exchange Network (NASEN), and the Tacoma Needle Exchange in Tacoma, Washington. I am pleased to submit testimony on behalf of these organizations and as a member of a large coalition of public health, HIV, viral hepatitis, and harm reduction organizations to urge Congress to appropriate $120 million for the Infectious Diseases and the Opioid Epidemic program at the Centers for Disease Control and Prevention (CDC) at the Department of Health and Human Services (HHS) to save lives and address the overdose crisis by supporting and expanding access to syringe services programs (SSPs).

Named in honor of its late, pioneering founder, Dave Purchase, Dave Purchase Project houses the nation's first legal syringe services program, created in 1988 at the height of the HIV epidemic in the United States. The program seeks to stop the spread of bloodborne pathogens, such as HIV and hepatitis C, among people who use drugs and to reduce the harm to individuals and communities associated with drug use. Although initially intended to address the spread of HIV, Dave Purchase Project now provides national leadership in its response to the opioid crisis. It also facilitates syringe services in Tacoma and throughout Pierce County, Washington.

Dave Purchase Project also houses the North American Syringe Exchange Network (NASEN). In 1992, NASEN formed to support syringe services programs (SSPs) and to expand the network of organizations and individuals that advocate for these life-saving programs. NASEN is the first and largest supplier of low-cost harm reduction resources in the US. In 2020, NASEN acquired and distributed approximately $18 million in harm reduction resources to the approximately 400 SSPs in the US, Puerto Rico, and the US Virgin Islands. NASEN also provided support valued at $25,000 to 28 newly emerging and/or struggling SSPs through start-up grant packages. As the Executive Director of these organizations, I am familiar with providing direct services to people who use drugs in Washington State, and with the significant gaps and need for resources and services nationwide.

The United States is experiencing an urgent and unprecedented drug overdose crisis, with approximately 100,000 overdose deaths expected to be counted in 2020 and potentially more in 2021. This would be an increase of more than 40% over the previous record year of 2019. According to the Washington State Department of Health, overdose deaths accelerated in 2020, increasing by 38% in the first half of 2020 as compared to the first half of 2019.

Overdose deaths have increased more dramatically among Black people and communities of color. From 2015 to 2018, overdose deaths among African Americans more than doubled (by 2.2 times) and among Hispanic people increased by 1.7 times while increasing among white, non-Hispanic people by 1.3 times. In Washington State, the increase in overdose deaths was highest among groups already dealing

with inequitable health outcomes: American Indian/Alaska Natives, Hispanic/Latinx, and Black people. While overdose deaths affect all racial and ethnic groups, American Indian and Alaskan Native (AI/AN) populations are disproportionately impacted in Washington State. The death rate among AI/AN is more than 3 times the rate of overdose in the state (9.6 per 100,000). Preliminary 2019 data suggest that this pattern is continuing, with AI/AN having the highest opioid overdose death rate among all race/ethnic groups. (Washington State Opioid Overdose Prevention Data Brief: DOH 971–043 October 2020.)

SSPs are an essential component of preventing overdose deaths. Tacoma Needle Exchange provides sterile syringes, which helps prevent the spread of infectious diseases such as HIV, as well as services such as opioid overdose prevention and awareness training, naloxone training and distribution, wound care, and referrals for medication assisted treatment and other medical and social services. Our outreach staff meets people where they are and helps them address their needs in the safest and healthiest way possible, free of judgement and stigma.

The following is but one example of what we do, and why we do it. On Saturday, August 24, 2019, Tacoma Needle Exchange participated in an event sponsored by the Pierce County Recovery Coalition. At this event we conducted opioid overdose reversal trainings and distributed free Narcan, a nasal version of naloxone (a drug which reverses an opioid overdose), to any individual who requested it. Approximately 1 month later, at another community event, I was approached by an individual who had attended the August event. He told me that as he was driving home the night of the 24th, just after the event, when he stopped for gas. As he was filling his car, a panicked woman came out of the gas station and stated that someone had overdosed in the restroom. He ran to the restroom and using the training and naloxone we had given him just 2 hours earlier, saved the life of that individual. He stated how grateful he was to us for providing him with the tools to save a life.

SSPs are the most effective way to get naloxone into the hands of people who use drugs and who are most likely to be at the scene of an overdose. In 2019/2020, our team distributed approximately 18,000 doses of naloxone and 1,259 overdose reversals were reported back to us (and many more occurred that went unreported). People who use drugs are essential partners in preventing overdose fatalities and are best reached by SSPs. In fact, more than 99% of the reported overdose reversals were performed by laypersons—other drug users, family members, friends, bystanders—not by first responders. With additional resources, SSPs can reach more people with naloxone, which would help reduce the dramatically increasing number of overdose deaths.

Congress must respond to the overdose crisis, as well as work to prevent and reduce infectious diseases related to drug use, such as HIV and hepatitis C, by supporting and expanding access to SSPs. Infectious diseases associated with opioid and other drug use have dramatically increased across the U.S. Since 2010, the number of new hepatitis C infections has increased by 380%. Outbreaks of viral hepatitis and HIV among people who inject drugs continue to occur nationwide. The CDC has documented over 30 years of studies that show that SSPs reduce overdose deaths and infectious diseases transmission rates as well as increase the number of individuals entering substance use disorder treatment. These studies also confirm that SSPs do not increase illicit drug use or crime and save money.

SSPs are among the only health care services trusted and used by people who use drugs and so can effectively engage this highly stigmatized population. SSPs help protect the community (including first responders) by ensuring safe disposal of syringes, reducing rates of infectious diseases, and can help providing a pathway to effective mental health and substance use treatment and other medical care.

Unfortunately, the nation has insufficient access to SSPs and the COVID–19 pandemic has decreased access to these life-saving services when the need for services has increased dramatically. In January 2021, Drug Policy Alliance conducted a survey of SSPs that showed that 91% of respondents experienced an increase in clients in 2020, many as a result of the COVID–19 pandemic. During this time of skyrocketing need, 42% of respondents experienced funding cuts in 2020 and expect such shortfalls to continue in 2021. In response to funding shortfalls, many SSPs have been forced to lay off staff and reduce services. Consequently, because of decreased and limited resources, SSPs cannot reach the millions of people who may benefit from their life-saving services.

Federal funding would expand access to critical and effective SSP programs. NASEN's own data show that there are only approximately 400 SSPs operating nationwide. Experts estimate that to sufficiently expand access to SSP programs, the U.S. would require at least 2,000 programs—5 times the number in existence now. NASEN routinely provides program support packages with essential harm reduction supplies to organizations wishing to start SSPs. We consistently have a wait list of

25–30 organizations seeking assistance, no matter how many support packages we distribute.

A recent study that assessed the startup costs of an individual program estimated that it would cost (in 2020 dollars) $490,000 for a small rural program and $2.1 million for a large urban program, resulting in an average start-up cost of $1.3 million per program. Based on these numbers, the requested funding could provide modest increases to currently operating SSPs to help address funding shortfalls and help expand the number of SSPs nationwide.

Finally, expanding access to SSPs would reduce health care costs, including for infectious diseases treatment. Hepatitis C treatment can cost more than $30,000 per person, while HIV treatment can cost upwards of $560,000 per person. Averting even a small number of cases would save millions of dollars in treatment costs in a single year.

The Infectious Diseases and Opioid Epidemic Program at CDC helps to eliminate infections related to injection drug-use and improve their prevention, surveillance, and treatment. It also strengthens and expands access to SSPs. In FY2019, CDC provided technical assistance to help ensure high-quality, comprehensive services and best practices for SSPs.

With additional FY22 funding, CDC could significantly expand SSPs at this critical time to help prevent overdose deaths, the spread of HIV and viral hepatitis, and connect people to life-saving medical care. Unfortunately, with just months in office during a historic COVID–19 pandemic and lacking a budget director, a director of the Office of National Drug Control Policy, and other key officials needed to respond to the overdose epidemic, the President's budget has only increased funding by $6.5 million. This amount is inadequate to reverse the dramatic increase in overdose deaths and to prevent continuing outbreaks of HIV and hepatitis. Congress must respond now and forcefully to this crisis or more lives will be lost to overdose and countless people will continue to contract infectious diseases that seriously compromise their personal health as well as the public health, creating long-term costs for all.

Finally, on a personal note, I speak to you as a public health researcher and SSP supporter and provider, but also—and more importantly—as the older brother of someone who has struggled with addiction his entire adult life and recently overdosed on fentanyl, but thankfully survived. Over the years I have given him money and I have paid his rent. I have purchased him clothes and bought him food. Yes, there are days when I just did not have the emotional energy to pick up the phone when I knew it was him calling. I admit this sadly and shamefully. On those days, and particularly on those days, I am thankful for the kind of people who work at syringe services programs. They give without expectation of return and without judgement. They give when others cannot or will not. It is with this experience and the life of my brother in mind that I respectfully urge you to increase funding for these life-saving programs.

Thank you for your time and consideration of my testimony, and please do not hesitate to contact me or Jenny Collier at jcollier@colliercollective.org if you have questions or need additional information.

[This statement was submitted by Paul LaKosky, Ph.D., Executive Director, Dave Purchase Project, the North American Syringe Exchange Network.]

PREPARED STATEMENT OF THE DEADLIEST CANCERS COALITION

On behalf of the Deadliest Cancers Coalition, a collaboration of national nonprofit organizations and industry focused on addressing issues related to our nation's most lethal cancers, we 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). For Fiscal Year 2022, we respectfully request $46.111 billion for the NIH's base program budget level, including $7.9 billion for the NCI, as well as the funding needed to establish a new Advanced Research Projects Agency for Health (ARPA–H) that includes a focus on finding tools to help patients diagnosed with one of the deadliest cancers. We further request report language in the LHHS bill that continues to hold NCI accountable for making progress on the goals and ideals of the Recalcitrant Cancer Research Act (RCRA).

In his address to Congress, President Biden called for an "end to cancer as we know it". As the national coalition that represents the cancers for which we've seen the least amount of progress, we wholeheartedly endorse this statement. 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

six years. Funding for the existing components of the NIH and NCI is a critical component of making the goal of "ending cancer" a reality, which is why we have joined with our partners in the One Voice Against Cancer Coalition to support the funding requests for NIH and NCI listed above.

We also support President Biden's call for a new ARPA–H that has an initial focus on cancer and other diseases for the purpose of driving transformational innovation in health research and speeding application and implementation of health breakthroughs. As representatives of patients who have been diagnosed with our nation's most lethal cancers and those who currently have the fewest early detection and treatment options available, we believe that ARPA–H has the potential to provide a vital bridge between this dearth of effective tools and the improved survival rates that are so desperately needed.

The discussion between physicians and patients diagnosed with a deadliest cancer are currently focused on end-of-life instead of exploring treatment options that will provide the best quality of life and the extension of life. These cancers exemplify areas where medical practice would be dramatically changed through the technologies and platforms that could be developed under ARPA–H. For these reasons, we urge Congress and the Administration to ensure that ARPA–H focuses on the hardest problems and areas where medical practice will be dramatically changed, including the deadliest cancers, as it develops authorizing language.

We know that this Subcommittee will face many difficult decisions as it is developing the FY 2022 Appropriations Bills. As you are considering these bills, we further encourage you to structure ARPA–H so that no funding is diverted from the core mission and budgets of the NIH and NCI, but also allows for true innovation.

It is also essential that critical stakeholders in the cancer community be involved at the earliest outset in the design, structure and budget of these endeavors. "Cancer" is not one disease, so it is therefore vital that stakeholders representing the range of the "cancer experience" be involved in these efforts. For this reason, the Deadliest Cancers Coalition respectfully requests to be involved in the process, starting in the initial phase.

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.

Next year (2022) will mark the 10-year anniversary of the passage of the RCRA, which requires that the NCI develop long-term strategic plans for addressing recalcitrant cancers beginning with pancreatic adenocarcinoma and small-cell lung cancer. The NCI has made progress in implementing the statute, particularly with respect to pancreatic adenocarcinoma and small-cell lung cancer. As a result of report language in the FY 2020 and FY 2021 LHHS Appropriations bills, NCI will undertake a scientific framework process for glioblastomas and gastroesophageal cancers and recently issued a notice of intent to publish a funding opportunity announcement for a Program on the Origins of Gastroesophageal Cancers. It is therefore crucial that Congress continue to shine a light on all recalcitrant cancers so they do not slip back into the shadows and so progress on implementing the RCRA for all of the deadliest cancers continues.

The Deadliest Cancers Coalition deeply appreciates the inclusion of report language focusing on these cancers in years past, including the FY 2021 language that reiterated Congress' intention that NCI develop a scientific framework using the process outlined in the RCRA for stomach and esophageal cancers and directed the NCI to identify future goals for each of the deadliest cancers in the fiscal year 2022 CJ.

We are seeking language in the FY 2022 LHHS Appropriations bills that continues to hold NCI accountable to the FY20 and FY21 language and the goals and ideals of the RCRA. Given that NCI has been responsive, to some degree, when Congress directs them to focus on specific cancers, we ask the language identify liver cancer as the next focus area. We are asking that the language specifies that the process should include cholangiocarcinoma, which is cancer that originates in the bile duct, but is grouped together with liver cancer, but want NCI to have flexibility on which other liver cancer subtype(s) should be included.

In addition, we continue to believe that it is critical that NCI stipulates 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 Representatives Anna Eshoo and Leonard Lance and Senator Whitehouse and

gained significant bi-partisan support because it was clear that just following "standard procedure" with respect to recalcitrant cancers was not working and there needed to be a specific focus on determining research priorities for these diseases. That need has not diminished.

The Deadliest Cancers Coalition was founded because we believe in a future in which there is no form of cancer for which a diagnosis is an automatic death sentence. All cancer patients should be able to select the best treatment option for them in consultation with their physician from a variety of effective treatments. Unfortunately, this year, approximately 44 percent of all cancer-related deaths will be due to one of the deadliest cancers, which means that we clearly have a long road ahead of us before that future is more than a dream. We therefore urge the Subcommittee to continue its leadership to ensure that NIH receives $46.111 billion for the NIH's base program budget level for FY 2022, including $7.9 billion for the NCI, as well as the funding needed to establish a new ARPA–H that includes a focus on the deadliest cancers. We further urge you to continue to hold the Institute accountable to making progress on the deadliest cancers through report language in the FY 2022 bill.

Prepared Statement of the Department of Preventive Medicine and Department of Medicine, Infectious Diseases

Dear Committee Members,

I am writing in support of a FY 2022 budget request for Department of Health and Human Services to develop a national strategy and implementation plan for the prevention, control and treatment of Herpes Simplex Virus, Types 1 and 2.

It is a critical public health imperative to address Herpes Simplex Virus (HSV), a chronic viral infection that impacts nearly half of Black women in our country, disproportionately impacts LGBTQ populations, and is a widely recognized driver of the HIV epidemic. Approximately 40% of new cases of HIV infection are attributable to chronic HSV infection. HSV also kills approximately 1,000 infants annually as a result of neonatal herpes which is currently not a reportable condition. Additionally, there is a growing body of research indicating HSV as a contributing factor to Alzheimer's Disease, Encephalitis, Bell's Palsy, among other neurodegenerative diseases.

There is currently no centralized national strategy to address HSV, it is not tracked or routinely tested for, and the majority of spread is via asymptomatic carriers unaware of their status. We can and should be doing more to stop the spread and provide better treatment to the nearly 1 in 3 Americans with this chronic condition.

If we prioritize women's and maternal health, the health of Black, Hispanic, LGBTQ, indigenous and other at-risk communities, we must prioritize Herpes Simplex Virus treatment and prevention. If we prioritize mental health, biomedical research for incurable diseases such as Alzheimer's or HIV, and dismantling systemic racism in healthcare, we must also prioritize Herpes Simplex Virus control. Addressing HSV addresses all of these national priorities and can improve the health, quality of life, and reduce the economic burden for millions of Americans.

Sincerely.

[This statement was submitted by Jeffrey D. Klausner, MD MPH, Clinical Professor, Department of Preventive Medicine and Department of Medicine, Infectious Diseases.]

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 during the COVID–19 public health emergency. COVID–19 has illustrated how vital the investments from this Subcommittee are for strengthening a health care 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 health care 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 FY 2022, Duke Health respectfully requests at least $46.1 billion for the NIH. This represents a $3.177 billion increase over the comparable FY 2021 funding level for the NIH, which would allow for the NIH's base budget to keep pace with the biomedical research and development price index (BRDPI) and allow meaningful growth of 5%.

At Duke, NIH funding plays a critical role in the advancement of research and clinical care. NIH has supported 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 home to one of 12 Regional Biocontainment Labs; and the Duke Cancer Institute, a top comprehensive cancer center in peer-reviewed research support.

We are grateful for the emergency investments made by Congress over the past year to meet historical challenges, and it is critical that we continue to build upon the current foundation to sustain and grow our nation's research enterprise.

We also are deeply grateful for the $40 million appropriated to the National Institute of Allergy and Infectious Disease for Regional Biocontainment Laboratories (RBLs) in the Consolidated Appropriations Act, 2021. This investment bolstered the nation's preparedness for biodefense and emerging infectious disease agents, including COVID–19, as RBLs continue to provide some of the major advancements in understanding and combating the coronavirus through the development of vaccines, prophylactic and therapeutic treatments, and diagnostic tests for SARS–CoV–2 and COVID–19 disease. We respectfully request that RBLs be considered for an annual appropriation of $60 million to be shared evenly among the 12 RBL research institutions beginning in FY 2022. The assays for live virus neutralization for all the monoclonal antibodies at Duke are done in the Duke RBL and it is where all live virus cultures are done for CoV2 work. Additionally, Duke researchers have created a vaccine with the potential to protect against all forms of coronavirus that move from animals to humans, now and in the future. The new vaccine has been 100 percent effective in non-human tests.

Finally, 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 and public health defense systems are critical. Duke Health urges the Subcommittee to provide at least $10 billion for the CDC in FY 2022. Among the CDC's many programs, the Prevention Epicenters Program connects CDC's Division of Healthcare Quality Promotion 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.

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 FY 2022, Duke Health respectfully requests that the Subcommittee provide $1.51 bil-

lion for Title VII and VIII programs overall, including $980 million to Title VII programs and $530 million to Title VIII 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 health care services to rural and underserved communities.

Duke Health urges the Subcommittee to provide $23 million in FY 2022 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, 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 $31 million for the C.W. Bill Young Cell Transplantation Program through the NCBI at HRSA in FY 2022. The Carolinas Cord Blood Bank (CCCB) at Duke is a member bank of the NCBI 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 $500 million for the Agency for Healthcare Research and Quality in FY 2022. This funding level is consistent with the FY 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 health care 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, 80 to 90 percent of medical center leaders at the Private Diagnostic Clinic (PDC), a multispecialty physician practice affiliated with Duke Health, reported fewer communications breakdowns and better handling of disagreements after using AHRQ's TeamSTEPPS(r) team training curriculum.

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 FY 2022, Duke Health urges the Subcommittee to provide $81.9 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 FY 2022 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 2022

—Provide $46.1 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).
—Provide the Centers for Disease Control and Prevention (CDC) with at least $10 billion to facilitate timely public health efforts.
—Please provide $5 million for the new Chronic Disease Education and Awareness Program at CDC.

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.

In 1967 at the age of 10, I lost the ability to write with either hand. Five years later, my father (at the age of 53) and I were diagnosed with focal dystonia, affecting our hands, which spasm and twist when we attempt to write. My sister, her son, and my daughter were later given the same diagnosis. Unlike the others, with every passing year, my daughter's dystonia began to affect other regions. By 19, she was unable to walk or feed herself. Later that year, she underwent deep brain stimulation (DBS) surgery which changed her life. She was later able to return to and graduate from college and now lives a relatively normal and active life.

I realized at the time of my daughter's diagnosis that I needed to do more. I became a clinical trial participant at the NIH and volunteered for any studies that could help researchers in finding a cure and or better treatments. I also became a passionate advocate for dystonia research funding.

DYSTONIA RESEARCH AT THE NATIONAL INSTITUTES OF HEALTH (NIH)

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. We continue to work with the leadership of NINDS on the recommendations stemming from 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 research 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 2021. We know firsthand that this will further NIH's ability to fund meaningful research that benefits our patients.

CDC'S CHRONIC DISEASE EDUCATION AND AWARENESS PROGRAM

We strongly support and thank the Subcommittee for the creation of the new Chronic Disease Education and Awareness Program at CDC. This critical program would provide a dedicated pool of resources that could be deployed to support meritorious public health projects with stakeholders. 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 PERSPECTIVES

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 three 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 one year. After a seven week delay, I am scheduled for my injection and am looking forward to a period of spasm-free speaking.

We are grateful to those persons who share their stories with the DMRF and other dystonia patient groups to help raise awareness of dystonia. The DMRF was founded in 1976 and since its inception, the goals 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 Carole Rawson, Vice President of Public Policy, Dystonia Medical Research Foundation.]

PREPARED STATEMENT OF EDUCATION FINANCE COUNCIL

Chairwoman Murray, Ranking Member Blunt, and members of the Subcommittee on Labor, Health and Human Services, Education and Related Agencies, Education Finance Council (EFC) is submitting this testimony because we have great concerns over the fast-approaching expiration of the COVID–19 payment pause on federally-owned student loans and the lack of certainty and guidance surrounding the September 30, 2021 date. There is speculation about an extension of that pause, and we must be cognizant of the herculean task of assisting more than 40 million borrowers in transitioning back into repayment. We request that you seek such certainty from the U.S. Department of Education (Department)/Federal Student Aid (FSA) and require them to provide servicers of federally-owned student loans, borrowers, and other stakeholders with the date when the COVID–19 payment pause for federally-owned loans will end.

This date certain must come as soon as possible as federal student loan servicers need appropriate time to hire and train staff and begin communication to borrowers in order to be fully prepared to successfully transition borrowers into repayment. The pause, which began in March 2020, is currently scheduled to end on September 30, 2021, and servicers are currently prohibited from communicating with affected borrowers regarding entering repayment.

It is imperative that FSA communicate clearly and consistently, as early as possible, with federal student loan servicers, borrowers, and all stakeholders about when the COVID–19 payment pause on federally-owned student loans will end. Borrowers need to have certainty about when their loans will enter repayment, and communication about this needs to begin as soon as possible with unified messaging. It all begins with the Department/FSA providing servicers, borrowers, and

other stakeholders certainty of the end of the payment pause date so that the information borrowers receive from servicers and other sources is consistent.

This document describes what EFC members that service federally-owned student loans must do to help borrowers prepare for the start of repayment, ensure a smooth transition, and remain in compliance with FSA requirements—a process that takes several months.

COMMUNICATION WITH BORROWERS

There are approximately 40 million borrowers that will enter repayment when the COVID–19 payment pause for federally-owned student loans ends. Outreach to these borrowers must begin many months before repayment begins, particularly to those who are at a high risk for falling into delinquency when payments resume,[1] and to borrowers who completed undergraduate study during the payment pause and have never had to make student loan payments. However, servicers have been instructed to temporarily cease communication with borrowers until notified differently by the Department. It is critical that servicers are allowed to begin this outreach as soon as possible to provide the borrowers the information they need to prepare to enter repayment on their student loans, especially certainty of the date that repayment will begin.

Informing borrowers that they will be entering repayment, when it will occur, and what will be required of them as early as possible and via as many channels as possible will prevent unnecessary delinquencies and default. Borrowers need time to budget and update their accounts. For example, borrowers using direct debits need to know as soon as possible if the direct debit will be automatically reapplied and the amount and date of when the first debit will occur. If it is not automatically reapplied, the borrower needs to know when and how to reestablish that process long before payment becomes due.

Furthermore, the pandemic has disrupted the living situation of many borrowers, making early outreach more important than ever. Many borrowers have experienced changes in their living situations. Some may have moved home with parents or relocated due to employment changes or for other reasons but may not have updated their contact information with servicers. It takes time to find those borrowers and ensure they receive the proper notifications. Servicers must comply with regulations that dictate how early different types of notices regarding repayment and repayments plans must be sent to borrowers, which is an impossibility until they are permitted to resume borrower communications.

STAFFING AND IT NEEDS

Many servicers experienced a reduction in staff during the COVID–19 pandemic and payment pause period due to attrition and the need for fewer employees. Servicers need to begin hiring and training additional staff as soon as possible to ensure that borrowers experience a smooth transition back into repayment. However, uncertainty about whether the payment pause will end on September 30, 2021, as scheduled is delaying this process.

It takes time to locate, hire, train and prepare individuals to service federal student loans. This process includes advertising and interviewing appropriate candidates, completing federally required background checks, completing application for and receiving FSA security clearance (a process that can take weeks to months), and training of new employees. Federal student loan programs and repayment options and rules are very complex and servicing federal student loans requires specialized training that can span 4 to 8 weeks, depending on the servicer's training process and the employees' position with the organization. In most cases, training will need to begin by mid-July to be completed in time. Ongoing training occurs with personnel even after they are released to communicate with borrowers to ensure they remain current with any regulatory or statutory changes that may impact a borrower.

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[1] The Department of Education's Congressional Budget Justification for Student Aid Administration for Fiscal Year 2022 acknowledges this risk for certain groups of borrowers: "...approximately 3.9 million borrowers shifted out of delinquency status through the government-provided-forbearance. The Department acknowledges that these borrowers are at high risk of re-entering delinquency, and eventually defaulting, once the payment pause ends. In addition, many borrowers who completed undergraduate study during the payment pause have never had to make student loan payments at all, which could also present special challenges. Further, some Americans have experienced unemployment or decreased earnings during the pandemic, and as a result, some borrowers who were current on their payments prior to the pause may be at higher risk of delinquency." (Department of Education, Congressional Budget Justification for Student Aid Administration for Fiscal Year 2022, AA–28).

There are also system changes that need to be implemented to get millions of accounts back into repayment. This will require IT staff time, and servicers need to know as soon as possible when this process can begin.

We appreciate your consideration of this request for timely communication to all parties in order to ensure we are collectively prepared to best communicate and assist federal student loan borrowers as they transition back to active repayment.

About Education Finance Council (EFC): EFC is the national trade association representing nonprofit and state-based higher education finance organizations that, as mission-driven, public purpose organizations, are dedicated to improving college access, success, and affordability in their states and nationwide. EFC members operate as loan servicers and supplemental loan originators and provide a wide array of college access and student success and support services and resources.

[This statement was submitted by Gail daMota, President, Education Finance Council.]

PREPARED STATEMENT OF THE ENDOCRINE SOCIETY

The Endocrine Society thanks the Subcommittee for the opportunity to submit the following testimony regarding Fiscal Year (FY) 2022 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. The Society is dedicated to promoting excellence in research, education, and clinical practice in the field of endocrinology. The impact of the coronavirus is a compelling illustration of why we must increase funding for the NIH and CDC to protect public health. To support necessary advances in biomedical research to improve health, the Endocrine Society recommends the NIH receive funding of at least $46.1 billion for fiscal year (FY) 2021; to facilitate the translation of these advances to improve public health, the Endocrine Society recommends the Centers for Disease Control and Prevention (CDC) receive funding of at least $10 billion; and to ensure that women have access to appropriate health services, we recommend that the Title X program be funded at $737 million. This request does not reflect emergency supplemental funds or new programs situated in NIH including the Advanced Research Projects Agency for Health proposed by the administration.

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. Physiological functions governed by the endocrine system are 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 influence the development of cancer or susceptibility to infections.

ENDOCRINE RESEARCH IS SUPPORTED BY NUMEROUS NIH INSTITUTES

Endocrine diseases and disorders are studied by researchers funded by multiple NIH Institutes and Centers (ICs). As such, it is critical for NIH to receive a strong base appropriation with proportional increases for all ICs. For example:

—Diabetologists funded by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) are advancing knowledge of inequities contribute to

health disparities in outcomes associated with COVID–19.[1] Despite the critical importance of this issue, NIDDK received a much lower increase in funding in FY 2021, relative to other ICs.

—Endocrine researchers funded by the National Institute of Aging increased our understanding of how hormonal treatment for menopause might improve stress responses in women.[2]

—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 (NCI) discovered how certain drugs used during pregnancy can contribute to cancer risk in offspring.[4]

—National Institute of Environmental Health Science (NIEHS)-funded researchers are investigating how chemicals found in cosmetic products can disrupt endocrine systems resulting in increased cancer risk.[5]

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 across the biomedical research enterprise in funding to ensure that the promise of scientific discovery can efficiently be translated into new cures. Research budgets have been further stretched across NIH to drive research to help us address the COVID–19 pandemic, and emergency supplemental funds have not provided sufficient resources to advance necessary research on COVID–19 while also sustaining progress on other national priorities. Consequently, NIH grant success rates are predicted to remain close to historically low averages, meaning 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.

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 chronic 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% in those under 60 and by 71% in those 60 and older.[6] 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

[1] Ebekozien, O., et al., The Journal of Clinical Endocrinology & Metabolism, Volume 106, Issue 4, April 2021, Pages e1755-e1762, https://doi.org/10.1210/clinem/dgaa920.

[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-and-advocacy/news-room/featured-science-from-endo-2021/drug-used-during-pregnancy-may-increase-cancer-risk-in-mothers-adult-children.

[5] https://endocrinenews.endocrine.org/edc-exposure-during-pregnancy-may-reduce-breast-cancer-protection/.

[6] The Diabetes Prevention Program (DPP) Research Group Diabetes Care. 2002 Dec;25(12):2165–71.

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.[7] Title X is the main point of care for low income, under- or uninsured, 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 2022 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-quality, evidence-based, and patient-centered family planning care, the Endocrine Society recommends that the Subcommittee provide at least the following funding amounts through the FY 2022 Labor, Health and Human Services, Education, and Related Agencies appropriations bill:

—$46.1 billion for the National Institutes of Health
—$10 billion for the Centers for Disease Control and Prevention
—$737 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 joins the research community by requesting $46.1 billion in fiscal year (FY) 2022 for the National Institutes of Health (NIH), including increased support for vector-borne disease (VBD) research at the National Institute of Allergy and Infectious Diseases (NIAID); $10 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 in 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 most 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

[7] Frost JJ, et al., Publicly Funded Contraceptive Services at U.S. Clinics, 2015, New York: Guttmacher Institute, 2017.

[1] https://www.gatesnotes.com/Health/Most-Lethal-Animal-Mosquito-Week.

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.

ESA requests robust support for CDC programs addressing VBD and support for the Centers of Excellence on VBD as authorized by the Kay Hagan Tick Act in 2022 and beyond with at least $10 million per year as well as $20 million for the Epidemiology and Laboratory Capacity (ELC) program. CDC, serving as the nation's leading health protection agency, conducts research and provides health information to prevent and respond to infectious diseases and other global health threats. 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 health care professionals in identifying and diagnosing these diseases. From 2016 to 2017, there was a 46% increase in reported cases of a group of tick-borne diseases known as spotted fever rickettsioses (spotted fevers), which includes the notably fatal Rocky Mountain spotted fever (RMSF).[3] Disability and death from RMSF are preventable 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, spotted fevers have non-specific symptoms, and fewer than 1% of the spotted fever 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 health care providers to effectively combat tick-borne diseases.

Using funding appropriated during the 2016 Zika crisis to help respond to that emergency and develop the necessary future workforce, CDC awarded $50 million to five universities to establish regional Centers of Excellence (COE) to address existing and emerging VBD. The five centers, for which current funding expires in 2021, generate research, education, outreach, and capacity to enable appropriate and timely local public health action for VBD throughout the U.S. The COE model requires collaboration between the research institutions and the local and regional departments of health (DOH), important relationships which have not generally arisen organically. This is critical given significant regional differences in vector ecology, disease transmission dynamics, and resources.

The Kay Hagan Tick Act also expands authorized support for the ELC program, critical to supporting state and local departments of health vector surveillance and management. For the last several years, the CDC has only been able to fund a third of the $50 million in requests they receive from states to meet these needs. ESA supports fully funding the $20 million authorized in the Kay Hagan Tick Act to support the ELC grants.

ESA requests robust funding for IMLS, including no less than $42.7 million for the Office of Museum Services in FY 2022. The services and funding provided by IMLS are critical in several areas—research infrastructure, workforce development, and economic impact. 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. 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 $21 billion. Museums are critical to the public understanding of science through exhibits and programs, and in so doing, support science education as an integral part of the nation's educational infrastructure. They also make significant long-term contributions to economic development in their local communities.

Thank you for the opportunity to offer the Entomological Society of America's support for NIH, CDC, and IMLS research programs.

[This statement was submitted by Michelle S. Smith, BCE, President, Entomological Society of America.]

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[2] https://www.sciencedirect.com/science/article/abs/pii/S0960982219311674.
[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.

PREPARED STATEMENT OF THE EPILEPSY FOUNDATION

SUMMARY OF FISCAL YEAR 2022 APPROPRIATIONS RECOMMENDATIONS

—Please provide $10 billion for the Centers for Disease Control and Prevention (CDC) including:
  —$13 million for the National Center for Chronic Disease Prevention and Health Promotion's Epilepsy program, an increase of $2.5 million over FY 2021.
  —$5 million for the CDC's National Neurological Conditions Surveillance System (NNCSS).
—Please provide at least $46.1 billion for the National Institutes of Health (NIH).
  —Please provide proportional increases for various NIH Institutes and Centers, including the National Institute of Neurological Disorders and Stroke (NINDS).

Thank you for the opportunity to submit testimony on behalf of the Epilepsy Foundation and the people with the epilepsies whom we serve. Chairwoman Murray, Ranking Member Blunt, and distinguished members of the subcommittee, we deeply appreciate the robust investments in medical research and public health programs over recent years which are helping us better understand and treat the epilepsies and better support people with epilepsy and their families day-to-day. As you and your colleagues work on appropriations for FY 2022, please continue this commitment and provide timely investments in the NIH and public health and research programs at the CDC. Thank you for your time and for your consideration of these requests.

ABOUT THE EPILEPSY FOUNDATION

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.

ABOUT THE EPILEPSIES

Epilepsy is a disease or disorder of the brain which causes reoccurring seizures affecting a variety of mental and physical functions. It is a spectrum disease comprised of many diagnoses including an ever-growing number of rare epilepsies. There are many different types of seizures and varying levels of seizure control.

3.4 million Americans live with active epilepsy including 470,000 children and teenagers. Thirty to forty percent of people with epilepsy live with uncontrolled seizures despite available treatments. Delayed recognition of seizures and inadequate treatment increase a person's risk of subsequent seizures, brain damage, disability, and death. Epilepsy imposes an annual economic burden of $19.4 billion on the country.

Please provide $10 billion for CDC including $13 million for CDC's Epilepsy program.

The Institute of Medicine's (IOM) report on epilepsy, *Epilepsy Across the Spectrum: Promoting Health and Understanding,* identifies the Epilepsy Foundation and the CDC as leaders in addressing many of its national recommendations to eliminate stigma, improve awareness and education and better connect people with the epilepsies to health and community services. The CDC Epilepsy program is the only public health program specifically related to epilepsy with a national scope and community programs. Focus areas requiring continued and increased investment include:

—In FY 20, 481 law enforcement and first responders, 5,033 school nurses, 214,702 school personnel, and 4,071 students have been trained on seizure recognition and seizure first aid. On-demand training modules are being developed to scale up training of these key, frontline community members.
—10,000 people have been certified in seizure first aid, though more focus is needed on rural and ethnically and racially diverse communities as nearly 40% of persons diagnosed with epilepsy are African American or Hispanic and many people with epilepsy in those communities have poorer health outcomes.
—To improve care in rural and underserved communities, Project ECHO has educated more than 400 healthcare providers about managing epilepsy, though

more focus is needed on management of severe, drug-resistant epilepsy and quality of care improvement methods.

—60 community health workers in Texas and Illinois have been trained to implement self-management programs resulting in improved health outcomes for people with epilepsy. More funding could scale up this evidence-based training in other states.

—By screening and addressing barriers to medication adherence, an Epilepsy Learning Healthcare System is reducing healthcare utilization and costs.

—Mental health screenings have been implemented and people with epilepsy are being connected to self-management programs that prevent and decrease depression since people with epilepsy at increased risk for depression and anxiety.

Testimonials from Participants in CDC Epilepsy Program-Funded Efforts

Margaret, Fairfield, CT: "Participating in HOBSCOTCH and learning more about epilepsy and the brain helped me realize this diagnosis is not something to be afraid or embarrassed of. By facing and dealing with my diagnosis head on, I can take control of certain aspects of epilepsy and improve my quality of life. HOBSCOTCH taught me strategies that I now use every day to improve my memory."

Kelsey, Seattle, WA: "During the 8 weeks that I participated in the PACES program, I learned a lot valuable information and had a wonderful time meeting other people experiencing similar struggles as me. I loved that the program integrated both a personable, solidarity like approach while providing evidence-based information with the most up to date epilepsy research. Having had epilepsy for over 15 years, I thought that I had a strong grasp on most epilepsy topics. However, the PACES program brought up different areas which I hadn't considered before and I found really useful for personal introspection and to share with other people in my life. I believe the PACES program is a wonderful opportunity for individuals who both have either been recently diagnosed or lived with epilepsy for a long time to share their own experiences in a way that might change another person's life and to learn important facts about the condition."

Nancy Tindell, Geneva County, Alabama: After taking the school nurse seizure training program myself in 2020, I strongly encouraged all school nurses and school personnel in my county to take the course because even I, as a nurse, learned a lot about both seizure types, new rescue therapies on the market and more. As a school nurse in a small town in Alabama, I am thankful for the support and trainings that empower us to support the students with seizures and epilepsy in our classroom and extracurricular settings.

Jon D. Brown, Founder and Chief Advocate, Black Men's Health, Tallahassee, FL: We had an opportunity to collaborate with the Epilepsy Foundation to not only bring awareness to and educate on the topic of Epilepsy, but together we were able to specifically leverage June, as Men's Health Month, to focus on a Seizure First Aid Certification Training. Throughout virtual discussions with Lowell Evans, who spoke on "Living with Epilepsy While Changing the World," and Michael Brown, who spoke on "Are You Certified in Epilepsy First Aid? You Should and Can Be," I learned so much vital information that provided me new-found awareness, information, education, and confidence (key!) to act if I am to find myself in the presence of someone having a seizure. And, the subsequent training, facilitated by Michael Brown and Luis Garcia, emphasized that this scenario might likely happen, as we learned that 1 in 10 people will experience a seizure in their lifetime. Mind-blowing, life-changing, and potentially life-saving information; important conversations that I am committed to continue having for broader reach throughout communities of color.

Fernando A., Columbus, Indiana: Project Uplift was very helpful to help my wife understand my daily struggles. It helped me learn ways to cope with my anxiety and to better communicate my thoughts and needs. I feel that Project Uplift is a very valuable resource to spread knowledge and awareness about the epilepsy community. I know that if the program continues, it will help reduce the stigma around what it means to be epileptic and create a safe community for those of us who just want to feel heard and understood.

Also as part of the $10 billion for the CDC, please provide $5 million for the CDC's National Neurological Conditions Surveillance System.

In 2016, Congress authorized the CDC to establish the NNCSS and it first received funding in FY 2019. The CDC is initially focusing on MS and Parkinson's, in order to learn through the process before extending to other neurological conditions. Extending to additional neurological conditions such as the epilepsies is contingent on continued funding for this program so the Foundation requests $5 million for the NNCSS in FY 2022.

Please provide at least $46.1 billion for NIH along with proportional increases for various NIH Institutes and Centers, including NINDS.

As a result of sustained investment in NIH, the epilepsy research portfolio has grown from about $150 million in FY 2017 to over $200 million in FY 2020. These resources have fueled scientific advancement and led to support for a variety of research initiatives including: Epilepsy Centers without Walls, The Epilepsy 4,000 (Epi4K) collaborative, The Center for Sudden Unexplained Death in Epilepsy (SUDEP) Research, The Epilepsy Bioinformatics Study for Antiepileptogenic Therapy (EpiBiosS4Rx), The Channelopathy Associated Epilepsy Research Center (CAREC), The Epilepsy Multiplatform Variant Prediction (EpiMVP) Center.

https://www.ninds.nih.gov/Current-Research/Focus-Disorders/Epilepsy

Much more can be done though, particularly in the area of bold cross-cutting initiatives and multi-center efforts. For FY 2022, we ask the subcommittee to include key committee recommendations, like the language below, to encourage additional epilepsy research in emerging areas.

NATIONAL INSTITUTE OF NEUROLOGICAL DISORDERS AND STROKE

Epilepsy.—The Committee notes the significant opportunities for the NINDS to advance research on the epilepsies through multi-center, multidisciplinary approaches like the Epilepsy Centers Without Walls that help address the need for biomarkers of epilepsy and precision medicine for new treatments and prevention for etiologically-defined populations. This approach is also suited for nation-wide, coordinated clinical and translational research frameworks to advance disease modifying or prevention strategies for the epilepsies.

The Epilepsy Foundation thanks the subcommittee for its consideration of these requests. If you have any questions, please contact me.

[This statement was submitted by Laura Weidner, Esq., Vice President, Government Relations & Advocacy.]

PREPARED STATEMENT OF EVERMORE

Chairwoman Murray, Ranking Member Blunt, and members of the Committee, thank you for the opportunity to provide testimony pertaining to fiscal year (FY) 2022 appropriations for the Centers for Disease Control and Prevention (CDC). 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 submit this testimony on behalf of Evermore, a nonprofit dedicated to making the world a more livable place for bereaved families by raising awareness of the consequences and implications of bereavement for society, advancing sound research that drives policy and program investments, and advocating on behalf of bereaved families for whom very limited legal protections are available in the aftermath. The purpose of my testimony today is to alert you to an emerging public health concern—bereavement—and its impact on millions of families throughout the nation. Bereavement shares a powerful intersectionality with multiple national public health emergencies, including COVID–19, overdose, homicide, and suicide. As such, bereavement plays a key gatekeeping role in determining whether we as a nation can turn the corner on these ongoing public health crises towards national recovery and wellbeing. This watershed moment offers us a rare opportunity to effect long-needed and long-awaited systemic changes. These changes can bring together a diverse array of seemingly disconnected, separately raging crises to support our nation's grieving individuals, families, and communities; compassionately lighten the burden of bereavement that encumbers and shortens so many lives, and re-enable them to reach their full potential.

Bereavement is a pernicious social concern threatening nearly every aspect of family wellbeing and solvency for millions across the country. The unexpected death of a loved one poses a dual threat to our national well-being, as it is both among the most common major life stressors, and the single worst lifetime experience, reported by Americans in national surveys. Losing a loved one is not only a personal tragedy, but casts a long shadow that can extend for decades as it places surviving parents, children, siblings, and spouses at significant risk for impaired health, premature death, and underachievement. Some additional risks include serious mental health disorders, teen pregnancy, violent crime involvement, youth delinquency, substance abuse, diminished academic attainment, diminished lifetime income, and less purpose in life, among many others.

Perhaps most concerning, our national life expectancy—an index of overall population health—has dropped by more than one full year. This last happened nearly 80 years ago following the United States' entry into World War 2. The implications of these statistics are sobering: They not only indicate that many middle-aged people of child-bearing and child-rearing years are dying, but that many children and adolescents are losing their parents, grandparents, aunts, uncles, and mentors. Recurring bereavement under tragic and often-traumatic circumstances has now become a commonplace fact of life for many US residents. Further, COVID and our other spiking epidemics have set back progress in closing the racial health disparities gap by some 20 years. Racial inequalities in bereavement are magnified across the life course as Black Americans are more likely than White Americans to experience the death of children, spouses, siblings, and parents. Black Americans are three times as likely as White Americans to have two or more family members die by the time they reach the age of 30. Black children are three times as likely to lose a mother and more than twice as likely to lose a father by age 10 when compared to White children.

To facilitate and inform future policymaking and national investments, as well as develop an evidenced-based bereavement care response system, Evermore encourages a budget increase of $2.5 million in CDC's Office of Surveillance, Epidemiology, and Laboratory Services/Division of Behavioral Health to collect bereavement prevalence and incidence data via its Behavioral Risk Factor Surveillance Survey (BRFSS). BRFSS is the nation's premier survey tool collecting data from 400,000 adults living in the 50 states, the District of Columbia, and three U.S. territories. It is the largest continuously-conducted health survey in the world.

The CDC is one the nation's most-trusted sources of data and evidence on population and public health. Our nation requires consistent and reliable data on the prevalence and sequelae of bereavement on which to formulate sound policy and practice. Today, the CDC collects mortality data, but not data pertaining to the bereaved families who survive these death events, and what the ramifications are. With five million individuals losing a loved one to COVID–19, including an estimated 46,000 children who lost a parent, the need for sound data collection to frame a federal response has never been greater. Indeed, we have relied on private researchers—including Ashton Verdery, Ph.D. of The Pennsylvania State University and Emily Smith-Greenaway of the University of Southern California—to provide these estimation models because the federal government does not measure bereavement exposure.

By extension, bereavement prevalence and incidence for homicide, suicide or overdose are currently unavailable, leaving us with no accurate means of capturing its impact (perhaps better designated as shockwaves) on individuals, families, and communities. This is a major missed opportunity for our social and health systems to surveil, monitor, and learn from our national epidemics and mount an effective response. Adding bereavement exposure to BRFSS would provide key demographic data, trends by race and geography, resulting in both a better understanding of the scope of the problem and informing future policymaking and program priorities and investments.

In 2019, Toni Miles, M.D., Ph.D. of the University of Georgia piloted three bereavement exposure questions in Georgia's BRFSS module, prior to the COVID–19 epidemic (see Figure 1). Her work found that 45 percent of Georgia BRFSS respondents were bereaved in the previous two years. Extrapolating this figure to the overall state population, she estimates that 3.7 million Georgian adults were recently bereaved. Her work also estimates that approximately 400,000 Georgia adults had two or more close family members die. African American adults are at particular risk, with 58 percent reporting a loss. Those in their prime working years are affected, with 48 percent of adults ages 35–64 experiencing a loss. Preliminary evidence indicates that bereavement exposure may undermine capacity to work; 53 percent of those newly out of work had experienced a family death.

Three Proposed Bereavement Exposure Questions for BRFSS

Interviewer: I'd like to ask you some questions about friends or family who have passed away in recent years.

1. Have you experienced the death of a family member or close friend in the years 2018 or 2019?

2. How many losses did you experience during that time?
___ losses
Don't know
Refused

3. For each loss, please tell me if he or she was a spouse, friend or a family member.
INTERVIEWER NOTE: With family members please indicate relationship; Mother, Father, Sister, Brother.

Figure 1. Bereavement questions piloted in Georgia's 2019 BRFSS. These questions are being proposed for inclusion in the 2022 CDC BRFSS.

Dr. Miles and her team found that persons who experienced any family loss in the past two years were at a heightened risk of reporting poor health, as well as physical and mental health problems over the past two weeks within taking the survey. Persons experiencing three or more losses were at the greatest risk of multiple health concerns, ranging from obesity to binge drinking, relative to those with no losses.

Appropriations Request
An increase of $2.5M to support the addition of an optional module to determine incidence and prevalence of bereavement exposure in CDC's annual BRFSS for all 50 states and U.S. territories. Module offering would commence in 2022.

In addition, we are requesting 1) the creation of a publicly available dataset featuring bereavement for use by behavioral health analysts and 2) a special highlight section in CDC's Health US, 2022, an annual snapshot of population health in the U.S.

Bill Language requested:
Of the funds made available under this heading, $2,500,000 shall be directed to the inclusion of three bereavement measures in the BRFSS.

Report Language requested:
The death of a loved one impacts millions of American residents leading to poor health, social and economic outcomes. This agreement includes $2.50 million for the Office of Surveillance, Epidemiology, and Laboratory Services to better understand the scope of bereavement exposure by including three new items to the Behavioral Risk Factor Surveillance Survey. Measures should be previously tested and fielded in at least one statewide survey. This data set should be available publicly to encourage and inform additional extramural research activities. This agreement encourages CDC to include a special highlight section in its Health US, 2022.

Figure 2. Appropriations request, bill and report language.

ADDITIONAL JUSTIFICATION FOR REQUESTS

Publicly-available bereavement dataset. We request the creation of a publicly available bereavement dataset enabling social and health scientists to extrapolate risk factors and potential implications for U.S.-based populations. Researchers will be able to examine interrelationships between exposure and outcomes, ask new research questions and begin to integrate this data into their existing research endeavors intended to help individuals reach their fullest potential. To that end, these data may influence CDC's Healthy People 2030 goals.

CDC's Health US, 2022. We request a special highlight section in CDC's 2022 health status report to the nation, Health, United States. This report presents key highlights and findings from federal health data systems.

CONCLUSION

To date, there is no national dataset capturing bereavement prevalence and incidence as our nation is facing unprecedented loss. Unequivocally, COVID–19 has reshaped our national landscape and is a seminal moment detailing how lack of quality bereavement care taxes individuals, families and the nation. Bereavement and its unintended outcomes are inextricably linked to many of our federal health agencies missions, priorities, and programs.

With more than millions of individuals in the United States suffering the loss of a loved one to COVID–19 and countless others who have lost a loved one to suicide, homicide, overdose, and chronic disesaes like cancer and Alzheimer's disease, combined with 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 priority for CDC and the federal government. Bereavement exposure and by extension its care is an essential element to any comprehensive public health strategy.

Thank you for the opportunity to present this testimony on behalf of millions of bereaved Americans and thank you for your continued leadership.

Sincerely.

[This statement was submitted by Joyal Mulheron, Executive Director, Evermore.]

PREPARED STATEMENT OF THE EVIDENCE-BASED LEADERSHIP COLLABORATIVE

Chair Murray and Ranking Member Blunt, and members of the Subcommittee, first, thank you for the opportunity to submit testimony to the Subcommittee to outline critical federal funding priorities for FY 2022. As we emerge from the health and economic crisis of the last year, the funding decisions that federal lawmakers make in FY 2022 will determine whether we have learned from the devastating consequences of the COVID–19 pandemic, or whether we default to a perilous status quo. It is with optimism that we will collectively improve upon the tragic lessons of the coronavirus crisis that we submit our funding requests for FY 2022.

In this sprit, we sincerely hope that Congressional Appropriators will recognize the value of evidence-based programs (EBPs) to promote health and prevent disease among older adults and make investments that increase support for, and expand access to, these vital activities. On behalf of the Evidence-Based Leadership Collaborative (EBLC)—a 501c3 organization that represents EBP developers, administrators, and providers with more than 200 combined years in developing, evaluating, scaling, implementing, and sustaining EBPs—we urge Subcommittee Members to include relatively modest, but meaningful, funding increases for the following programs within the Administration for Community Living (ACL):

—$50,000,000 for Older Americans Act Title III D, Preventative Health Services

—$16,000,000 for Older Americans Act Title IV, Chronic Disease Self-Management Education (CDSME) Programs

—$10,000,000 for Older Americans Act Title IV Falls Prevention Programs

Additionally, within the Centers for Disease Control and Prevention (CDC), we urge the Subcommittee to make important additional investments in chronic disease prevention programs, which are especially important given the significant impact of COVID–19 on older adults living with multiple chronic diseases.

These funding requests align with those of other national aging advocacy organizations and coalitions that focus on disease prevention, health promotion, and home and community-based services (HCBS) provision for older Americans, including the National Council on Aging (NCOA), the National Association of Area Agencies on Aging (n4a), and the Leadership Council of Aging Organizations (LCAO).

THE CASE FOR EVIDENCE-BASED PROGRAMING FOR OLDER AMERICANS

Evidence-based programs offer proven ways to promote health and prevent disease among older adults. These interventions have a decades-long track record of improving health and reducing costs when delivered within community settings across the country. Community and home-based delivery means improved access to quality care for older adults who are traditionally underserved, by organizations that also address those social needs that drive poor health and costs of care. These evidence-based programs include, but are not limited to:

—the Chronic Disease Self-Management suite of programs, which teach individuals how to manage ongoing health conditions;

—a Matter of Balance, EnhanceFitness, and Fit & Strong!, which increase awareness of and target interventions to help prevent fall-related injuries;

—Healthy IDEAS and PEARLS, which help to address and identify the underlying symptoms of depression; and
—Healthy MOVES and other programs focused on improving physical and emotional health through physical activity.

All of these programs, which are represented by the Evidence-Based Leadership Collaborative, meet the Administration for Community Living's criteria for the highest level of evidence. In addition to ACL, the Centers for Disease Control and Prevention Arthritis Program, Substance Abuse and Mental Health Services Administration's (SAMHSA) National Registry of Evidence-Based Programs, and the Agency for Healthcare Research and Quality Innovations Exchange recommend these programs and find them to be the strongest of evidence-based programs.

The scale and scope of the challenges that the suite of EBPs address demonstrates the importance of investing in effective interventions. For example, chronic diseases are the leading causes of death and disability in the U.S., whose costs constitute 90 percent of the nation's $3.8 trillion in health expenditures. Older Americans are disproportionately affected by chronic conditions; 80 percent have at least one chronic condition, and nearly 70 percent of Medicare beneficiaries have two or more. Older adults living with chronic conditions, particularly Black, Indigenous, and other Persons of Color (BIPOC), were more vulnerable to COVID–19 hospitalizations and deaths, highlighting inequities in both health outcomes and access to quality care.

Furthermore, falls are the primary cause of injuries and deaths from injuries among older adults. Each year, an estimated one in four older adults falls. Annually, more than three million fall injuries are treated in emergency departments, resulting in nearly 800,000 hospitalizations. Yearly spending to treat injuries resulting from falls totals $50 billion, 75 percent of which is paid for by Medicare and Medicaid. These costs are expected to exceed $101 billion by 2030.

The pandemic exacerbated these challenges and contributed to other emerging widespread concerns. For example, social isolation and loneliness-a major contributor to poor physical, behavioral, and cognitive health-increased drastically for high-risk older Americans adhering to long-term stay-at-home orders and community shut-downs. The spike in social isolation and loneliness among older adults also spurred declines in physical functioning for many older Americans because of reduced access to community supports and evidence-based programs health promotion programs.

OPPORTUNITIES TO EXPAND EVIDENCE-BASED HEALTH PROMOTION AND DISEASE PREVENTION PROGRAMS WITH INCREASED FEDERAL INVESTMENTS

Despite the growing and widespread barriers to EBP delivery during COVID–19, program developers and community-based providers were quick to adapt to the new reality and adopt program delivery models suitable to a virtual world. Rapidly pivoting previously in-person programs to online and telephonic delivery methods ensured that many of these trusted, proven, and popular health promotion and disease prevention strategies could continue and remain accessible during the health crisis. Additionally, adapting EBPs to remote delivery demonstrated long-term potential to address program participation barriers for especially high-risk and historically marginalized populations including rural and home-bound older adults.

Increasing FY 2022 investments in evidence-based disease prevention and health promotion programs will allow providers to expand their reach to older Americans whose health conditions worsened because of the prolonged pandemic. Increased investments will also allow EBP interventions to continue to offer, expand, and improve upon remote program delivery options to overcome long-standing barriers for older adults lacking access to in-person programing and to reaching underserved communities with culturally and linguistically appropriate services. This opportunity is a potential paradigm shift for these proven, trusted, cost-effective interventions.

Given the potential to expand these programs as we recover from the pandemic, we respectfully request that the Subcommittee prioritize the following FY 2022 federal investments to support these important disease prevention and health promotion programs.

OAA TITLE III D PREVENTIVE HEALTH SERVICES

Title III D of the Older Americans Act delivers evidence-based health promotion and disease prevention programs to prevent or better manage the conditions that most affect quality-of-life, drive up health care costs and reduce an older adult's ability to live independently. However, investments have not been sufficient to ensure the diverse array of proven, cost-effective interventions can be implemented in

communities nationwide, nor do they allow the to-date underfunded network to amass the critical evidence-based data lawmakers seek. Additional resources are needed to maintain the new reach and means of both in-person and remote delivery so older adults maintain access to these key services. We urge Congress to double appropriations funding for OAA Title III D programs in FY 2022 to $50 million.

OAA TITLE IV CHRONIC DISEASE SELF-MANAGEMENT EDUCATION (CDSME)

CDSME is a low-cost, evidence-based disease management intervention which studies show to be effective at helping people with all types of chronic conditions adopt healthy behaviors, improve health status, and reduce use of hospital stays and emergency room visits. Prevention and Public Health Fund allocations to ACL for CDSME have remained at $8 million since FY 2016, supporting over 14,000 community-based delivery sites which have provided services to more than 550,000 individuals. However, given that nearly 200 million people report having a chronic disease, the reach of these programs has been only 0.25 percent of the full population reach potential. We urge appropriators to increase FY 2022 funding for these programs to $16 million to expand access to evidence-based, cost-effective chronic disease management programs to a greater number of states and older adults in need across the country.

OAA TITLE IV FALLS PREVENTION

Evidence-based fall prevention programs offer cost-effective interventions by reducing or eliminating risk factors, promoting behavior change, and leveraging community networks to link clinical treatment and community services. These programs have been shown to reduce the incidence of falls by as much as 55 percent and produce a return on investment of as much as 509 percent. In fact, in an October 2019 report on falls prevention, the Senate Special Committee on Aging recommended continued investment and expanded access to EBPs aimed at mitigating the risk of falls among older adults. Despite this bipartisan support, falls prevention has been flat funded while the incidence and costs of falls continues to climb. Therefore, we urge your Subcommittee to increase the investment in these cost-effective programs to $10 million to make these programs more widely available to at-risk older Americans in every community.

In closing, these vital federal efforts that support health promotion and disease prevention interventions across the country have a profound impact on the quality-of-life of older Americans. On behalf of myself, the Evidence-Based Leadership Collaborative, and other national aging advocates, I implore you and your Subcommittee to support FY 2022 funding levels for these programs that recognize the value of, and expand access to, proven solutions for older Americans.

[This statement was submitted by Paul Hepfer, CEO, Project Open Hand & Evidence-Based Leadership Collaborative Board Chair.]

PREPARED STATEMENT OF THE FEDERAL AIDS POLICY PARTNERSHIP'S RESEARCH WORK GROUP

On behalf of the Federal AIDS Policy Partnership's Research Working Group, we thank Chairwoman Senator Murray, Ranking Member Senator Blunt, and members of the subcommittee for the opportunity to submit testimony to the Senate LHHS Subcommittee on Fiscal Year 2022 (FY 2022) 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 FY 2022 budget request level of at least $46.1 billion for the NIH consistent the request of the Ad Hoc Group for Medical Research. We also ask that $3.845 billion be allocated for HIV research at the NIH in FY 2022, which is the research need identified by the Office of AIDS Research in their Congressionally mandated FY 21 Professional Judgment Budget.

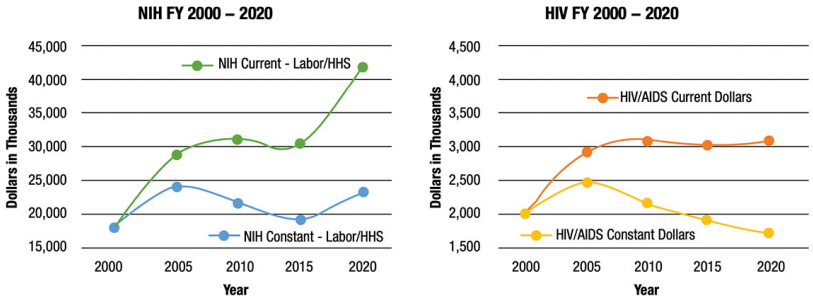
Public investments in health research via NIH have paid enormous dividends in the health and wellbeing of people in the U.S. and around the world, particularly for people living with, or vulnerable to, HIV. NIH funded AIDS research has supported innovative basic science for better drug therapies, and 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% effective in preventing sexual transmission. NIH-supported HIV research is now critical to advancement of possible treatments and several vaccines against COVID–19.

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 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. NIH research is critical to ensuring that aging population stays healthy and virally suppressed.

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 FY 2003 and FY 2020, the NIH budget in constant dollars according to BRDI will have declined by almost half.

Inflation Effect on Research Purchasing Power



Note: The above funding does not include COVID-19 appropriations.
Source: Biomedical Research and Development Price Index (BRDPI).

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.

Federal support for HIV/AIDS research has also led to new treatments for other diseases, including cancer, COVID–19, heart disease, Alzheimer's, hepatitis, osteoporosis, and a wide range of autoimmune disorders. Several HIV/AIDS treatments have been researched as treatments for the novel coronavirus—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 and mRNA, previously developed for use as an HIV vaccine.

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 FY 2022 budget request level of at least $46.1 billion for the National Institutes of Health (NIH) consistent with the request of the Ad Hoc Group for Medical Research. While this increase may get us closer to meeting the OAR By-Pass Budget Estimate for FY 2022, we ask the committee direct that increased funding be allocated for HIV research at the NIH in FY 2022. We urge the subcommittee to consider approaches to ensure the HIV research budget receives increases alongside other important and intersecting biomedical research at NIH.

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 FY 2022. 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

My testimony is in support of FY22 funding for the National Institutes of Health under the Department of Health and Human Services , Agency Subdivision: National Institutes of Health, Account: 550.

SUMMARY

Federal investments in fundamental research have led to remarkable progress in the biological and biomedical sciences. Basic research was the groundwork for the speed—months instead of years—in the development of COVID–19 vaccines, and pre-clinical research, such as animal studies, has been essential to every step of achieving medical progress.

Despite Congress' bipartisan support for investing in science, federal funding for research has not kept pace, posing a threat to our nation's competitiveness. We face a real threat of losing our edge in industries such as biotechnology if we do not prioritize increasing investments in science and building a diverse workforce [1] The U.S. spends less on research and development (R&D) than many countries. If the U.S. is to be prepared to respond to future threats, our scientific leadership must progress. According to Science Is Us, there is the added benefit of jobs. STEM supports 69 percent of U.S. gross domestic product, touches two out of three workers, and generates $2.3 trillion in tax revenue.[2]

The federal government should commit to robust, predictable, and sustained funding increases for science agencies.

NATIONAL INSTITUTES OF HEALTH

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. NIH supports biomedical discoveries, innovations, and treatments that were made possible because of scientific research using animals.

Congress has renewed its commitment to this critical research agency, providing robust, sustained, and predictable budget increases over the last five fiscal years (Table 1).[3] With these resources, NIH has accelerated progress across all areas of medical science, including regenerative medicine, cancer immunotherapy, and neu-

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[1] NSF Science Indicators 2018.

[2] STEM and the American Workforce. You've heard it before: STEM jobs—... | by Science is US | Medium.

[3] FASEB Federal Funding Data.

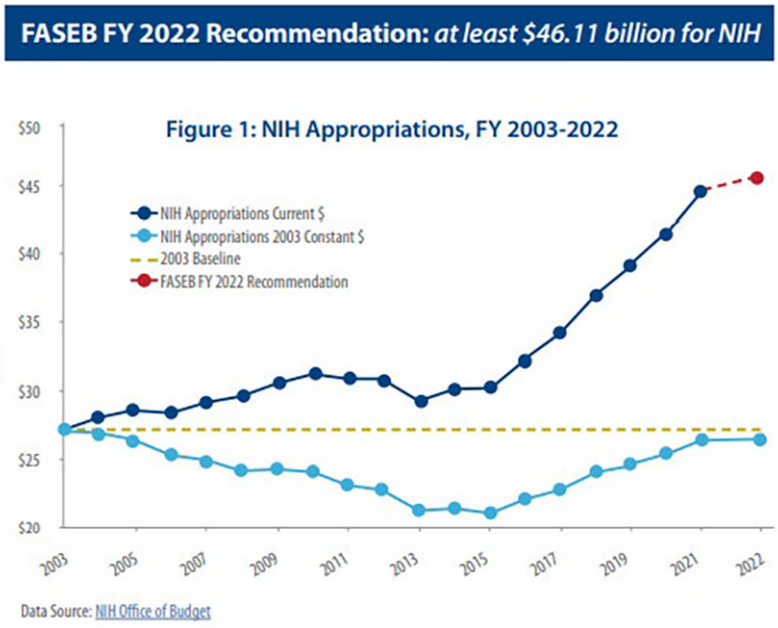
rological health.[4,5,6] The agency is also committed to supporting the next generation of our biomedical research enterprise.[7]

Though the NIH is in a stronger position than it was a few years ago, Congress must continue to increase biomedical research funding. Our nation is confronting public health threats, especially given global climate change negatively impacting biodiversity and geohealth—the intersection of biological science, Earth sciences, and ecology—on mankind. More research will be needed to address increased risks posed by future pandemics, infectious diseases, and greater exposure to environmental pollutants.[8]

In the U.S., we continue to address the needs of an aging population and obesity.[9,10] NIH research is developing therapies for a whole spectrum of age-related disorders.[11] Obesity impacts 42% of the U.S. population and increases the likelihood of developing costly medical conditions.[12]

Our recommendation of $46.11 billion is $3.2 billion above FY 2021 allowing NIH to continue support for the Next Generation Researchers Initiative; provide a five percent increase across NIH institutes and centers; and expand dual purpose research in biomedicine and agriculture among NIH and other federal agencies.[13]

FASEB FY 2022 Recommendation: at least $46.11 billion for NIH (chart below):



[This statement was submitted by Ellen Kuo, Associate Director, Legislative Affairs, Federation of American Societies for Experimental Biology.]

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[4] NIH Regenerative Medicine Innovation Project, National Institutes of Health, Bethesda, MD.
[5] NCI's Role in Immunotherapy Research, National Cancer Institute, Bethesda, MD.
[6] The BRAIN Initiative Summary, National Institutes of Health, Bethesda, MD.
[7] NIH Grants and Funding, Next Generation Research Initiative, National Institutes of Health, Bethesda, MD.
[8] IPCC AR5 Climate Change 2014, Chapter 11: Human Health: Impacts, Adaptation, and Co-Benefits.
[9] https://www.census.gov/newsroom/press-releases/2018/cb18-41-population-projections.html.
[10] NIDDK Health Information.
[11] Aging Well in the 21st Century: Strategic Directions for Research on Aging, National Institute on Aging, Bethesda, MD.
[12] CDC Obesity Data.
[13] BILLS–116RCP68–JES–DIVISION–H.pdf (house.gov) pg. 63.

PREPARED STATEMENT OF THE FEDERATION OF ASSOCIATIONS IN BEHAVIORAL AND BRAIN SCIENCES

Chairwoman Murray, Ranking Member Blunt, and Members of the Subcommittee:

The Federation of Associations in Behavioral and Brain Sciences (FABBS) is grateful for the opportunity to submit testimony for the record in support of the National Institutes of Health (NIH) and the Institute of Education Sciences (IES) budgets for fiscal year (FY) 2022. FABBS represents twenty-seven scientific societies and over sixty university departments whose members and faculty share a commitment to advancing knowledge of the mind, brain, and behavior. For fiscal year (FY) 2022, FABBS encourages your subcommittee to provide the National Institutes of Health (NIH) with a budget of at least $52 billion and the Institute of Education Sciences (IES) within the Department of Education a budget of $700 million.

Our members are thankful that appropriators were able to secure $42.9 billion for NIH and over $646 million for IES in FY21. We also appreciate the supplemental appropriations to NIH and IES included in COVID–19 response legislation. At NIH, these funds have played a central role in the pandemic response, not only developing vaccines and treatments but also supporting behavioral research to inform public health strategies. At IES, these investments are already helping to conduct essential research into the learning disruptions caused by the pandemic and providing educators the tools to chart a path forward for students. We hope to see similar success funding these agencies' vital contributions in FY22.

NATIONAL INSTITUTES OF HEALTH

We sincerely thank the Subcommittee for its diligent work and considerable increases to NIH in recent years. As members of the Ad Hoc Group for Medical Research and the Coalition for Health Funding, FABBS recommends at least $52 billion for NIH in FY 2022. 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 NIH Institutes and Centers (IC).

FABBS members have a particular interest in the Office of Behavioral and Social Science Research. OBSSR was created to coordinate and promote basic, clinical, and translational behavioral and social science research at NIH and plays an essential role, 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 in partnership with ICs. OBSSR co-funds highly rated grants that the ICs cannot fund alone.

OBSSR is an integral component of many high-profile NIH programs and initiatives:

—OBSSR has played a role in the fight against COVID–19, supporting behavioral and social science research to address the pandemic and disseminating best practices to encourage uptake of COVID–19 vaccines. The Office, for example, has made over 50 awards to study mitigation efforts, the long-term health and health care effects of the resulting economic downturn, and potential interventions to limit these effects.

—The Office also coordinates NIH's high-priority program on gun violence prevention research, identifying effective public health interventions to prevent firearm violence, and the trauma, injuries, and mortality resulting from it.

—Additionally, OBSSR is central to the NIH UNITE initiative to end structural racism and racial inequalities in health research. A working group of the Behavioral and Social Sciences Research Coordinating Committee is responsible for examining OBSSR-funded research on racism and health to inform broader agency-wide efforts to promote inclusion within NIH and in the research it funds.

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 and highlight that additional funding should enable the Office to expand its work addressing the behavioral, social, and economic impacts of the COVID–19 pandemic, measuring the effects of mitigation strategies on vulnerable individuals and communities in preparation for future pandemics, while maintaining its broad work in support of the NIH mission.

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 $700 million to IES in FY 2022. At this critical juncture, a significant

increase in IES funding is essential to addressing learning loss caused by the COVID–19 pandemic and better preparing American students for the future.

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.

Already, the Institute has done important work to gauge the impact of school closures on students, teachers, and school leaders, while providing evidence-based guidance and technical assistance to inform school reopening plans and support instruction in remote and hybrid learning. IES launched Operation Reverse the Loss to identify specific and actionable interventions that can reverse learning losses for clearly identified populations of students.

Robust funding for IES in FY22 will allow the Institute to continue its important work studying the effects of and developing strategies to address learning loss due to COVID–19 and create a stronger educational system.

Thank you for considering this request.

FABBS Member Societies:

Academy of Behavioral Medicine Research, American Educational Research Association, American Psychological Association, American Psychosomatic Society, Association for Applied Psychophysiology and Biofeedback, Association for Behavior Analysis International, Behavior Genetics Association, Cognitive Neuroscience Society, Cognitive Science Society, International Congress of Infant Studies, International Society for Developmental Psychobiology, Massachusetts Neuropsychological Society, National Academy of Neuropsychology, The Psychonomic Society, Society for Behavioral Neuroendocrinology, Society for Computation 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 Pittsburgh; 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

Chairman Leahy, Chair Murray, Vice Chairman Shelby, Ranking Member Blunt, 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 (FY) 2022 appropriations bill. Florida A&M University (FAMU) supports maintaining or enhancing funding 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 FY 2022 budget requests $402.6 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 FY 2019, FAMU received $7 million under the program.

We also support the President's FY 2022 budget request of $102.3 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 FY 2021 enacted level of $48.848 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 requested funding would be used to pay the loan subsidy costs in guaranteed loan authority under the program. We urge the Subcommittee to maintain the current level of funding for FY 2022, 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. Over 60% 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 FY 2022 budget requests $25.475 billion for Discretionary Pell Grants and proposes an increase in the maximum award to $8,370 in academic year 2021–2022. FAMU would encourage Congress to support the President's budget request substantially increasing the total maximum Pell grant award in FY 2022 to provide critical support for economically disadvantaged college students as we continue to rebound from one of the most challenging periods in our nation's history.

NATIONAL INSTITUTES OF HEALTH RESEARCH CENTERS IN MINORITY INSTITUTIONS

FAMU supports funding at the FY 2022 President's budget request of $80 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. 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.

Since program inception, the FAMU RCMI Center has received over $85 million from NIH, which has provided critical infrastructure to enable the College to achieve national prominence and become a competitive biomedical research center nationally. The RCMI support of FAMU led the College to implement four doctoral tracks in pharmaceutical sciences, including pharmacology/toxicology, medicinal chemistry, pharmaceutics, and environmental toxicology. Moreover, as an outcome of the RCMI support, our College of Pharmacy has graduated more than 60 percent of the African American doctoral recipients in the pharmaceutical sciences nationally.

DEPARTMENT OF HEALTH AND HUMAN SERVICES, HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA), HEALTH CAREERS OPPORTUNITY PROGRAM

FAMU supports the President's budget request 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 FY 2022 budget maintains 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 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. The impact of the COVID–19 pandemic on the nation has demonstrated the importance of a well-funded research enterprise. Thanks to decades of strong congressional support for NIH, the scientific community was well-equipped to rapidly respond to COVID–19. In fiscal year (FY) 2022, Fred Hutch recommends at least $46.1 billion for the NIH. As the research enterprise recovers from pandemic-related disruptions, now, more than ever, it is essential to continue the trend of recent budget increases to NIH to support lifesaving research.

Through strong, bipartisan leadership over the last six budget cycles, the Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies (Labor-HHS) has helped the NIH regain lost ground after a period of effectively flat budgets. In the FY 2021 omnibus bill, the Subcommittee's leadership continued this trajectory by providing a substantial increase to all NIH institutes and centers in addition to supplemental funding dedicated to COVID–19 research.

The federal investment in biomedical research has yielded a significant number of scientific advances that improve health outcomes for patients. Fred Hutch is committed to working with Labor-HHS, Congress and the Administration to further bipartisan support for increasing federal investment in biomedical science and ensuring NIH remains a top priority in FY 2022. Because of NIH funding, Fred Hutch can pursue fearless science and collaborations across its five scientific divisions.

Founded in 1975, Fred Hutchinson Cancer Research Center is guided by a mission to eliminate cancer and related diseases as causes of human suffering and death. Fred Hutch's interdisciplinary teams of world-renowned scientists and humanitarians work together to prevent, diagnose, and treat cancer, HIV/AIDS and emerging infectious 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. The leadership, depth and breadth of Fred Hutch's transdisciplinary research makes the center one of the National Cancer Institute's 51 designated Comprehensive Cancer Centers, serving patients in five northwestern states.

In addition to groundbreaking discoveries in science, Fred Hutch is investing in research to help narrow health inequities, implementing initiatives that embrace diversity and inclusion in science and empowering early career researchers. Below are

some examples of how NIH funding fuels Fred Hutch innovation and fosters future generations of scientists:

—*Responding to COVID–19.* Researchers across Fred Hutch have moved at lighting speed to test and develop potential therapies and vaccines, increase and expand testing capacity, model the course of the pandemic and emerging variants and study the molecular interactions between SARS–CoV–2 and the human body. Utilizing the expertise and clinical infrastructure of the HIV Vaccine Trials Network (HVTN), headquartered at Fred Hutch, the center also leads operations for the COVID–19 Prevention Network (CoVPN), funded by the National Institute of Allergy and Infectious Diseases, and co-leads the five large-scale COVID–19 vaccine efficacy trials with over 200 clinical trial sites in the U.S. and abroad.

—*Mitigating Health Inequities.* Fred Hutch understands the importance of community engagement to overcome the pandemic and the HVTN's community engagement experts have worked tirelessly for inclusive and diverse participation in each of the CoVPN's 30,000 person vaccine trials. In just six months, the team registered nearly 600,000 volunteers and has expanded recruitment to volunteers for pediatric COVID–19 trials, long COVID, and anticipated trials testing vaccines for variants. Fred Hutch is also utilizing the decades-long work of its public health scientists to disrupt the flood of misinformation during the pandemic, so underrepresented communities receive reliable, scientifically sound and understandable information about COVID–19 and the vaccines.

—*Embracing Diversity and Inclusion in Science.* Fred Hutch recognizes the importance of programs that promote diversity, equity and inclusion. As the first U.S. Cancer Center to commit to the CEO Action for Diversity & Inclusion plan and a member of the Washington Employers for Racial Equity, Fred Hutch strives to establish itself as a national exemplar in academia for its Diversity, Equity and Inclusion (DEI) approaches and practices. DEI is integrated as core values, principles and practices in Fred Hutch's approach to research, its workforce development, workplace culture and the communities Fred Hutch engages with. The NIH's emphasis on DEI, including the Agency's DEI initiative, UNITE and the FIRST faculty cohort program for early career researchers are instrumental in ensuring the most creative minds have the opportunity to contribute to the nation's research and health goals. Congress' continued support of the NIH funds vital efforts to increase representation and promote varied perspectives throughout the entire biomedical research enterprise.

—*Empowering Early Career Researchers.* Fred Hutch is inspiring the next generation of researchers who will work at the frontiers of life sciences. The center invests $2 million annually on science education programs ranging from internship opportunities for high school and college students, to development resources and mentorship for graduate students, postdoctoral fellows and early career faculty. The COVID–19 pandemic had an acute impact on these early career researchers, and it revealed the need for a well-trained, motivated scientific workforce. Ongoing investment in the NIH improves the quality and cultural proficiency of science by increasing access to scientific research and prepares young scientists to become tomorrow's leaders.

The federal government has an irreplaceable role in supporting biomedical research. No other public, corporate or charitable entity is willing or able to provide the broad and sustained funding for cutting-edge research that catalyzes innovative breakthroughs. The partnership between NIH and America's research institutions and scientists is highly productive.

As an independent research institute (IRI) with a mission to eliminate cancer and related diseases, Fred Hutch depends on NIH funding to conduct 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 salary support for extramural researchers—which would harm the appeal of academic research and disproportionately affect IRIs. Policies to cut salary support undermine Fred Hutch's ability to recruit and retain the talented researchers who keep U.S. institutions at the vanguard of biomedical sciences.

Robust increases to the NIH budget do more than bolster important research programs; it secures the future of science. Budget increases enable initiatives that reduce barriers to academia, provides training and education for young scientists starting independent careers and encourages culturally inclusive research. Fred Hutch supports these initiatives and principles and is applying them to its own workplace and research pursuits.

Fred Hutch thanks the Labor-HHS Subcommittee for its leadership and dedication to ensuring the health of the nation and your unwavering support for NIH

funding in FY 2022. We appreciate the opportunity to urge the Subcommittee to provide at least $46.1 billion in FY 2022 for NIH. Advances in bioscience, technology and data science have given the life sciences tremendous momentum. This is not a time to pull back. Given the abundance of scientific opportunity, this recommendation represents a minimum investment to sustain progress that would be amplified through an even more robust commitment.

[This statement was submitted by Thomas J. Lynch Jr., MD, President and Director, Fred Hutchinson Cancer Research Center.]

PREPARED STATEMENT OF THE FRED HUTCHINSON CANCER RESEARCH CENTER

Dear Senator Murray,

I am writing in support of the FY 2022 budget request for the Department of Health and Human Services (DHHS) to develop a strategic plan and national strategy for herpes simplex virus requested by Herpes Cure Advocacy, an international patient-oriented nonprofit group dedicated to alleviate the morbidity and mortality from herpes simplex virus type-1 & type 2 (HSV–1 & HSV–2). While HSV as an infectious disease is more than worthy of a public health research effort to develop vaccines and curative therapies, recent work has suggested HSV may also be a major player in Alzheimer's disease. Specifically, the strategic plan and national strategy will request $2.5 billion from the NIH and CDC over the next 3 years to address the immediate and critical need for research into prevention, treatment and cure options to end this silent pandemic of herpes simplex infections in our country.

I have been an advocate and investigator on herpesviruses for over 40 years, having founded the first patient advocacy group for genital herpes (THE HELPER). Over 400 million new cases of genital herpes occur each year. The disease is underappreciated due to its asymptomatic spread, and in the normal host, HSV–2 mucosal ulcerations are normally self-limited. However, systemic complications such as recurrent meningitis, hepatitis, and pneumonitis occur during acquisition or reactivation of infection, particularly among patients with poor T-cell immunity due to AIDS, organ transplantation or chemotherapy. The major complication of HSV worldwide is it increases the risk of HIV acquisition 3–4 fold. The HIV prevention literature indicates that 40% of HIV acquisitions are HSV-related; thus, 420,000 of the 1.2 million new HIV cases yearly.

Recent epidemiological observations suggest many causes of Alzheimer's disease are HSV–1-related. This is a plausible hypothesis as HSV resides in the brain and the concept is that its presence spreads the development of the protein plaques associated with Alzheimer's. There are suggestions that treating HSV early may slow progression of Alzheimer's. Better research is needed to define this and see if novel therapies can be developed. The first antiviral drug—acyclovir—invented by Dr. Gertrude Elion, one of the first women scientists to receive a Nobel Prize, was developed in the early 1980s. I was lucky enough to be a disciple of Dr. Elion and did the first studies of the drug for genital herpes. It paved the way for HIV drugs, yet it's 40 years later and we have the tools to make better drugs and, more importantly, vaccines; vaccines to provide a cure and vaccines to prevent HSV from being acquired. Imagine a vaccine that reduces HIV and Alzheimer's disease. This is possible by preventing HSV infection.

One thing the COVID–19 pandemic has done is brought the injustice and inequality of health care and resources for infectious diseases to light in a way not previously advertised. We are at a crossroads now with great levels of advocacy and the ability to make real change with new technologies to tackle these silent epidemics.

Sincerely.

[This statement was submitted by Lawrence Corey, MD, Past President and Director, Fred Hutchinson Cancer Research Center.]

PREPARED STATEMENT OF THE FRIENDS OF THE HEALTH RESOURCES AND SERVICES ADMINISTRATION

The Friends of HRSA coalition is a nonpartisan coalition of nearly 170 national organizations representing tens of millions of public health and health care 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 $9.2 billion for the Health Resources and Services Administration in FY 2022. We are grateful for the increases provided for HRSA programs in FY 2021 and for the emergency supplemental funding to bat-

tle the COVID–19 pandemic, but HRSA's discretionary budget authority is far too low to effectively address the nation's current public health and health care needs. We urge Congress to continue efforts to build upon these investments to strengthen all of HRSA's programs.

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 health care and services; fostering a health care 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 health care 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 health care.

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 health care services for underserved areas and populations. AHECs play an integral role to recruit providers into primary health careers, 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 diagnosed HIV infections dropping 7 percent between 2014 and 2018, with HRSA's Ryan White HIV/AIDS Program serving as the foundation for delivering health care and support services to reach the public health goal of ending the HIV epidemic. Despite this success, an estimated 1.2 million people in the U.S. are living with HIV today, and approximately 36,400 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 health care challenges including the rise in maternal mortality, the severe shortage of health professionals, the high cost of health care, and behavioral health issues related to substance use disorder—including opioid misuse. We recommend Congress build upon the important increases they provided for HRSA programs in FY 2021 and provide at least $9.2 billion for HRSA's total discretionary budget authority in FY 2022. Additional funding will allow HRSA to pave the way for new achievements and continue supporting critical HRSA programs, including:

—Primary care programs support nearly 13,000 health center sites in every state and territory, improving access to preventive and primary care for nearly 30 million people in geographic areas with few health care 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 4 uninsured persons; and 1 in 8 children.

—Health workforce programs at HRSA support the entire training continuum by strengthening the workforce and connecting skilled professionals to communities in need. Programs such as the Public Health Training Centers assess and

respond to critical workforce needs through training, technical assistance and student support.

—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 health care 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 health care and public health services for an estimated 60 million people, reaching 92% of pregnant women, 98% of infants, and 60% 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 519,000 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 88.1% of clients achieving viral suppression, compared to just 64.7% 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 communities of color.

—Title X ensures access to a broad range of reproductive, sexual and related preventive health services for over 3.1 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 health care delivery in rural communities. Rural health programs support community-based disease prevention and health promotion projects and expand health information technology and telehealth.

—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 facilitate organ marrow and cord blood donation, support transplantation and research and increase organ donation rates. The Poison Control Program oversees poison control centers which contribute to decreasing a patient's length of stay in a hospital and save the government $1.8 billion each year in medical costs and lost productivity.

—HRSA is well positioned to respond to infectious disease outbreaks and has been active in the COVID–19 pandemic response, awarding billions of dollars to health centers to administer COVID–19 tests and reimbursing providers who offer COVID–19 care to uninsured individuals.

To meet the many ongoing public health challenges facing the nation, including those outlined above, we urge you to support at least $9.2 billion for HRSA's programs in FY 2022.

[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

Chair Murray, Ranking Member Blunt, 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 committed to supporting the mission of IES and the use of research and statistics. We recommend $737.47 million for the Institute of Education Sciences (IES) in the FY 2022 Labor, Health and Human Services, and Education Appropriations bill. This request is aligned with the top line amount included for IES in the president's budget request.

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. Throughout the pandemic, IES has sought to meet the demand for evidence-based resources to help facilitate remote instruction, address academic and socioemotional needs of students, and support teachers and school leaders in adapting to the ever-changing conditions resulting from the pandemic.

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.

Our member organizations rely on IES to support vital research that addresses many of the most important issues in our nation's schools. We are deeply thankful for the increases provided to IES in recent years to further invest in the education research and statistical infrastructure and to respond to the impact of COVID–19 on our most marginalized populations.

At the same time, IES remains constrained in its flexibility to fully fund emerging research areas and scale up promising interventions and resources. Only one of every ten grant proposals receives funding support, limiting the ability of IES to tackle pressing questions in education, such as what can be done to support student learning in informal settings, address challenges facing rural districts, and improve literacy for adult learners. Additional investment in Research, Development, and Dissemination could support new high-risk, high-reward research with the potential for transforming education, along with funding research in foundational and emerging areas in education and supporting the synthesis of research findings for use by all education stakeholders.

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, trustworthy, and scientifically valid data on the condition of education that is essential to policy, practice, and research being conducted across the nation. Most recently, NCES' pivoting and partnering with the Census Bureau and four other federal statistical agencies to get weekly estimates of the impact of COVID–19 is just one palpable example of its vital role. Sufficient funding for NCES can enhance the ability of NCES to develop and administer surveys, analyze data on timely education issues, and link administrative education data to health and employment data for evidence-based policymaking and to understand the broader context of outcomes.

NCES importantly 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. Additional resources for SLDS can support states in linking data across education and workforce systems.

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. During the pandemic, the RELs have provided a wide range of evidence-based resources to guide teachers, school leaders, and state and local officials on COVID–19 response. This work is all driven by the state education agencies and other stakeholders in the regions. Additional funding is needed to research and support growing local and regional needs to respond to the impact of the pandemic on academic, social and emotional learning.

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 such as those 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. COVID–19 has had a disproportionate impact on students with or at-risk of disabilities who have faced significant barriers to educational access over the past year.

Although funding from the American Rescue Plan will support such research in an FY 2022 grant competition, NCSER will not hold a competition for non-pandemic-related research due to limited funding. With additional funding, NCSER could support data and evidence-based resources to guide teachers, administrators, and policymakers in state and local agencies.

Alongside the recommendation regarding the investment in IES, we encourage you to include language in the Program Administration line to allow for IES to hire additional staff. Understanding that the Department of Education approves hiring authority, IES can be more innovative and flexible in carrying out its mission and support emerging areas of research and statistical collection with additional staff. As one example, NCES staff have technical expertise but are also responsible for managing contracts for its surveys. Providing authority for NCES to hire more staff can allow the agency to fully discharge its responsibilities, including the integration of new forms of massive and fast data. To execute these functions effectively requires staff of adequate size.

To this end, we recommend that the Committee provide IES $737 million in FY 2022. As our country emerges from a year of the greatest national disruption our schools have ever seen, it is clear that there is a demand for evidence-based resources for our teachers, school leaders, students, and families to support learning and instruction. 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 THE NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT

I write on behalf of the Friends of NICHD, a coalition of more than 100 organizations representing patients, providers, scientists, and caregivers who are united in our support for ensuring the health and welfare of women, children, families, and people with disabilities through research funded by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) and the National Institutes of Health (NIH). We urge the subcommittee to provide NICHD with no less than $1.7 billion in Fiscal Year (FY) 2022, an increase of $117 million over FY 2021. We also respectfully ask the subcommittee to maintain its commitment to increasing funding for the National Institutes of Health (NIH) by providing no less than $46.1 billion in FY 2022.

We are pleased to support the extraordinary achievements of NICHD in meeting the objectives of its biomedical, social, and behavioral research mission, including research on child development before and after birth; women's health throughout the life cycle; maternal, child, and family health; learning and language development; reproductive biology; population health; and medical rehabilitation. With these necessary resources, NICHD can ensure proportional growth to that of its counterpart institutes and build upon the initiatives we've listed below to provide new insights and solutions to benefit women, children, and families in your districts and states.

COVID–19: NICHD has played a key role in understanding the impact of the COVID–19 pandemic on the institute's populations, including pregnant and postpartum women, children and adolescents, people with intellectual and developmental disabilities, and people with physical disabilities and mobility impairments. This work includes intramural research studies, collaborations with other NIH institutes and centers, and major undertakings like the Gestational Research Assessments for COVID–19 (GRAVID) study and the Predicting Viral-Associated Inflammatory Disease Severity in Children with Laboratory Diagnostics and Artificial Intelligence (PreVAIL kIds) which are advancing our knowledge of understudied COVID–19 research questions. NICHD also continues to advocate for inclusion of its key populations in major trans-NIH programs like the Rapid Acceleration of Diagnostics (RADx) initiative.

Maternal Mortality: The Pregnancy and Perinatology Branch, through networks including the Maternal-Fetal Medicine Units (MFMU) Network, supports research to improve the health of women before, during and after pregnancy. Maternal mortality rates are at an unprecedented high in the United States and significant racial and ethnic disparities persist. Research to better understand the mechanisms of disparities, to include social determinants of health and genetic factors that adversely affect pregnancy outcomes, are vitally needed.

Data on Pediatric Enrollment in NIH Trials: NIH requires investigators to submit deidentified demographic data on study participants, including age at enrollment. It is important for NIH to analyze and publicly report on this data to ensure that all populations, including children, benefit from research. This data should be used proactively NIH-wide to address recruitment issues in ongoing studies in real time and to drive forward the inclusion of individuals across the lifespan, including children. NICHD should play a leading role in the implementation of this policy vis-á-vis age.

Infant and Childhood Health: Through the Best Pharmaceuticals for Children Act (BPCA), NICHD funds the study of old, off-patent drugs important to children but inadequately studied in pediatric populations. We urge continued funding for this research and for training the next generation of pediatric clinical investigators. We also strongly support NICHD's ongoing research into the causes and prevention strategies for the major causes of death in infancy and childhood, including sudden unexpected infant death, accidents, and suicide.

Behavioral Health Research: NICHD supports a range of research on child development and behavior and has made great progress developing sophisticated tools to measure children's cognitive, emotional, and social functioning. To build on these successes, we encourage more integrated behavioral and biobehavioral work on child developmental trajectories, across infancy, childhood, and adolescence, in both normative and at-risk environments, across diverse contexts (school, home, and community) and including underrepresented and vulnerable groups. More research is also needed on integrated behavioral health in primary care settings, including cost effectiveness comparisons, and the impact of behavioral interventions on mental health, physical health, and quality of life. Child health would also benefit from additional work on the role of technology to support optimal development in children, including those with disabilities, and increased access to and engagement with effective psychological and behavioral interventions for childhood conditions.

Poverty and Child Health: Poverty can be especially detrimental in childhood and adolescence, leading to adverse impacts on physical health, mental health, social well-being, cognitive and emotional development, and the acquisition of motor and language skills. NICHD is in the unique position to examine the biological, psychological, social, cultural, and environmental factors that impact the developing child in high-poverty environments—including challenges due to chronic stress, neighborhood safety, school environments, family health status, education, job instability, unstable family structures, and substandard living conditions—and to evaluate interventions aimed at improving the developmental trajectories of these children.

Reproductive Sciences: Research on the basic biological mechanisms of reproduction is a crucial foundation for all NICHD's work. Understanding reproductive biology and associated biological phenomena provides the foundation for innovative medical therapies and technologies and improves existing treatment options for gynecologic conditions. Often, this research focuses on serious conditions that are overlooked and underfunded, even though they impact many women. Future work could address infertility and the need for treatments for endometriosis, polycystic ovarian syndrome (PCOS) and uterine fibroids.

Pelvic Floor Disorders Network (PFDN): Female pelvic floor disorders represent a major public health burden with high prevalence, impaired quality of life and substantial economic costs affecting 25% of American women. The PFDN conducts research to improve treatment of these painful gynecological conditions. Current research aims to improve female urinary incontinence outcome measures and ensure high-quality outcomes.

PregSource: NICHD's PregSource™ Initiative enables pregnant women to track their health data from gestation to early infancy and access evidence-based information about healthy pregnancies. It will also allow researchers to utilize aggregated data and potentially recruit participants for clinical trials so that knowledge gaps can be eliminated and care for pregnant and post-partum women can be improved.

Task Force Specific to Research in Pregnant Women and Lactating Women (PRGLAC): We urge Congress to continue its strong support of the NICHD-led PRGLAC Task Force, and to support the recommendations contained in the report to achieve broader inclusion of pregnant and lactating women in research and expansion of the workforce of clinicians and researchers with expertise in obstetric and lactation pharmacology and therapeutics, so that lifesaving treatments for this population are known to be safe and effective.

NIH Pediatric Research Consortium (N-PeRC): N-PeRC is an NICHD-led, trans-NIH initiative that aims to harmonize pediatric research and training activities across the NIH. N-PeRC capitalizes on pediatric expertise at the NIH by enabling collaboration to explore gaps in the overall pediatric research portfolio and share best practices to advance science. N-PeRC has played a vital role throughout the

COVID–19 pandemic in identifying key child and adolescent research needs related to SARS–CoV–2.

Human Development, Infancy Through Adulthood: NICHD supports research on infant-through-adult development, including how father-child relationships and co-parenting positively impacts children's socio-emotional development and decreases behavior problems; children's adjustment after the birth of a sibling; pathways and outcomes associated with mothers' postseparation co-parenting relationships, with a particular focus on experiences of intimate partner violence and negative outcomes; and the health and well-being across three generations of lesbians, gay men, and bisexuals.

Intellectual and Developmental Disabilities Research Centers (IDDRC): The IDDRCs are a critical national resource for basic research into the genetic and biological basis of human brain development, greatly improving our understanding of the causes of developmental disabilities and contributing to the development and implementation of evidence-based practices by evaluating the effectiveness of biological, biochemical, and behavioral interventions. These centers have contributed to new treatments for genetic disorders through the study of intellectual and developmental disabilities, such as Everolimus for epilepsy in TSC. We must build on progress in the understanding and treating this class of disorders that affect so many. We urge resources and support for the IDDRCs for research infrastructure and expansion to conduct basic and translational research to develop effective prevention, treatment and intervention strategies for children and adults with developmental disabilities.

Preterm Birth: NICHD supports a comprehensive research program on the causes, prevention and treatment of preterm birth, the leading cause of infant mortality and intellectual and physical disabilities. Research shows the survival rate and neurological outcomes may be improving for very early preterm infants, but continued prioritization is needed through extramural preterm birth prevention research, the MFMU Network, the Neonatal Research Network, and intramural research program. Robust funding is needed for research to determine the complex interaction of behavioral, social, environmental, genetic, and biological influences on preterm birth with the goal of developing the interventions necessary to decrease prematurity.

Population Dynamics: The NICHD Population Dynamics Branch supports research on how population change affects the health, development, and well-being of children and their families. Longitudinal surveys, such as the Fragile Families and Child Wellbeing Study, have demonstrated the role that family stability and parental involvement play in the long-term health and development of children, facilitating tremendous progress in the population sciences. NICHD also supports the Population Dynamics Centers Research Infrastructure Program, which supports research and research training in demographic or population research. These centers focus on research such as family demography and intergenerational relationships; education, work, and inequality; population health; and reproductive health.

Male Infertility: Male infertility is another relevant area of inquiry that would benefit from NICHD-sponsored research. For instance, the biological mechanisms associated with common causes of male infertility, such as varicoceles, remain poorly understood. These research domains represent important opportunities to develop better treatments for male infertility.

[This statement was submitted by KJ Hertz, 2021 Chair, Friends of the National Institute of Child Health and Human Development.]

PREPARED STATEMENT OF THE FRIENDS OF THE NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES

On behalf of the 35 patient, physician, and research organizations that are members of the Friends of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), we want first to thank you for your ongoing bipartisan investment in the National Institutes of Health (NIH). We ask you to support our FY 2022 NIH funding recommendation of at least $46.111 billion, a $3.177 billion increase over the comparable FY 2021 funding level for the NIH, which would allow for the NIH's base budget to keep pace with the biomedical research and development price index of 2.3% and allow meaningful growth of 5%. We also request a proportionate increase for the NIDDK of at least $157 million for a total of $2.289 billion in FY 2022. This level of increase over its FY 2021 funding is necessary for NIDDK to fulfill its mission to conduct and support medical research, research training, and to disseminate science-based information on diabetes and other endocrine and metabolic diseases; digestive diseases, nutritional disorders, and obesity; and kidney, uro-

logic, and hematologic diseases and to support the Institute's multi-pronged efforts toward the goal of health equity. We also strongly encourage you to provide supplemental emergency funding of $10 billion for NIH, ensure dedicated support for the NIDDK to enable critical COVID-related research, and support research recovery from the impact of the pandemic.

NIDDK supports and conducts research to combat a portfolio of diseases that encompass some of the most chronic, common, consequential, and costly diseases and conditions affecting people in this country. Many of these diseases and disorders are also associated with health disparities. These disparities are exacerbated by the COVID–19 pandemic, with increased rates of infection and poor outcomes from COVID–19 seen in people with these same conditions.

We want to share just a few NIDDK-supported research highlights to demonstrate the great impact and promise of NIDDK research to improve people's health and quality of life (more thorough descriptions are in NIDDK's Recent Advances & Emerging Opportunities):

—Research on an immune-targeting drug has delayed type 1 diabetes progression in high-risk individuals for at least 3 years. This is the first time ever that early preventive therapy was found to delay onset of clinical type 1 diabetes.

—Research defining subgroups of people with chronic kidney disease is paving the way for kidney precision medicine.

—Adult and pediatric studies are testing potential therapies and uncovering genetic and racial/ethnic risk factors for nonalcoholic fatty liver disease and nonalcoholic steatohepatitis.

—The Intestinal Stem Cell Consortium is studying intestinal stem cells' roles in intestinal health and disease, aiming to identify and develop novel therapies to regenerate the human intestine.

—The NIDDK sponsored Symptoms of Lower Urinary Tract Dysfunction Research Network (LURN) is working to improve the lives of patients affected by lower urinary tract dysfunction (LUTD) through overcoming barriers to diagnosis and treatment.

—Innovative research by NIDDK scientists showed the potential importance of speech-generated droplets in SARS–CoV–2 transmission.

—NIDDK research has led to better treatments such as new drugs that can dramatically reduce disease burden for many with cystic fibrosis; increased understanding and treatment of inflammatory bowel diseases such as Crohn's disease and ulcerative colitis; and to new Type 2 diabetes drugs that provide cardiovascular health benefits in people with diabetes.

Our organizations are grateful for the funding that you have provided to the NIH and the NIDDK as part of the appropriations process and the support Congress has given to the NIH, including several of its institutes and centers, to respond to the public health emergency. However, we note that NIDDK's FY 2021 appropriation was proportionally less than other Institutes and NIDDK and has not received any emergency funding despite researching diseases that are associated with increased risk of severe COVID–19 outcomes and are themselves public health crises.

As health professionals and researchers continue to respond to this pandemic, our understanding of COVID–19 continues to evolve. What we originally understood to be an infectious, respiratory virus, we now know disproportionately impacts individuals with diabetes, obesity, liver diseases and kidney diseases. COVID–19 infection damages a variety of organ systems, including the kidneys and it may even contribute to new onset of kidney failure and diabetes. Patients also are experiencing hematologic complications, including issues related to coagulation and blood cell production. Yet, without additional funding, NIDDK will be forced to continue to divert crucial funds from its existing priorities to better understand these characteristics of COVID–19, a loss to the patients who ultimately benefit from research funded by NIDDK.

With emergency supplemental funding, NIDDK will be able to support research on SARS–CoV–2/COVID–19 as it intersects with and affects people with or at risk for diabetes and other metabolic diseases, obesity, and endocrine, digestive, hepatobiliary, pancreas, kidney, urological and hematologic diseases. Specific areas of research include: determining the basis for the link between COVID–19 severity and diseases in the NIDDK's portfolio; identifying novel pathogenic pathways and potential translational targets for the treatment or prevention of kidney, gastrointestinal, and endocrine/metabolic diseases associated with SARS–CoV–2 infection; and understanding the roles of health disparities associated with SARS–CoV–2 infection, organ injury, and adverse disease outcomes.

Further, the occurrence of Post-Acute Sequelae of SARS–CoV–2 infection (PASC), in which individuals experience persistent symptoms involving multiple body systems after recovering from their initial illness, shows that while new infections with

SARS–CoV–2 have decreased in the US, our understanding of the long-term consequences of COVID–19 is far from over and creates another important and emerging research opportunity.

In addition to new areas of research, the pandemic has created additional barriers and expenses that complicate restarting research. Supplemental funds are needed to:

—Restart research projects, programs, and clinical trials that were underway before the onset of the pandemic and were stopped or delayed for safety reasons, consequently stalling or delaying new discoveries.

—Support early-stage investigators as they face uncertainties and challenges in making progress in their careers, especially women investigators and others who are disproportionately affected by caregiving roles during the pandemic and members of groups underrepresented in research.

—Provide financial support so that critical research support staff can be retained and to accelerate the eventual resumption of research activities post-pandemic.

—Address increasing research costs. The burden of restarting clinical trials, animal colonies, and other programs and resources has made conducting research more challenging and expensive during the pandemic. Costs for personal protective equipment (PPE), comprehensive cleaning, and "time sharing" in laboratories are a few examples.

All of this leads to a simply put yet challenging goal: While addressing the immediate challenges of COVID–19, we also need to continue to combat the diseases within NIDDK's mission, which will continue to place an enormous personal and financial toll on this country long after the pandemic is over. Bolstering support for NIDDK will help ensure that critical research in these areas continues and will support the institute's commitment to understanding the roles of social determinants of health and health disparities with the goal of improving health for all. Our nation's progress against COVID–19—and every other health threat—is built on the longstanding bipartisan commitment to medical research. Preserving that investment will be key to continued advances. We urge you to support the NIH with a $3.1 billion increase for FY 2022 with a proportionate increase of $157 million for NIDDK and provide emergency supplemental funds for NIH, including dedicated support for the NIDDK, to ensure we lead the world in providing new and better cures, diagnostics, and treatments while protecting all patients and the research enterprise.

Prepared Statement of the Friends of the National Institute of Mental Health

Chair Murray, Ranking Member Blunt, and Members of the Subcommittee:

I write on behalf of the Friends of NIMH, a newly formed coalition of more than 30 organizations representing scientists, physicians, health care providers, individuals, families, and communities. The members of the Friends of NIMH are dedicated to supporting the mission of the National Institute of Mental Health (NIMH) to transform the understanding of mental health and the treatment of mental illnesses through basic biomedical, behavioral, and clinical research, to best inform prevention, early intervention, recovery, and cures. We write to encourage you to provide robust funding for NIMH in FY 2022 so that the institute can build upon the significant achievements to advance the behavioral, biomedical, and social research mission and important initiatives to provide new insights and solutions to benefit your constituents. Our member organizations represent communities with interest across the National Institutes of Health (NIH). Individually and collectively, our members also belong to the Ad Hoc Group for Medical Research, a coalition of over 330 patient and voluntary health groups, medical and scientific societies, academic and research organizations, and industry that support enhancing the federal investment in the behavioral and biomedical research conducted and supported by the NIH. Aligned with the Ad Hoc request, we respectfully request that the subcommittee provide at least $46.1 billion for the agency in Fiscal Year (FY) 2022, $3.2 billion above the final FY21 funding level.

Thank you for considering this request.

The Friends of NIMH Executive Committee:

Juliane Baron
Federation of Associations in Behavioral and Brain Sciences

Diana E. Clarke
American Psychiatric Association

Brian Hepburn
National Association of State Mental Health Program Directors

Pat Kobor
American Psychological Association

Theresa Nguyen
Mental Health America

Anna Platt
Research!America

Andrew Sperling
National Alliance on Mental Illness

PREPARED STATEMENT OF THE FRIENDS OF THE NATIONAL INSTITUTE ON AGING

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 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.

We are writing to request that federal resources continue to be dedicated to sustaining and enhancing timely and promising aging research at NIA and across NIH.

Specifically, FoNIA requests:

—No less than $46.1 billion—a $3.3 billion increase—in fiscal year (FY) 2022 for total spending at NIH for current institutes and operations, including funds from the 21st Century Cures Act for targeted initiatives which corresponds with the overall recommendation of the Ad Hoc Group for Medical Research.

—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. This increase must be separate from whatever funds are allocated to the Advanced Research Projects Agency for Health (ARPA–H) at NIH. Investment in ARPA–H should not come at the cost of the existing NIH institutes and centers conducting and supporting research on aging.

—A minimum increase of $289 million specific to research on Alzheimer's disease and related dementias (ADRD). NIA is the primary federal agency supporting and conducting Alzheimer's disease and related dementias research.

FoNIA understands that during this time, Congress is working hard to stem fallout of both the human and fiscal toll of COVID. In this rapidly evolving crisis, NIH/NIA has played an extremely vital role in examining how COVID impacts older adults, why they may be more susceptible to the virus, how they can be protected, and the social and economic effects of the pandemic on older adults.

NIA sponsors and conducts the lion's share of federal aging-related research, and this pioneering science contributes significantly to the improved care and quality of life of older adults. A key NIA priority is translating research into better and more efficient care through the development of effective interventions that are disseminated to health care 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's COVID response has been wide and varied. NIA has been heavily involved in the work of the Rapid Acceleration of Diagnosis (RADx) program designed to speed innovation in the development, commercialization, and implementation of technologies for COVID testing. NIA is especially active in the RADx Underserved Populations (RADx-UP) program, which strives to understand the factors associated with disparities in COVID morbidity and mortality.

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.

NIH's Brain Research through Advancing Innovative Technologies (BRAIN) Initiative works to develop a dynamic picture of how neurons act, both individually and together in circuits. The initiative revolutionizes our understanding of the human brain and provides insight into how to treat, prevent and cure brain disorders. In addition to NIH, this public-private partnership involves other federal agencies such as the National Science Foundation (NSF), Defense Advanced Research Projects Agency (DARPA), Intelligence Advanced Research Projects Activity (IARPA), the Food and Drug Administration (FDA) and the Department of Energy (DOE).

Lastly, NIH funding provides a vital economic boost to local economies. Most of NIH/NIA funding is distributed as grants to universities and other research institutions across the US, and acts as an economic engine and multiplier in local and regional communities. According to United for Medical Research, total FY 2020 NIH research spending of $34.65 billion supported more than 536,338 American jobs and generated nearly $91.35 billion in economic activity across the country.

Thanks to your support, NIH/NIA is continuing to accelerate scientific discoveries which will benefit us all as we age. Only through continued, and meaningful investments in NIH/NIA will it be possible to 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 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 substance use disorders 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 2022 Labor, Health and Human Services Appropriations bill we request that the subcommittee include the President's requested level of $51 billion for the National Institutes of Health (NIH), including no less than $46.1 billion for NIH's base program level budget. In addition, we greatly appreciate the President Budget's recognition of the need to significantly increase our nation's investment in the National Institute on Drug Abuse (NIDA) and its response to the opioid epidemic. The President's Fiscal 2022 Budget recommends a $372.2 million increase in NIDA's budget, a 25 percent increase. We strongly encourage the Subcommittee to include the President's recommended funding level of $1.852 billion for NIDA in the Senate version of the Fiscal Year 2022 Labor, Health and Human Services Appropriations bill.

We also respectfully request the inclusion of the following NIDA specific report language.

Opioid Initiative. The Committee continues to be concerned about the opioid overdose epidemic and appreciates the important role that research plays in the various federal initiatives aimed at this crisis. The Committee is also aware of the most recent data from the Centers for Disease Control and Prevention that shows opioid overdose fatalities increasing from 2018 to 2019, with the primary driver being the increased overdose deaths involving synthetic opioids, primarily illicitly manufactured fentanyls. To combat this crisis the Committee has provided within NIDA's budget no less than $270,295,000 for the Institute's share of the HEAL Initiative and in response to rising rates of stimulant use and overdose, the Committee has included language expanding the allowable use of these funds to include research related to stimulant use and addiction.

Methamphetamine and Other Stimulants. The Committee is concerned that, according to data released by the Centers for Disease Control and Prevention, 32,000 overdose deaths involved drugs in the drug categories that include methamphetamine and cocaine in 2019, an increase of over 700%. The sharp increase has led 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. Methamphetamine is highly addictive and there are no FDA-approved treatments for methamphetamine and other stimulant use disorders. 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 which effectively limits 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 and antidotes for their harmful effects, we should be lowering regulatory and other barriers to conducting this research. The Committee appreciates NIDA's completion of a 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 to sources of marijuana including dispensary products.

COVID Pandemic and Impact on Substance Use Disorders. The Committee is acutely aware of the risks that the ongoing COVID–19 pandemic poses to individuals with substance use disorders. According to the Centers for Disease Control and Prevention, drug overdose deaths accelerated during the pandemic which saw over 81,000 drug overdose deaths in the United States in the 12 months ending in May 2020, the highest number of overdose deaths ever recorded in a 12-month period. Moreover, research supported by the National Institute on Drug Abuse found that individuals with substance use disorders are at increased risk for COVID–19 and its more adverse outcomes. The Committee commends NIDA for conducting research on the adverse impact of the pandemic on SUDs and encourages the Institute to expand its research on these issues.

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 area, 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. The Committee recommends that NIDA increase its support for the education of scientists and practitioners to find improved prevention and treatments for substance use disorders as the Institute has done for the COVID–19 pandemic.

Marijuana Research. The Committee is concerned that marijuana policies on the federal level and 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 continue to fund research on the use and consequences of these devices.

In addition, we request the following report language within the Office of the Director account:

> *The HEALthy Brain and Child Development (HBCD) 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 impacts of pre- and postnatal exposure to drugs or adverse environments, including risk for future substance abuse, mental disorders, and other behavioral and developmental problems. The Committee recognizes that the HBCD Study is supported in part by the NIH HEAL Initiative, and NIH Insti-

tutes, Centers, and Offices (ICOs), including OBSSR, ORWH, NIMHD, NIBIB, NIMHD, NIEHS, NICHD, NINDS, NIAAA, NIMH, and NIDA, and encourages other NIH ICOs to support this important study.

Substance use disorders (SUD) are 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 SUD as a chronic, often-relapsing brain disease -this new knowledge has helped to correctly emphasize the fact that SUD 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 fatalities due to heroin and synthetic fentanyl, as well as continued illicit use of prescription opioids. Our knowledge of how drugs work in the brain, their health consequences, how to treat people with SUDs, and what constitutes effective prevention strategies has increased dramatically due to research. However, because 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 FY2022 budget cycle will involve setting priorities and accepting compromise, however, in the current climate we believe a focus on substance use disorders deserves to be prioritized accordingly. Thank you for your support for the National Institute on Drug Abuse.

PREPARED STATEMENT OF FSHD SOCIETY

Honorable Chairwoman Murray, Ranking Member Blunt, and distinguished members of the Subcommittee, thank you for the opportunity to testify. We are requesting the FY2022 appropriation of an amount of $33 million for the agency U.S. DHHS National Institutes of Health (NIH) program on research specifically directed at facioscapulohumeral disease and facioscapulohumeral muscular dystrophy (hereafter called FSHD).

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 skeletal muscle strength that is asymmetric in pattern 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 respiratory failure and breathing issues,[62] mild-profound hearing loss, eye problems and cardiac bundle blockage and arrhythmias.[79] FSHD causes significant disability and death according the U.S. Centers for Disease Control and Prevention (CDC), National Center on Birth Defects and Developmental Disabilities, Atlanta, Georgia and others.[80,81]

FSHD is associated with epigenetic changes on the tip of human 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 5] Ectopic expression of DUX4 in skeletal muscle is associated with the disease and the disease's pathophysiology that leads to muscle death. DUX4 is never expressed in 'healthy' muscle. FSHD has had few clinical trials,[6 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 24] The genetics of FSHD are so remarkable, that NIH Director Dr. Francis Collins said on the front page of the New York Times, "If we were thinking of a collection of the genome's greatest hits, this [FSHD] would go on the list."[78]

Blocking DUX4's DNA, DUX4's RNA or DUX4's protein ability to activate its targets has profound therapeutic relevance.[25] The FSHD scientific community has in recent years pioneered inroads to treating FSHD using the enormous potential of genomic sequencing, genomic medicine, gene editing and next generation diagnostics. Table 1 lists a dozen approaches detailed in thirty-eight proof-of-concept publications that molecular and genetic treatment approaches work in cellular and animal models for FSHD. All with the central paradigm of the reduction of: DUX4, DUX4 expression, DUX4 protein activity, or the effects of DUX4-mediated toxicity.

Strategies include modulating DUX4 repressive pathways, targeting DUX4 mRNA, DUX4 protein, or cellular downstream effects of DUX4 expression. Simply unfathomable as to why NIH funding is this area is not increasing with the pace of discovery.

TABLE 1: Genetic Approaches with Potential to Treat FSHD

—Targeting the DUX4 gene itself by repression using CRISPR/dSaCas9 or CRISPR/dCas9–KRAB;
—Targeting and correcting the FSHD2 SMCHD1 gene mutation with CRISPR/Cas9;
—Knockdown and silencing of the DUX4 gene by going after DUX4 mRNA with antisense oligonucleotides and with RNA interference; U7-asDUX4 snRNAs;
—Targeting DUX4 protein expression using through DNA aptamers; proteins homologous to DUX4; and DNA decoys;
—Going after and controlling expression target downstream [post-expression] of DUX4;
—Going after genetic modifiers of DUX4 expression and DUX4-mediated toxicity between the DUX4 gene and DUX4 mRNA; G-quadruplexes (GQs); and
—Targeting proteins that perturb DUX4-mediated toxicity or secondary features of FSHD pathology.[26 63]

The clinical trials readiness priorities remain similar to last year's testimony. The FSHD scientific community has listed emphasis areas as: 1.) clinical trials readiness infrastructure and therapeutics; 2.) direct and surrogate biomarkers; 3.) genetic testing, genetics and epigenetics; 4.) imaging and outcome measures; and, 5.) registries and patient focused and reported outcomes.[73] The way to measuring disease progression and the effectiveness and safety of drugs remains deep and hard-going for industry, clinical partners and patients.

Serendipitously, new NextGen genomic sequencing and diagnostic technologies, as well as gene-targeted therapeutic approaches have emerged that will be game changing for FSHD patients and families. Understanding one's disease or condition is key for both mental and physical health. This can also aid with family and life planning decisions. With certainty many barriers to matching FSHD disease severity to outcome measures would rapidly fall. We could better align drug and therapeutic modalities with proper phenotypic/genotypic silos of FSHD based on repeat unit, methylation ranges and other requisites for FSHD. The current testing approach in the US, albeit excellent, has created a drag on the momentum towards clinical trials. With therapies on the way, identifying asymptomatic carriers and those that will decades later have later onset or mild symptoms, will allow us to then halt the disease in its early formative stages.[64,66 69,72]

Recently in 2021, two excellent papers were published on FSHD and DUX4. Both were outstanding—one was using Oxford Nanopore long read sequencing of direct-RNA to locate DUX4 gene targets and the other was a careful study of DUX4 expression in its endogenous [native] form versus the more common recombinant [created] form used in the laboratory.[70,71] As I read, I asked myself of each: "does this tell us anything more about what DUX4's function is? No. How DUX4 works? Nada. Or how DUX4 causes FSHD pathophysiology? Nothing at all. How and if DUX4 itself is toxic to skeletal muscle? Zilch. If all research using FSHD transgenic cells an animals is simply result of an artifact? Not sure now." Both papers yield the same thought: though DUX4 is the prime therapeutic target—we know next to nothing about it. It is still a complete black box; yet the central focus for FSHD therapy. Questions and areas of research interest emerge from these publications and allied considerations; flowing fast—each one hypothesis worthy of several NIH grants. "Is DUX4 cytotoxicity pathogenic in vivo? How does expression of DUX4 lead to muscle loss? What is the role of non-muscle cells in FSHD pathology? Can muscle pathology be stopped once it has started (as visualized via MRI images) or is it too late? How is DUX4 bursting regulated in vivo? What other cell types express DUX4 in FSHD and/or healthy individuals? Does the DUX4 mRNA play a nuclear role in FSHD? Are there noncoding RNA roles for DUX4? Are DUX4 induced protein aggregates cause or consequence for FSHD? Does autoimmunity play a role in FSHD? Are there other DUX4-dependent therapeutic targets?" NIH should certainly encourage proposals here. New data/information generated on the basic mechanism of DUX4 and how it causes muscle disease has the potential to focus the design of future clinical trials on muscles and measurements that will increase the rigor of the design and decrease the number of individuals necessary for initial tests of drug activity. It is absolutely necessary to increase our resolution, clarity and understanding of what DUX4 is and what it does to muscle in FSHD. The gains in this area will effectively unpin or untether FSHD from the difficulty category of "slowly progressing neuro-

muscular diseases remaining recalcitrant" to timely ascertainment that a clinical intervention can work.

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). Since passing the MD CARE Act in 2001, NIH funding for FSHD has not kept up pace with scientific opportunities listed herein. The NIH is the principal worldwide source of funding of research on FSHD. Currently active projects are $16.554 million FY2022 (current actual 23June2021), a 21% 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').

FSHD RESEARCH DOLLARS & FSHD AS A PERCENTAGE OF TOTAL NIH MUSCULAR DYSTROPHY FUNDING

[Dollars in millions]

Fiscal Year	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021
All MD ($ millions) ..	$83	$86	$75	$75	$76	$78	$77	$79	$81	$81	$83	$88e	$80e
FSHD ($ millions)	$5	$6	$6	$5	$5	$7	$8	$9	$11	$11	$10	$11e	$10e
FSHD (% total MD)	6%	7%	8%	7%	7%	9%	10%	11%	14%	14%	12%	13%	13%

Sources: NIH/OD Budget Office & NIH OCPL & NIH RePORT RCDC (e=estimate, a=actual)

We request for FY2022, a doubling of the NIH FSHD research portfolio to $33 million. At this moment in time, FSHD needs an infusion of NIH grants both submitted and funded. NIH needs to increase funding by adding exploratory/developmental research grants (parent R21) and research project grants (parent R01) in areas outlined by experts both in this testimony and in the 2015 DHHS NIH MD Plan.[77] NIH can issue targeted funding announcements covering FSHD. These efforts will help NIH receive more grant applications. This is NIH's wheelhouse and forte without a doubt.

Madam Chairman, this is my sixty-second testimony before the U.S. Congress' Appropriations Subcommittee on this matter. My FSHD is a strong fort; it has lasted my lifetime of fifty-nine years. That is a long time to live with a disease of this burden.[80] I hope with your help and action to be able to outlive my disease. I need your help, my friends and fellow FSHD patients and families need your help. Please implore NIH to double funding on FSHD and kindly remember that our lives matter. Madam Chairman, thank you again for your help and efforts.

References

[1] Deenen, J. C. W. et al. Population-based incidence and prevalence of facioscapulohumeral dystrophy. Neurology 83, 1056–9 (2014).

[2] Wang, L. H. & Tawil, R. Facioscapulohumeral Dystrophy. Curr. Neurol. Neurosci. Rep. 16, 66 (2016).

[3] Hendrickson, P. G. et al. Conserved roles of mouse DUX and human DUX4 in activating cleavage-stage genes and MERVL/HERVL retrotransposons. Nat. Genet. 49, 925–934 (2017).

[4] Whiddon, J. L., Langford, A. T., Wong, C.-J., Zhong, J. W. & Tapscott, S. J. Conservation and innovation in the DUX4-family gene network. Nat. Genet. 49, 935–940 (2017).

[5] De Iaco, A. et al. DUX-family transcription factors regulate zygotic genome activation in placental mammals. Nat. Genet. 49, 941–945 (2017).

[6] Tawil, R. et al. A pilot trial of prednisone in facioscapulohumeral muscular dystrophy. FSHDY Group. Neurology 48, 46–9 (1997).

[7] Passerieux, E. et al. Effects of vitamin C, vitamin E, zinc gluconate, and selenomethionine supplementation on muscle function and oxidative stress biomarkers in patients with facioscapulohumeral dystrophy: a double-blind randomized controlled clinical trial. Free Radic. Biol. Med. 81, 158–69 (2015).

[8] Kissel, J. T. et al. Randomized, double-blind, placebo-controlled trial of albuterol in facioscapulohumeral dystrophy. Neurology 57, 1434–40 (2001).

[9] Elsheikh, B. H. et al. Pilot trial of diltiazem in facioscapulohumeral muscular dystrophy. Neurology 68, 1428–9 (2007).

[10] Wagner, K. R. et al. A phase I/II trial of MYO–029 in adult subjects with muscular dystrophy. Ann. Neurol. 63, 561–71 (2008).

[11] Rickard, A. M., Petek, L. M. & Miller, D. G. Endogenous DUX4 expression in FSHD myotubes is sufficient to cause cell death and disrupts RNA splicing and cell migration pathways. Hum. Mol. Genet. 24, 5901–14 (2015).

[12] Sandri, M. et al. Caspase 3 expression correlates with skeletal muscle apoptosis in Duchenne and facioscapulo human muscular dystrophy. A potential target for pharmacological treatment? J. Neuropathol. Exp. Neurol. 60, 302–12 (2001).

[13] Block, G. J. et al. Wnt/β-catenin signaling suppresses DUX4 expression and prevents apoptosis of FSHD muscle cells. Hum. Mol. Genet. 22, 4661–72 (2013).

[14] Statland, J. M. et al. Immunohistochemical Characterization of Facioscapulohumeral Muscular Dystrophy Muscle Biopsies. J. Neuromuscul. Dis. 2, 291–299 (2015).
[15] Rickard, A. M., Petek, L. M. & Miller, D. G. Endogenous DUX4 expression in FSHD myotubes is sufficient to cause cell death and disrupts RNA splicing and cell migration pathways. Hum. Mol. Genet. 24, 5901–14 (2015).
[16] Kowaljow, V. et al. The DUX4 gene at the FSHD1A locus encodes a pro-apoptotic protein. Neuromuscul. Disord. 17, 611–23 (2007).
[17] Bosnakovski, D. et al. An isogenetic myoblast expression screen identifies DUX4-mediated FSHD-associated molecular pathologies. EMBO J. 27, 2766–79 (2008).
[18] Wallace, L. M. et al. DUX4, a candidate gene for facioscapulohumeral muscular dystrophy, causes p53-dependent myopathy in vivo. Ann. Neurol. 69, 540–52 (2011).
[19] Geng, L. N. et al. DUX4 activates germline genes, retroelements, and immune mediators: implications for facioscapulohumeral dystrophy. Dev. Cell 22, 38–51 (2012).
[20] Yao, Z. et al. DUX4-induced gene expression is the major molecular signature in FSHD skeletal muscle. Hum. Mol. Genet. 23, 5342–52 (2014).
[21] Homma, S., Beermann, M. Lou, Boyce, F. M. & Miller, J. B. Expression of FSHD-related DUX4–FL alters proteostasis and induces TDP–43 aggregation. Ann. Clin. Transl. Neurol. 2, 151–66 (2015).
[22] Jagannathan, S. et al. Model systems of DUX4 expression recapitulate the transcriptional profile of FSHD cells. Hum. Mol. Genet. 25, 4419–4431 (2016).
[23] Jones, T. I. et al. Facioscapulohumeral muscular dystrophy family studies of DUX4 expression: evidence for disease modifiers and a quantitative model of pathogenesis. Hum. Mol. Genet. 21, 4419–30 (2012).
[24] Campbell AE, Shadle SC, Jagannathan S, Lim JW, Resnick R, Tawil R, van der Maarel SM, Tapscott SJ. NuRD and CAF–1-mediated silencing of the D4Z4 array is modulated by DUX4-induced MBD3L proteins. Elife. 2018 Mar 13;7. pii: e31023. doi: 10.7554/eLife.31023 (2018).
[25] Jagannathan S1,2,3, Ogata Y4, Gafken PR4, Tapscott SJ3, Bradley RK1. Quantitative proteomics reveals key roles for post-transcriptional gene regulation in the molecular pathology of facioscapulohumeral muscular dystrophy. Elife. 2019 Jan 15;8. pii: e41740. doi: 10.7554/eLife.41740 (2019).
[26] Vanderplanck, C., Ansseau, E., Charron, S., Stricwant, N., Tassin, A., Laoudj-Chenivesse, D., et al. The FSHD atrophic myotube phenotype is caused by DUX4 expression. PLoS One6, e26820. doi:10.1371/journal.pone.0026820 (2011).
[27] Wallace, L. M., Liu, J., Domire, J. S., Garwick-Coppens, S. E., Guckes, S. M.,Mendell, J. R., et al. RNA interference inhibits DUX4-induced muscletoxicity in vivo: implications for a targeted FSHD therapy. Mol. Ther.20,1417–1423. doi:10.1038/mt.2012.68 (2012)
[28] Pandey, S. N., Lee, Y. C., Yokota, T., and Chen, Y. W. Morpholino treatment improves muscle function and pathology of Pitx1 transgenic mice. Mol. Ther.22, 390–396. doi:10.1038/mt.2013.263 (2014).
[29] Lim, J. W., Snider, L., Yao, Z., Tawil, R., Van Der Maarel, S. M., Rigo, F., et al. DICER/AGO-dependent epigenetic silencing of D4Z4 repeats enhanced by exogenous siRNA suggests mechanisms and therapies for FSHD. Hum. Mol.Genet. 24, 4817–4828. doi:10.1093/hmg/ddv206 (2015).
[30] Marsollier, A.C., Ciszewski, L., Mariot, V., Popplewell, L., Voit, T., Dickson, G., et al. Antisense targeting of 3'end elements involved in DUX4 mRNA processing is an efficient therapeutic strategy for facioscapulohumeral dystrophy: a new gene-silencing approach. Hum. Mol. Genet.25, 1468–1478. doi:10.1093/hmg/ddw015 (2016).
[31] Himeda CL, Jones, et al. CRISPR/dCas9-mediated Transcriptional Inhibition Ameliorates the Epigenetic Dysregulation at D4Z4 and Represses DUX4-fl in FSH Muscular Dystrophy. Mol Ther. Mar;24(3):527–35. epub 2015 Nov 3. (2016).
[32] Chen JC, King OD, Zhang Y, et al. Morpholino-mediated Knockdown of DUX4 Toward Facioscapulohumeral Muscular Dystrophy Therapeutics. Molecular Therapy. 24 (8):1405–1411. doi:10.1038/mt.2016.1118. (2016).
[33] Ansseau, E., Vanderplanck, C., Wauters, A., Harper, S. Q., Coppée, F., and Belayew, A. Antisense oligonucleotides used to target the DUX4 mRNA as therapeutic approaches in FaciosScapuloHumeral muscular dystrophy (FSHD). Genes 8, 93. doi:10.3390/genes8030093 (2017).
[34] Bosnakovski, D., Toso, E. A., Hartweck, L. M., Magli, A., Lee, H. A., Thompson, E.R., et al. The DUX4 homeodomains mediate inhibition of myogenesis and are functionally exchangeable with the Pax7 homeodomain. J. Cel Sci.130,3685–3697. doi:10.1242/jcs.205427 (2017).
[35] Marsollier AC, Joubert R, Mariot V, Dumonceaux J. Targeting the Polyadenylation Signal of Pre-mRNA: A New Gene Silencing Approach for Facioscapulohumeral Dystrophy. Int J Mol Sci. May 3;19(5). pii: E1347. doi: 10.3390/ijms19051347. Review. (2018).
[36] Lee JK, Bosnakovski D, Toso EA, Dinh T, Banerjee S, Bohl TE, Shi K, Orellana K, Kyba M, Aihara H. Crystal Structure of the Double Homeodomain of DUX4 in Complex with DNA. Cell Rep. Dec 11;25(11):2955–2962.e3. doi: 10.1016/j.celrep.2018.11.060. (2018).
[37] Lim, K. R. Q., and Yokota, T. Invention and early history of exon skipping and splice modulation, in Exon skipping and inclusion therapies: methods and protocols. Editors T. Yokota and R. Maruyama (New York, NY: Springer), 3–30. (2018).
[38] Himeda CL, Jones TI, Virbasius CM, Zhu LJ, Green MR, Jones PL. Identification of Epigenetic Regulators of DUX4-fl for Targeted Therapy of Facioscapulohumeral Muscular Dystrophy. Mol Ther. Jul 5;26(7):1797–1807. doi: 10.1016/j.ymthe.2018.04.019. Epub 2018 Apr 26. (2018).
[39] Wallace, L. M., Saad, N. Y., Pyne, N. K., Fowler, A. M., Eidahl, J. O., Domire, J. S., et al. Pre-clinical safety and off-target studies to support translation of AAV-mediated RNAi therapy for FSHD. Mol. Ther. Methods Clin. Dev.8,121–130. doi:10.1016/j.omtm.2017.12.005 (2018).

[40] Giesige CR, Wallace LM, Heller KN, Eidahl JO, Saad NY, Fowler AM, Pyne NK, Al-Kharsan M, Rashnonejad A, Chermahini GA, Domire JS, Mukweyi D, Garwick-Coppens SE, Guckes SM, McLaughlin KJ, Meyer K, Rodino-Klapac LR, Harper SQ. AAV-mediated follistatin gene therapy improves functional outcomes in the TIC–DUX4 mouse model of FSHD. JCI Insight. 2018 Nov 15;3(22). pii: 123538. doi: 10.1172/jci.insight.123538. (2018).

[41] Jones, T., and Jones, P. L. (2018). A cre-inducible DUX4 transgenic mouse model for investigating facioscapulohumeral muscular dystrophy. PLoS One 13,e0192657. doi:10.1371/journal.pone.0192657 (2018).

[42] Mitsuhashi, H., Ishimaru, S., Homma, S., Yu, B., Honma, Y., Beermann, M. L., et al. Functional domains of the FSHD-associated DUX4 protein. Biol. Open7, bio033977. doi:10.1242/bio.033977 (2018).

[43] Goossens, R., van den Boogaard, M. L., Lemmers, R. J. L. F., Balog, J., van der Vliet, P. J., Willemsen, I. M., et al. Intronic SMCHD1 variants in FSHD: testing the potential for CRISPR-Cas9 genome editing. J. Med. Genet. 56, 828–837. doi:10.1136/jmedgenet-2019–106402 (2019).

[44] Dion C, Roche S, Laberthonnière C, Broucqsault N, Mariot V, Xue S, Gurzau AD, Nowak A, Gordon CT, Gaillard MC, El-Yazidi C, Thomas M, Schlupp-Robaglia A, Missirian C, Malan V, Ratbi L, Sefiani A, Wollnik B, Binetruy B, Salort Campana E, Attarian S, Bernard R, Nguyen K, Amiel J, Dumonceaux J, Murphy JM, Déjardin J, Blewitt ME, Reversade B, Robin JD, Magdinier F. SMCHD1 is involved in de novo methylation of the DUX4-encoding D4Z4 macrosatellite. Nucleic Acids Res. 2019 Jan 30. doi: 10.1093/nar/gkz005. [Epub ahead of print] (2019).

[45] Jagannathan S, Ogata Y, Gafken PR, Tapscott SJ, Bradley RK. Quantitative proteomics reveals key roles for post-transcriptional gene regulation in the molecular pathology of facioscapulohumeral muscular dystrophy. Elife. 2019 Jan 15;8:e41740. doi: 10.7554/eLife.41740. PMID: 30644821 (2019).

[46] Lim, K. R. Q., and Yokota, T. (2020). Invention and early history of gapmers. Methods Mol. Biol. 2176, 3–19. doi:10.1007/978–1–0716–0771–8_1 (2020).

[47] Ciszewski L, Lu-Nguyen N, Slater A, Brennan A, Williams HEL, Dickson G, Searle MS, Popplewell L. G-quadruplex ligands mediate downregulation of DUX4 expression. Nucleic Acids Res. 2020 May 7;48(8):4179–4194. doi: 10.1093/nar/gkaa146. (2020).

[48] Lim KRQ, Maruyama R, Echigoya Y, Nguyen Q, Zhang A, Khawaja H, Sen Chandra S, Jones T, Jones P, Chen YW, Yokota T. Inhibition of DUX4 expression with antisense LNA gapmers as a therapy for facioscapulohumeral muscular dystrophy. Proc Natl Acad Sci U S A. 2020 Jul 14;117(28):16509–16515. doi: 10.1073/pnas.1909649117. (2020).

[49] Lim, K. R. Q., Nguyen, Q., and Yokota, T. DUX4 signaling in the pathogenesis of facioscapulohumeral muscular dystrophy. Int. J. Mol. Sci.21,729. doi:10.3390/ijms21030729.

[50] Derenne, A., Tassin, A., Nguyen, T. H., De Roeck, E., Jenart, V., Ansseau, E., et al. (2020). Induction of a local muscular dystrophy using electroporation in vivo: an easy tool for screening therapeutics. Sci. Rep.10, 11301. doi:10.1038/s41598–020–68135–7 (2020).

[51] Bittel, A. J., Sreetama, S. C., Bittel, D. C., Horn, A., Novak, J. S., Yokota, T., et al. Membrane repair deficit in facioscapulohumeral muscular dystrophy. Int. J. Mol. Sci.21, 5575. doi:10.3390/ijms21155575 (2020).

[52] Jones TI, Chew GL, Barraza-Flores P, Schreier S, Ramirez M, Wuebbles RD, Burkin DJ, Bradley RK, Jones PL. Transgenic mice expressing tunable levels of DUX4 develop characteristic facioscapulohumeral muscular dystrophy-like pathophysiology ranging in severity. Skelet Muscle. Apr 11;10(1):8. doi: 10.1186/s13395–020–00227–4 (2020).

[53] Mariot, V., Joubert, R., Marsollier, A.-C., Hourdé, C., Voit, T., and Dumonceaux, J. A deoxyribonucleic acid decoy trapping DUX4 for the treatment of facioscapulohumeral muscular dystrophy. Mol. Ther. Nucleic Acids. doi:10.1016/j.omtn.2020.10.028 (2020).

[54] Cohen, J., DeSimone, A., Lek, M., and Lek, A. Therapeutic approaches in facioscapulohumeral muscular dystrophy. Trends Mol. Med.27, 123–37.doi:10.1016/j.molmed.2020.09.008 (2020).

[55] Lek, A., Zhang, Y., Woodman, K. G., Huang, S., DeSimone, A. M., Cohen, J., et al. Applying genome-wide CRISPR-Cas9 screens for therapeutic discovery in facioscapulohumeral muscular dystrophy. Sci. Transl. Med.12, eaay0271.doi:10.1126/scitranslmed.aay0271 (2020).

[56] Lemmers RJLF, van der Vliet PJ, Blatnik A, Balog J, Zidar J, Henderson D, Goselink R, Tapscott SJ, Voermans NC, Tawil R, Padberg GWAM, van Engelen BG, van der Maarel SM. Chromosome 10q-linked FSHD identifies DUX4 as principal disease gene. J Med Genet. 2021 Jan 12;jmedgenet-2020–107041. doi: 10.1136/jmedgenet-2020–107041 (2021).

[57] Rashnonejad A, Amini-Chermahini G, Taylor NK, Wein N, Harper SQ. Designed U7 snRNAs inhibit DUX4 expression and improve FSHD-associated outcomes in DUX4 overexpressing cells and FSHD patient myotubes. Mol Ther Nucleic Acids. 2020 Dec 10;23:476–486. doi: 10.1016/j.omtn.2020.12.004. eCollection 2021 Mar 5 (2021).

[58] Himeda CL, Jones TI, Jones PL. Targeted epigenetic repression by CRISPR/dSaCas9 suppresses pathogenic DUX4-fl expression in FSHD. Mol Ther Methods Clin Dev. 2020 Dec 10;20:298–311. doi: 10.1016/j.omtm.2020.12.001. eCollection 2021 Mar 12 (2021).

[59] Schätzl T, Kaiser L, Deigner HP. Facioscapulohumeral muscular dystrophy: genetics, gene activation and downstream signaling with regard to recent therapeutic approaches: an update. Orphanet J Rare Dis. 2021 Mar 12;16(1):129. doi: 10.1186/s13023–021–01760–1. Review (2021).

[60] Lim KRQ, Yokota T. Genetic Approaches for the Treatment of Facioscapulohumeral Muscular Dystrophy. Front Pharmacol. 2021 Mar 12;12:642858. doi: 10.3389/fphar.2021.642858. eCollection 2021. Review (2021).

[61] Mellion ML, Ronco L, Berends CL, Pagan L, Brooks S, van Esdonk MJ, van Brummelen EMJ, Odueyungbo A, Thompson LA, Hage M, Badrising UA, Raines S, Tracewell WG, van Engelen B, Cadavid D, Groeneveld GJ. Phase 1 clinical trial of losmapimod in facioscapulohumeral dystrophy: Safety, tolerability, pharmacokinetics, and target engagement. Br J Clin Pharmacol. 2021 Apr 30. doi: 10.1111/bcp.14884. (2021).

[62] Lu-Nguyen N, Malerba A, Herath S, Dickson G, Popplewell L. Systemic antisense therapeutics inhibiting DUX4 expression ameliorates FSHD-like pathology in an FSHD mouse model. Hum Mol Genet. 2021 May 13:ddab136. doi: 10.1093/hmg/ddab136. (2021).

[63] Das S, Chadwick BP. CRISPR mediated targeting of DUX4 distal regulatory element represses DUX4 target genes dysregulated in Facioscapulohumeral muscular dystrophy. Sci Rep. 2021 Jun 15;11(1):12598. doi: 10.1038/s41598–021–92096–0. (2021).

[64] Goselink RJM, Mul K, van Kernebeek CR, Lemmers RJLF, van der Maarel SM, Schreuder THA, Erasmus CE, Padberg GW, Statland JM, Voermans NC, van Engelen BGM. Early onset as a marker for disease severity in facioscapulohumeral muscular dystrophy. Neurology. 2019 Jan 22;92(4):e378-e385. doi: 10.1212/WNL.0000000000006819. Epub 2018 Dec 19 (2019).

[65] Henke C, Spiesshoefer J, Kabitz HJ, Herkenrath S, Randerath W, Brix T, Görlich D, Young P, Boentert M. Respiratory muscle weakness in facioscapulohumeral muscular dystrophy. Muscle Nerve. 2019 Dec;60(6):679–686. doi: 10.1002/mus.26717. Epub 2019 Oct 23 (2019).

[66] Sacconi S, Briand-Suleau A, Gros M, Baudoin C, Lemmers RJLF, Rondeau S, Lagha N, Nigumann P, Cambieri C, Puma A, Chapon F, Stojkovic T, Vial C, Bouhour F, Cao M, Pegoraro E, Petiot P, Behin A, Marc B, Eymard B, Echaniz-Laguna A, Laforet P, Salviati L, Jeanpierre M, Cristofari G, van der Maarel SM. FSHD1 and FSHD2 form a disease continuum. Neurology. 2019 May 7;92(19):e2273-e2285. doi: 10.1212/WNL.0000000000007456. Epub 2019 Apr 12 (2019).

[67] Salort-Campana E, Fatehi F, Beloribi-Djefaflia S, Roche S, Nguyen K, Bernard R, Cintas P, Solé G, Bouhour F, Ollagnon E, Sacconi S, Echaniz-Laguna A, Kuntzer T, Levy N, Magdinier F, Attarian S. Type 1 FSHD with 6–10 Repeated Units: Factors Underlying Severity in Index Cases and Disease Penetrance in Their Relatives Attention. Int J Mol Sci. 2020 Mar 23;21(6):2221. doi: 10.3390/ijms21062221 (2020).

[68] Wong CJ, Wang LH, Friedman SD, Shaw D, Campbell AE, Budech CB, Lewis LM, Lemmers RJFL, Statland JM, van der Maarel SM, Tawil RN, Tapscott SJ. Longitudinal measures of RNA expression and disease activity in FSHD muscle biopsies. Hum Mol Genet. 2020 Apr 15;29(6):1030–1043. doi: 10.1093/hmg/ddaa031. PMID: 32083293 (2020).

[69] Rieken A, Bossler AD, Mathews KD, Moore SA. CLIA Laboratory Testing for Facioscapulohumeral Dystrophy: A Retrospective Analysis. Neurology. 2021 Feb 16;96(7):e1054-e1062. doi: 10.1212/WNL.0000000000011412. Epub 2020 Dec 21 (2021).

[70] Chau J, Kong X, Viet Nguyen N, Williams K, Ball M, Tawil R, Kiyono T, Mortazavi A, Yokomori K. Relationship of DUX4 and target gene expression in FSHD myocytes. Hum Mutat. 2021 Jan 27. doi: 10.1002/humu.24171 (2021).

[71] Mitsuhashi S, Nakagawa S, Sasaki-Honda M, Sakurai H, Frith MC, Mitsuhashi H. Nanopore direct RNA sequencing detects DUX4-activated repeats and isoforms in human muscle cells. Hum Mol Genet. 2021 Mar 9:ddab063. doi: 10.1093/hmg/ddab063 (2021).

[72] Goselink RJM, Schreuder THA, Mul K, Voermans NC, Erasmus CE, van Engelen BGM, van Alfen N. Muscle ultrasound is a responsive biomarker in facioscapulohumeral dystrophy.Neurology. 2020 Apr 7;94(14):e1488-e1494. doi: 10.1212/WNL.0000000000009211. (2020).

[73] Wang LH, Shaw DWW, Faino A, Budech CB, Lewis LM, Statland J, Eichinger K, Tapscott SJ, Tawil RN, Friedman SD. Longitudinal study of MRI and functional outcome measures in facioscapulohumeral muscular dystrophy. BMC Musculoskelet Disord. 2021 Mar 10;22(1):262. doi: 10.1186/s12891–021–04134–7 (2021).

[74] Greco A, Straasheijm KR, Mul K, van den Heuvel A, van der Maarel SM, Joosten LAB, van Engelen BGM, Pruijn GJM. Profiling Serum Antibodies Against Muscle Antigens in Facioscapulohumeral Muscular Dystrophy Finds No Disease-Specific Autoantibodies. J Neuromuscul Dis. 2021 May 15. doi: 10.3233/JND–210653. (2021).

[75] Karpukhina A, Galkin I, Ma Y, Dib C, Zinovkin R, Pletjushkina O, Chernyak B, Popova E, Vassetzky Y. Analysis of genes regulated by DUX4 via oxidative stress reveals potential therapeutic targets for treatment of facioscapulohumeral dystrophy. Redox Biol. 2021 Jul;43:102008. doi: 10.1016/j.redox.2021.102008. (2021).

[76] Banerji CRS, Zammit PS. Pathomechanisms and biomarkers in facioscapulohumeral muscular dystrophy: roles of DUX4 and PAX7. EMBO Mol Med. 2021 Jun 21:e13695. doi: 10.15252/emmm.202013695. (2021).

[77] Rieff HI, Katz SI et al. The Muscular Dystrophy Coordinating Committee Action Plan for the Muscular Dystrophies. Muscle Nerve. 2016 Mar 21. [Epub ahead of print] (2016).

[78] Kolata, G., Reanimated 'Junk' DNA Is Found to Cause Disease. New York Times, Science. Published online: August 19, 2010 http://www.nytimes.com/2010/08/20/science/20gene.html.

[79] Ducharme-Smith A, Nicolau S, Chahal CAA, Ducharme-Smith K, Rehman S, Jaliparthy K, Khan N, Scott CG, St Louis EK, Liewluck T, Somers VK, Lin G, Brady PA, Milone M. Cardiac Involvement in Facioscapulohumeral Muscular Dystrophy (FSHD). Front Neurol. 2021 May 24;12:668180. doi: 10.3389/fneur.2021.668180. (2021).

[80] Blokhuis AM, Deenen JCW, Voermans NC, van Engelen BGM, Kievit W, Groothuis JT. The socioeconomic burden of facioscapulohumeral muscular dystrophy. J Neurol. 2021 May 27. doi: 10.1007/s00415–021–10591-w. (2021).

[81] Wallace B, Smith KT, Thomas S, Conway KM, Westfield C, Andrews JG, Weinert RO, Do TQN, Street N; Muscular Dystrophy Surveillance, Tracking, and Research Network (MD STARnet). Characterization of individuals with selected muscular dystrophies from the expanded pilot of the Muscular Dystrophy Surveillance, Tracking and Research Network (MD STARnet) in the United States. Birth Defects Res. 2021 Apr 15;113(7):560–569. doi: 10.1002/bdr2.1764. (2020).

[1] U.S. Department of Education (2016). FY 2017 Department of Education Justifications of Appropriation Estimates to the Congress: Higher Education (Volume II). Retrieved from: https://www2.ed.gov/about/overview/budget/budget17/justifications/index.html.

PREPARED STATEMENT OF THE GBS|DCIDP Foundation International

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2022

—Provide $46.1 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)
—Provide $10 billion for the Centers for Disease Control and Prevention (CDC) and $5 million for the Chronic Disease Education and Awareness Program

Chairwoman Murray, Ranking Member Blunt 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 FY2022 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 six months to two 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% 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 continued support of the 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|DCIDP community. Last May we participated in a conference with NINDS that discussed how intramural and extramural researchers can 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 follow up and plan for a more robust agenda and list of goals for a future in person 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 $46.1 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|DCIDP Foundation International.]

PREPARED STATEMENT OF GEAR UP

Distinguished members of the Senate Labor-Health and Human Services-Education Appropriations Subcommittee, thank you for the giving me the opportunity to provide testimony on the profound impact that the Gaining Early Awareness and Readiness for Undergraduate Programs (GEAR UP) initiative has had on my life. My name is William Ruiz, and it is my honor and pleasure to be writing this testimonial on behalf of GEAR UP alumni and over half a million GEAR UP students across the country. Given the program's return on investment, I urge the committee to appropriate $435,000,000 for GEAR UP in fiscal year 2022 to support an additional 100,000 students across our country so that they, too, can have the support I received through GEAR UP.

GEAR UP provides 6- or 7-year grants to states and partnerships comprised of K–12, higher education, and community-based organizations that strengthen pathways to college and careers in low-income communities. GEAR UP exposes students, and their families, starting in the 7th grade to comprehensive interventions that follow them through high school graduation and optionally through the first year of postsecondary education. GEAR UP uses early and sustained interventions to ensure that students are successful in rigorous courses, are prepared for life beyond high school, and ultimately enroll in a high-quality certificate, associates', or bachelors' degree program that suits their goals. In the most recent year in which we had a large class of graduating seniors, the postsecondary enrollment rates of GEAR UP students were over 31% higher than the rates for low-income students nationally.[1] Considering that GEAR UP achieves this critical goal at a cost of approximately $694 per student, per year, I strongly believe that the investment in GEAR UP pays significant dividends. GEAR UP is a powerful catalyst for sustained community improvement.

Being the son of immigrant parents and growing up in a low-socioeconomic neighborhood in Los Angeles, California, I never envisioned myself going to college. My parents worked exceptionally hard to provide for my siblings and me, but because they had to drop out of school at a very young age to leave Mexico and move to the United States, they had very little knowledge of the education system. While I wasn't introduced to higher education by my family, my parents did teach me about the value of hard work and made sure that I attained good grades throughout my time in K–12 education. As I navigated my way through elementary and middle school, I always looked forward to high school graduation because I thought that that would be the end of my educational journey. It was always my plan to graduate high school and enter the workforce full-time, just like how my older siblings did. It wasn't until I was introduced to the GEAR UP program in 7th grade that I was exposed to college. At that time, college was the last thing on my mind, but the GEAR UP staff continued to remind us that they would pack up their office and follow us to our local high school.

Fast forwarding to my first day at Benjamin Franklin High School, I remember the first adult I saw on campus: GEAR UP Counselor Mr. Burton. I was shocked to see that they were serious when they said they would follow us. Throughout the rest of my freshman year, we would participate in various workshops with GEAR UP. I always enjoyed talking to the GEAR UP team, but I still couldn't see myself pursuing higher education. At the end of my first year of high school, GEAR UP started recruiting students for their peer mentor and summer programs.

After signing up for summer school and participating in the peer mentor camps with GEAR UP, I immersed myself in all things GEAR UP. At the beginning of my sophomore year, I met an individual who, to this day, has a special place in my heart. I can never truly thank Mr. Robert Aguirre for all the help and support he has provided me with since 2009. While I had the grades to attend college and pursue a degree, Mr. Aguirre provided me with the structure and gave me all the resources I needed to pursue higher education. Growing up in a neighborhood with a lot of gang violence and having friends who dropped out of school a young age, it was reassuring to have a positive male role model that I could look up to. I always heard that it only takes one adult to care for a student to do well in school. I can undoubtedly say Mr. Aguirre was that person for me. I always knew that if I had any issues regarding school, I could easily walk to the GEAR UP office to talk to him.

I wouldn't have gone to a 4-year university if it wasn't for Mr. Aguirre and GEAR UP. Not only did GEAR UP teach me about admission requirements and financial

[1] U.S. Department of Education (2016). FY 2017 Department of Education Justifications of Appropriation Estimates to the Congress: Higher Education (Volume II). Retrieved from: https://www2.ed.gov/about/overview/budget/budget17/justifications/index.html.

aid, but they also exposed me to different colleges and universities. One of my fondest memories of high school was traveling up the California coastline on a bus to visit colleges in Northern California. Because of the field trips and the exposure to colleges, I began to imagine myself on college campuses. When I started my senior year of high school, the GEAR UP staff sat me down in the school's computer lab to apply to college. As someone who had simply gone through the motions, I really appreciated GEAR UP for giving me that extra push to take education more seriously.

I will always be grateful for all the love and support that GEAR UP provided as I navigated high school. Yes, GEAR UP is an acronym and a federally funded program, but to me, GEAR UP is family.

Because of what GEAR UP gave me, I wanted to give back to GEAR UP. I currently have the honor and privilege of working with over 800 students in the Compton Unified School District as a GEAR UP Program Coordinator. I am also a Founding Board Member of the GEAR UP Alumni Association. The GEAR UP Alumni Association aims to support GEAR UP Alumni so that GEAR UP students can not only get to college but also graduate. Our vision is to eventually branch out and support GEAR UP students across the country.

I am also happy to share with you that beginning in August 2021, I will be pursuing my Master of Arts in Diverse Community Development Leadership (DCDL) at California State University, Northridge. As a GEAR UP alum and current educator, I want to continue my educational journey so that I can best assist students like me. My initial goal was only to graduate high school. Now, I am proud of the fact that I am the first in my family to graduate college and will be the first to receive a graduate degree.

None of this would have been possible without GEAR UP. I will always be open and honest about my journey because there are a lot of students who have similar backgrounds as me. I wake up every day grateful that I was able to be a GEAR UP student because it changed my life for the better.

As you take on the work of preparing for the fiscal year 2022 appropriations, I urge you to consider increasing the investment in the GEAR UP program to $435,000,000 so that 100,000 more students just like me can benefit from the program. Thank you to the committee for taking the time to read my testimony.

Prepared Statement of Global Health Council

Global Health Council (GHC) is the leading membership organization for 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 (FY) 2022, GHC encourages continued support for global health at a minimum of FY21 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 FY22, which includes at a minimum: $6,356,000,000 for the National Institute of Allergy and Infectious Disease (NIAID), $3,845,000,000 for the Office of AIDS Research, and $91,000,000 for the Fogarty International Center at the National Institutes of Health (NIH); an investment of $735,000,000 for the Center for Emerging Zoonotic and Infectious Diseases, $300,000,000 for the Infectious Diseases Rapid Response Fund, and no less than $898,000,000 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 to sustain America's legacy abroad and to support existing programs in their ongoing response to the coronavirus. It is our hope that appropriators will consider the additional needs and negative effects of the COVID–19 pandemic when making appropriations for FY22. We have seen significant declines across global health programs in their capacity to reach the same or more people for preventative care, ongoing care for diseases ranging from HIV/AIDS, tuberculosis, non-communicable diseases, malaria, and more.

We know that these programs work and have secured their place as some of the most critical and successful tools for U.S. global health. By investing in these programs, the United States is continuing to build healthier and more self-reliant communities, which ultimately become economically and politically stable. We have seen the COVID–19 pandemic exacerbate weak points in health systems in rich and poorer countries alike, ultimately weakening our own health system. It highlighted inefficiencies and a sheer lack of access to care around the world. We cannot afford to lose more ground on the progress that the United States has already made towards building healthier communities. A failure to backstop these investments would roll

back the progress we have spent decades achieving and ultimately undermine U.S. foreign policy and global health priorities.

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.

We must 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 Kiki Kalkstein, Director of Advocacy & Engagement, Global Health Council.]

PREPARED STATEMENT OF THE GLOBAL HEALTH TECHNOLOGIES COALITION

On behalf of the Global Health Technologies Coalition (GHTC), a group of 37 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 2022 (FY22) 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). These recommendations reflect the needs expressed by our members working across the globe to develop new and improved technologies for the world's most pressing health issues. We appreciate the Committee's support for global health, particularly for continued research and development (R&D) to advance new drugs, vaccines, diagnostics, and other tools for longstanding and emerging health challenges, including COVID–19. To accelerate progress toward lifesaving tools for a range of health threats, we respectfully request increased funding for NIH, including an additional $10 million for the Fogarty International Center (FIC); funding to match CDC's increased responsibilities in global health and global health security-in line with the overall increase for CDC proposed in the President's Discretionary Budget Request, which should be reflected in increases for the Center for Global Health (CGH) and National Center for Emerging Zoonotic and Infectious Diseases (NCEZID)—and the creation of a new, dedicated funding line to support BARDA's critical work in emerging infectious diseases (EIDs), which accelerated to unprecedented levels over the past year and should be sustainably funded beyond the COVID–19 pandemic.

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. Coordination is also key: we urge the Committee to request that leaders of Department of Health and Human Services agencies work with counterparts at the State Department and the US Agency for International Development to develop a cross-government global health R&D strategy to ensure that US investments are efficient, coordinated, and streamlined.

While we have made tremendous gains in global health over the past 15 years, millions of people around the world are still threatened by neglected diseases and conditions. In 2019, tuberculosis (TB) killed 1.4 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 68 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. 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, both to address unmet global health needs and to address challenges of drug resistance, toxic treatments, and health technologies that are difficult to administer in poor, remote, and unstable settings.

The COVID–19 pandemic has again demonstrated that we do not have all the tools needed to prevent, diagnose, and treat many neglected and EIDs—a reality foreshadowed by the recent Zika and Ebola epidemics. The lifesaving effects of the first COVID–19 vaccines demonstrate the power of having the right tools to respond to a health emergency. These new vaccines, developed with critical funding from BARDA, NIH, and other US government partners, are highly effective and built upon past global health research advances. Notably, the Johnson & Johnson vaccine is based on technology used in its Ebola vaccine and Zika, respiratory syncytial virus, and HIV/AIDS vaccine candidates, and the Moderna-National Institute of Allergy and Infectious Diseases (NIAID) vaccine platform was previously being used to develop vaccines against other respiratory viruses and the chikungunya virus. This demonstrates how strong, sustained investment in R&D allows us to tackle today's health threats and prepare for those of the future. The United States remains at the forefront of global health innovation because of long-term investments in R&D agencies such as NIH, CDC, and BARDA.

NIH: The groundbreaking science conducted at NIH has long underpinned US leadership in biomedical research. Within NIH, NIAID, the Office of AIDS Research, and FIC all play critical roles in developing new health technologies that save lives at home and around the world. FIC, in particular, is a leader in accelerating global scientific progress through international research partnerships, technical assistance, and training. Many FIC-trained scientists have led their countries' responses to COVID–19, Zika, and Ebola, as well as long-standing challenges such as HIV/AIDS. COVID–19 has underscored that science capacity gaps remain between low- and middle-income countries and high-income countries. With additional funding, FIC could leverage its extensive network and training capacity to improve global genomic surveillance and coordination. We urge Congress to request information from FIC on how it might address global scientific capacity gaps in modeling, genomic surveillance, researcher training, and pandemic preparedness and urge appropriators to consider sustainably increasing FIC's relatively modest budget by $10 million dollars in each of the next five fiscal years to enable work in new areas.

Across NIAID, FIC, and other institutes and centers, NIH leadership has long supported 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. It remains critical that support for NIH extend to all pressing areas of research—including research in neglected diseases and EIDs.

CDC: CDC 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. CDC monitors 30 to 40 international public health threats each day, has identified disease outbreaks in more than 150 countries, responded to more than 2,000 public health emergencies, and discovered 12 previously unknown pathogens—and in complement to these disease monitoring and detection functions, plays a leading role in related R&D. Important work at NCEZID includes the development of diagnostics, including the first diagnostic test for COVID–19 with authorization from the US Food and Drug Administration and Trioplex, a diagnostic that can differentiate Zika, dengue, and chikungunya viruses. NCEZID is a leader in early-stage R&D for vaccines for infectious diseases such as Nipah virus and dengue, Lassa, and Rift Valley fevers. 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.

In complement, CGH is a global leader in immunization, public health capacity-building, and preventing, detecting, and responding to infectious diseases. Programs at CGH—including the Divisions of Global HIV and TB, Global Immunization, Parasitic Diseases and Malaria, and Global Health Protection—have yielded advances in the development of vaccines, drugs, 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 US bilateral and multilateral global health programs and leads laboratory efforts to monitor and combat drug and insecticide resistance to ensure that global health programs are 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 work to end the recent Ebola outbreaks in Africa through its international leadership on the Global Health Security Agenda. GHTC supports the funding increase to CDC proposed by the administration for

FY22 and urges the Committee to increase funding for CDC's critical global health R&D work at CGH and NCEZID.

BARDA: BARDA plays an unmatched role in global health R&D by using unique contracting authorities and targeted incentive mechanisms to advance the development and purchase of critical medical technologies for public health emergencies. 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 other R&D agencies do not operate. BARDA has been a critical funder of countermeasures for naturally occurring health security threats including EIDs such as COVID–19, Ebola, and Zika, as well as pandemic influenza and antimicrobial resistance. To date, BARDA's work in advancing tools for EIDs has largely been funded through emergency supplemental funding. A dedicated funding line of at least $300 million annually for EID R&D would ensure that BARDA is resourced to respond quickly to future threats, rather than wait on haphazard infusions of supplemental funding during health emergencies.

In addition to bringing lifesaving tools to those who need them most, investment in global health R&D is also a smart economic investment in the United States with 89 cents of every US dollar invested in global health R&D going directly to US-based researchers. US government investment in global health R&D between 2007 and 2015 generated an estimated 200,000 new jobs and $33 billion in economic growth. Investments in global health R&D today can help achieve significant cost-savings in the future—a fact made plain by the economic devastation of the COVID–19 pandemic.

Now more than ever, Congress must make smart investments. Global health R&D, which improves the lives of people around the world while supporting US health security, creating jobs, and spurring economic growth, is a win-win.

PREPARED STATEMENT OF HARVEY FRIEDMAN, MD

I am an Infectious Disease physician scientist on faculty at the Perelman School of Medicine of the University of Pennsylvania. My research interest is herpes simplex virus. I am working on a vaccine that uses messenger RNA technology for the herpes vaccine that is like that applied to COVID 19 messenger RNA vaccines by Pfizer and Moderna.

My research has caught the interest of the public. I have received thousands of emails from people globally expressing their hope that the vaccine works. Most of the people are already infected with genital herpes. Their stories are heart-wrenching! Genital herpes is not a life-threatening infection; however, for many people, it is a life altering infection, while for some it leads to life ending decisions.

My laboratory has focused on preventing genital herpes, but we are now turning our attention to preventing oral herpes (HSV–1) and the many dreaded complications of both viruses, including fever blisters, infection of the cornea (eye), infection of the brain (encephalitis), infection of newborns, genital herpes, increasing susceptibility to HIV infection, and possibly contributing to dementia.

Medical research is at a point that we have the tools to come up with vaccines that will prevent genital herpes for those not yet infected, and approaches to rid the body of the dormant (latent) virus as a cure for subjects already infected.

Please set a priority to establish a strategic plan and national strategy for treating and preventing herpes infections, particularly genital herpes.

Sincerely,

Harvey Friedman, MD, Email: hfriedma@pennmedicine.upenn.edu, Office address: Infectious Disease Division, 522E Johnson Pavilion, 3610 Hamilton Walk, Philadelphia, PA 19104–6073.

PREPARED STATEMENT OF THE HEALTH PROFESSIONS AND NURSING EDUCATION COALITION

The Health Professions and Nursing Education Coalition (HPNEC) is an alliance of over 90 national organizations representing schools, students, health professionals, and communities dedicated to ensuring that the health care 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 (FY) 2022, HPNEC encourages the subcommittee to adopt at least $1.51 billion for HRSA Titles VII and VIII programs.

The HRSA Titles VII and VIII programs are essential to educating our health care workforce to manage health care crises, such as the COVID–19 pandemic. The immense challenges of the pandemic have underscored the need to increase and reshape our health workforce, and the HRSA Titles VII and VIII programs successfully recruit, train, and support public health practitioners, nurses, geriatricians, advanced practice registered nurses, mental health providers, and other frontline health care workers critical to addressing COVID–19. Additionally, HRSA tasked Title VII and Title VIII grantees to utilize innovative models of care, such as training providers in telehealth, to improve patients' access to care during the pandemic.

The U.S Census Bureau projects that by 2045:

—the US population will grow by over 18%,

—more than half the country will come from a racial or ethnic minority group, and

—one in five Americans will be over 65.

To prepare for these changing demographics, we urge Congress to increase funding for the HRSA Title VII and Title VIII programs to educate current and future providers that serve these ever-growing needs while preparing for the health care demands of tomorrow.

Diversity Pipeline Programs.—The COVID–19 pandemic has underscored the pervasive health inequities facing minority communities, as well as gaps in care for our most vulnerable patients, including an aging population that requires more health care services. The HRSA Title VII and Title VIII programs play an essential role in improving the diversity of the health workforce and connecting students to health careers by supporting recruitment, education, training, and mentorship opportunities. Inclusive and diverse education and training experiences expose providers to backgrounds and perspectives other than their own and heighten cultural awareness in health care, resulting in benefits for all patients.

HRSA 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 13,500 students in the 2019–2020 academic year (AY), with SDS graduating nearly 1,400 students, and COE reaching nearly 5,000 health professionals, 72% 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 2019–20, the program supported more than 11,000 students, with approximately 45% of the training sites located in underserved communities.

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 Primary Care Training and Enhancement (PCTE) and Primary Care Medicine and Dentistry Career Development programs. The primary care programs are also intended to encourage health professionals to work in underserved areas. In AY 2019–20, PCTE grantees trained over 14,000 individuals at over 1,100 sites, with 54% in medically underserved communities and 26% in rural areas; 30% of sites trained providers in telehealth services.

The Medical Student Education program, which supports the health care workforce by expanding training for medical students to become primary care clinicians, targets higher education institutions in states with the highest primary care workforce shortages. The program help develop 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. In AY 2019–2020, Medical Student Education grantees trained over 1,100 health professionals, 88% of which located in primary care settings, 68% in medically underserved communities, and 66% in rural areas.

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, HRSA Title VII programs can fill gaps in the workforce and increase access to care for all populations. The programs emphasize interprofessional education and training, bringing 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, and Behavioral Health Workforce Education and Training (BHWET) 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, provide training to expand access to mental and behavioral health services for vulnerable and underserved populations. In AY 2019–20, nearly 50% of all BHWET and GPE grantees provided substance use disorder treatment services.

Area Health Education Centers (AHEC) support the recruitment and training of future physicians in rural areas and provide interdisciplinary health care delivery sites, which respond to community health needs. In AY 2019–20, AHECs supported 192,000 pipeline program participants and 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 offer training across the provider continuum, focusing on interprofessional and team-based care and academic-community partnerships to address gaps in health care for older adults. To advance the training of the current workforce, the Geriatrics Workforce Enhancement Program (GWEP) provided 2,068 unique continuing education courses to over 200,000 faculty and practicing professionals in AY 2019–20, including 906 courses on Alzheimer's and dementia-related diseases.

Nursing Workforce Development.—HRSA Title VIII nursing workforce development programs provide federal support to address all aspects of nursing workforce demands, including education, practice, recruitment, and retention, focusing 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 2019–2020, the Title VIII Advanced Education Nursing programs supported more than 8,000 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 primary dental 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.

Public Health.—Public Health Workforce Development 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 health departments. Public health student trainees partnered with 278 sites in AY 2019–20, with 74% of these training sites located in medically underserved communities and 29% in primary care settings.

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 competing demands facing appropriators, funding for HRSA's workforce development programs is critical to creating a culturally competent workforce that can respond to future health threats and challenges facing all Americans. Therefore, HPNEC encourages the subcommittee to provide at least $1.51 billion in the FY 2022 appropriations bill for HRSA's Title VII and VIII programs to continue the nation's investment in our health workforce.

PREPARED STATEMENT OF THE HEARING INDUSTRIES ASSOCIATION AND THE HEARING LOSS ASSOCIATION OF AMERICA

Dear Chairwoman Murray, Ranking Member Blunt, and Members of the Subcommittee,

Thank you for the opportunity to submit testimony concerning Fiscal Year 2022 (FY22) Labor, Health and Human Services, Education and Related Agencies appropriations. The Hearing Industries Association (HIA) and the Hearing Loss Association of America (HLAA) are requesting inclusion of report language to direct the National Institutes of Health (NIH) Office of the Director to provide an accounting of funds currently used for hearing screening research and encourage NIH to prioritize funding for studies that address the research needs and gaps identified by the U.S. Preventive Services Task Force (USPSTF).

HIA is the national organization of the manufacturers, suppliers and distributors of hearing aids, implants, assistive listening devices, component parts and power sources. HIA's mission is to be a trusted voice on product innovation, patient safety and education, and public policy. HLAA is the nation's leading organization rep-

resenting consumers with hearing loss and seeks to enable people with hearing loss to live life fully and without compromise. We are pleased to work together to support the more than 38 million individuals in the United States with untreated hearing loss,[1] including one in three people between the ages of 65 and 74 and over half of those older than 75. Hearing loss is associated with many comorbidities, including cognitive decline, dementia, falls, depression, reduced quality of life, and an increased number of emergency department visits and hospitalizations.

In March 2021, the USPSTF, a volunteer panel of national experts in prevention and evidence-based medicine tasked with providing recommendations regarding preventive screening and services, issued its final recommendations regarding hearing screening for older adults over the age of 50. The USPSTF ultimately declined to make a recommendation in support of hearing screening, finding that "current evidence is insufficient to assess the balance of benefits and harms of screening for hearing loss in older adults."[2] The final recommendation notes that more research is needed.

We understand the gaps in research identified by the USPSTF's recommendations and agree that additional research to support a universal hearing screening recommendation for older adults is needed. Given the significant associated comorbidities of hearing loss discussed below, we also believe this research should be prioritized. Therefore, we urge this Subcommittee to support inclusion of report language to convey the importance of building the research base for older adult hearing screening, as follows:

Hearing Health Screening. The Committee recognizes the associated comorbidities and costs of untreated hearing loss and, with the growing aging population, the importance of hearing screening for older Americans. The Committee directs the National Institutes of Health (NIH) Office of the Director to provide an accounting of all funds used for hearing screening research across all Institutes within 90 days of enactment of this Act. The Committee encourages NIH to prioritize funding through the Office of the Director and engage appropriate Institutes like the National Institute on Deafness and Other Communication Disorders (NIDCD) and National Institute on Aging (NIA) for studies that address the research needs and gaps identified by the U.S. Preventive Services Task Force (USPSTF). These research needs may include gaps identified in USPSTF review of hearing screening recommendations for older Americans.

Earlier diagnosis of hearing loss and appropriate intervention are crucial to avoiding the negative social, emotional, and health consequences of hearing loss. Age-related hearing loss is the third leading cause of chronic disability in older adults and has shown to be associated with predisposing cognitive impairment and dementia.[3] According to the Lancet Commission, as of 2020, there are twelve behaviorally modifiable risk factors associated with dementia prevention, accounting for approximately 40 percent of dementias globally. Of note, hearing impairment accounts for approximately nine percent of the modifiable risk and the Lancet Commission recommends reducing noise-related hearing loss and treating hearing loss with the use of hearing aids.[4] Additionally, a recent study found that mild hearing loss doubled the risk of dementia, moderate loss tripled risk, and those with severe hearing impairment were five times more likely to develop dementia.[5] Emerging evidence indicates that hearing interventions can delay the onset or reduce the rate of cognitive decline.[6,7] Additional studies, including the Aging and Cognitive Health Evaluation in Elders (ACHIEVE) study,[8] are expected to further address the role and efficacy of hearing treatment in reducing cognitive decline in older adults.

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[1] "How Many People Have Hearing Loss in the United States?", Johns Hopkins Cochlear Center for Hearing and Public Health, https://www.jhucochlearcenter.org/how-many-people-have-hearing-loss-unaited-states.html.

[2] https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/hearing-loss-in-older-adults-screening.

[3] Jafari Z, Kolb BE, Mohajerani MH. Age-Related Hearing Loss and Tinnitus, Dementia Risk, and Auditory Amplification Outcomes. Ageing research reviews. 2019:100963.

[4] Livingston G, Huntley J, Sommerland A, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. Lancet. 20202 [Aug 8]; 396 (10248); 413–446.

[5] "The Hidden Risks of Hearing Loss", Johns Hopkins Medicine, https://www.hopkinsmedicine.org/health/wellness-and-prevention/the-hidden-risks-of-hearing-loss.

[6] Maharani A, Dawes P, Nazroo J, Tampubolon G, Pendleton N, on behalf of the SENSE-Cog WP1 group. Am Geriatr Soc. 2018;66(6):1130–1136. https://agsjournals.onlinelibrary.wiley.com/doi/abs/10.1111/jgs.15363.

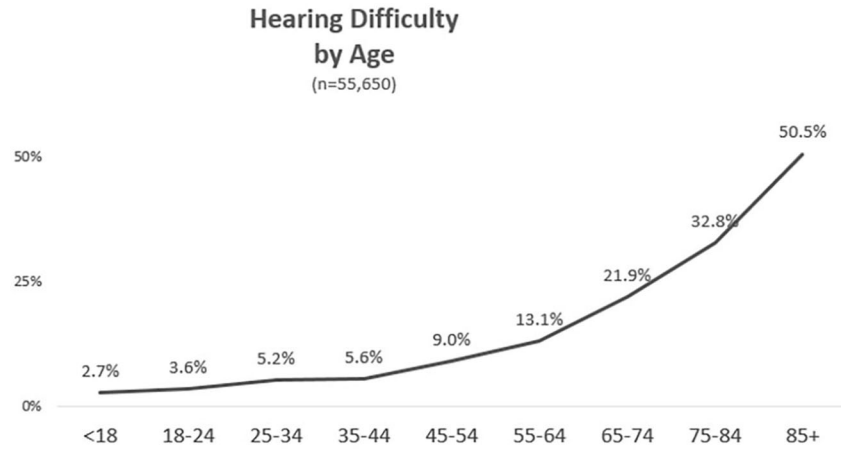
[7] Sarant J, Harris D, Busby P, Maruff P, Schembri A, Lemke U, & Launer S (2020). The Effect of Hearing Aid Use on Cognition in Older Adults: Can We Dely Decline or Even Improve Cognitive Function? Journal of Clinical Medicine, 9(1), 254.

[8] https://clinicaltrials.gov/ct2/show/NCT03243422.

As hearing loss progresses, it manifests via profound consequences on verbal communication and social, functional, and psychological wellbeing of the person. The National Institutes of Health (NIH) has found that over 78 percent of participants with insufficient or poor hearing suffered from at least one additional chronic condition, leading to increased health care costs in any given year.[9] For adults over 60 years of age, untreated hearing loss is associated with approximately 46 percent higher total health care costs over a 10-year period compared with costs for those without hearing loss.[10] People with even a mild hearing loss are also three times more likely to fall, compared to individuals with normal hearing.[11] When hearing loss does occur, early diagnosis and intervention are crucial for avoiding the negative social, emotional, and health consequences already described.

There is evidence that rates of hearing loss begin to rise around the age of 50, but the prevalence of hearing loss dramatically increases as an individual grows older (Figure 1).[12] Individuals may underestimate their hearing difficulty and fail to pursue potentially beneficial treatment for their hearing loss that could lead to better health outcomes. Thus, hearing screening should be a part of every wellness check or physical exam for older adults, the population most at risk of age-related hearing loss.

Figure1.



As the Subcommittee develops its FY22 Labor-HHS-Education appropriations bill and accompanying report language, we respectfully request your support for the millions of Americans suffering from hearing loss by encouraging NIH to pursue hearing screening research. Hearing health is essential and hearing screening is the first step. We look forward to working with you and appreciate your attention to this important issue.

[This statement was submitted by Kate Carr, President, Hearing Industries Association, and Barbara Kelley, Executive Director, Hearing Loss Association of America.]

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[9] Maharani A, Dawes P, Nazroo J, Tampubolon G, Pendleton N, on behalf of the SENSE-Cog WP1 group. Am Geriatr Soc. 2018;66(6):1130–1136. https://agsjournals.onlinelibrary.wiley.com/doi/abs/10.1111/jgs.15363.

[10] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6439810/.

[11] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3518403/.

[12] Jorgensen, L. & Novak, M. (2020). Factors Influencing Hearing Aid Adoption. Seminars in Hearing, 41(1), 7. https://doi.org/10.1055/s-0040-1701242.

PREPARED STATEMENT OF THE HEPATITIS B FOUNDATION

HEPATITIS B FOUNDATION RECOMMENDATIONS FOR FISCAL YEAR 2021 APPROPRIATIONS

National Institutes of Health

—Along with the biomedical research community, the Hepatitis B Foundation (HBF) supports the President's request for $51 billion for the National Institutes of Health. While we are anxious to see the details of the President's request, specifically the details of the proposed ARPA–H initiative, we appreciate President Biden's commitment to allowing for meaningful growth in the base budget and expanding NIH's capacity to support promising science in all disciplines.

—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 $10 billion for the Centers for Disease Control and Prevention programs in FY 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.

—HBF urges the Division of Viral Hepatitis to fund both the Hepatitis B and the Hepatitis C community infrastructure grants in order to maintain and grow progress to address the public health threats of both hepatitis B and hepatitis C.

HHS Office of the Secretary

—HBF supports the newly released Viral Hepatitis National Strategic Plan and urges the establishment of an office or initiative to lead this elimination strategy and the provision of adequate staff and other resources needed for success.

Mrs. Chairwoman and Members of the Subcommittee, thank you for the opportunity to provide testimony as you consider funding priorities for Fiscal Year (FY) 2022. 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 the most exciting and promising work in the field.

Mrs. Chairwoman, HBF strongly supports the President's $51 billion request for NIH funding in FY 2022. HBF further urges that NIH increase investments in hepatitis B research in order to find a cure for the 2.4 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 $10 billion for the Centers for Disease Control and Prevention in the FY 2022 bill. Within that total, we join the Hepatitis Appropriations Partnership in urging $134 million for the CDC's Division of Viral Hepatitis.

Finally, we would urge that the newly released Viral Hepatitis National Strategic Plan be led and funded fully as necessary to move us toward the goal of the elimination of viral hepatitis in the United States.

RECOGNIZING THE LEADERSHIP OF THE SUBCOMMITTEE

Mrs. Chairwoman, 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.

NATIONAL INSTITUTES OF HEALTH

As previously noted, HBF supports the President's request for $51 billion for the NIH. We look forward to learning more about the proposed ARPA–H initiative to accelerate the implementation of research findings. While we appreciate the President's bold vision to promote transformational innovations against the range of diseases facing humankind, we want to be sure that new investments are not made at the expense of the important basic science that is critical to our scientific enterprise. 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 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 FY 2022 Report urging the NIAID and NIDDK to issue targeted calls for hepatitis B research proposals in FY 2022 focused on the many new research opportunities identified by the Strategic Plan.

In the U.S., an estimated 2.4 million are chronically infected with hepatitis B virus (HBV). 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 FY 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, 3–7 million people worldwide are infected, and the epidemic continues to grow. 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 developing liver cancer by 40–60%.

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 $10 billion for CDC's programs in FY 2022. This is $1.3 billion 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. While recent emergency funding has supported efforts to defeat COVID–19, we must provide stable, sufficient public health preparedness funding to allow our state and local health departments to maintain a standing set of core capabilities, so they are ready when needed, regardless of the next challenge or threat.

The CDC's Division of Viral Hepatitis (DVH) is part of the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP) 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 FY 2022 and within this level urges the Division to fund both the Hepatitis B and Hepatitis C community infrastructure grants. To discontinue one of these grants would be a step backward in the progress being made.

The CDC Division of Viral Hepatitis spends less than 10% of its budget on HBV focused projects, despite hepatitis B infected patients comprising more than 35% of all those infected with viral hepatitis in the U.S. Furthermore, tremendous HBV-related health disparities exist for Asian Americans and Pacific Islanders and recent African immigrants. These groups represent less than 6% of the U.S. population but make up 50%-80% 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 is that the CDC surveillance

program is not robust enough to accurately report the prevalence of hepatitis B 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% 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 public, and to improve collaboration and coordination across CDC to achieve this goal.

SUMMARY AND CONCLUSION

Mrs. Chairwoman, 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. 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

Chairwoman Murray, Ranking Member Blunt, and members of the Subcommittee, my name is Dr. Marwan Haddad, MD, MPH, Chair-elect of the HIV Medicine Association (HIVMA), and I serve as the Medical Director of the Center for Key Populations at the Community Health Center, Inc. (CHCI), in Middletown, Connecticut, one of the largest Federally Qualified Health Center in the country. I am pleased to submit testimony on behalf of HIVMA. HIVMA represents nearly 5,000 physicians, scientists, and other health care professionals around the country on the frontlines of the HIV epidemic. Our members provide care and treatment to people with HIV, lead HIV prevention programs, and conduct research in communities across the country. Many of them have been on the frontlines of their community's coronavirus (COVID–19) response.

For the FY2022 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 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 public health, including these vital programs which support global and domestic health security measures and our public health infrastructure.

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.

ENDING THE HIV EPIDEMIC INITIATIVE—U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Over the last two years, on a bipartisan basis, Congress has appropriated funding for the EHE Initiative, which sets the goal of reducing new HIV infections by 50% by 2025, and 90% by 2030. We recommend funding the EHE initiative at least at the President's budget request for $670 million in support of ending HIV as an epidemic to be used for expanded access to antiretroviral treatment and PrEP to prevent HIV transmissions as well as improved access to routine and critical health services.

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. Over three-quarters of Ryan

White clients are Black, Latinx or other people of color, and nearly two-thirds have incomes under the federal poverty level. To continue providing comprehensive, life-saving treatment and to bring many more people into care through the EHE Initiative, we urge Congress to fund the Ryan White HIV/AIDS Program at a total of $2.768 billion in FY2022, an increase of $345 million over FY2021. We strongly recommend providing at least $222 million in EHE funding for the Ryan White Program.

HIVMA urges an allocation of $225.1 million, or a $24 million increase over current funding, for Ryan White Part C programs. The flexibility of the Ryan White Program and its providers' expertise has also allowed Part C clinics to respond to the changing needs of patients and the health care system throughout the COVID–19 pandemic. Ryan White clinics serve a significant number of individuals living with both substance use disorder and HIV, delivering a range of medical and support services, including overdose prevention and harm reduction services, needed to prevent, intervene, and treat substance use disorder as well as related infectious diseases, including HIV, HCV, and sexually-transmitted infections (STI).

CHCI's Ryan White-Funded Clinic in Connecticut is Leading on Expanding Access to HIV Prevention, Care, & Treatment

CHCI's Center for Key Populations, Ryan White-funded Early Intervention Services Program, has served as the leading source of HIV primary care in Connecticut for 22 years. Each year our Ryan White program serves more patients from almost every city and town across Connecticut.

The needs of both established and newly diagnosed patients with HIV are growing more complex. In 2020, even as HIV care was innovatively transformed to mostly telehealth due to COVID–19, CHCI experienced an increase in the number of patients living with HIV who accessed services at our sites. Of all new patients enrolled in care at CHCI in 2020, 69% self-reported as racial and ethnic minorities and 56% reported food and housing insecurity as major barriers to achieving optimal healthcare. Additionally, 4% of all Ryan White patients were uninsured, 87.9% had at least one clinical co-morbidity, and 62% reported unmet mental health needs at the time of intake. Among Ryan White Program patients at CHCI, 12% reported unstable housing, which means they were living in a shelter, vehicle, or completely unsheltered, creating additional challenges to retention in care.

CHCI's Ryan White Program eligible patients who are engaged in care are screened for substance use disorders routinely and 63% screened positive with 11% considering those needs urgent or severe. CHCI, like most Ryan White Part C programs, also receives funding from other parts of the Ryan White Program, and these help us provide support services that were particularly important during the COVID–19 pandemic. These services included home medical monitoring equipment, transportation, case management, patient navigation, home-delivered meals, grocery delivery, check-in phone calls, and other key components of care unique to the Ryan White Program care model and contribute to optimal healthcare outcomes for all patients.

HEALTH RESOURCES AND SERVICES ADMINISTRATION—BUREAU OF PRIMARY HEALTH CARE

We recommend appropriating $152 million in new funding for HRSA's Community Health Center program for the EHE initiative. In those community health centers funded by the EHE Initiative, they were able to increase PrEP uptake from 19,000 in 2020 to nearly 50,000 people in early 2021. CDC estimates only 10% 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. Scaling up PrEP among the most affected populations is critical to reducing health disparities and ending HIV as an epidemic.

CENTERS FOR DISEASE CONTROL AND PREVENTION—NATIONAL CENTER FOR HIV/AIDS, VIRAL HEPATITIS, SEXUALLY TRANSMITTED DISEASES, AND TUBERCULOSIS PREVENTION

From the CDC's leadership role in responding to the COVID–19 pandemic to its ongoing efforts to address persistent public health epidemics and threats, such as HIV, STIs, and viral hepatitis, the CDC is a critical national and global expert resource and response center. To meaningfully address these epidemics and the co-occurring crisis of substance use disorder—especially injection drug use—we request a $731 million overall increase above FY2021 levels for a total of $2.045 billion.

For the Division of HIV/AIDS Prevention (DHAP), we request a total of $1.293 billion, which is a $328 million increase over FY2021 levels. DHAP conducts our national HIV surveillance and funds state and local health departments and commu-

nities to conduct evidence-based HIV prevention activities. CDC's national surveillance system is critical to monitoring populations and regions impacted by the HIV epidemic and identifying outbreaks. We also strongly recommend appropriating at least the $371 million requested by the Administration for the EHE initiative, allowing the CDC to scale up HIV testing to ensure early diagnosis and care linkage and PrEP programs to prevent new infections.

Additionally, we urge the appropriation of $120 million for the CDC to fund surveillance and programming to monitor and prevent opioid-related infectious diseases as well as expand access to syringe services programs, harm reduction, and overdose prevention. Funding for CDC's Infectious Diseases and Opioid Epidemic programming is critical to respond to increases in serious infections linked to substance use, including HIV, hepatitis B and C, and life-threatening bacterial infections such as endocarditis.

For the Division of Viral Hepatitis (DVH), we request a total of $134 million, which is a $94.5 million increase over FY2021 levels. We have the tools to prevent this growing epidemic, but increased funding is urgently needed to expand testing and screening, prevention, and surveillance 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 $272.9 million, which is a $111.1 million increase over FY2021 levels. For the sixth year in a row, the CDC reports dramatic increases in STIs in the U.S. 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 advance discoveries important to end HIV epidemic as an epidemic, including improved HIV prevention modalities and treatment options and ultimately a cure and a vaccine, we ask that at least $3.854 billion be allocated for HIV research in FY2022, an increase of $755 million over FY2021. The return on investment in HIV research extends beyond HIV and includes contributing to the record-breaking timelines for the development of COVID–19 vaccines.

INDIAN HEALTH SERVICE—ELIMINATING HIV AND HEPATITIS C IN INDIAN COUNTRY

Between 2011 and 2015, there was a 38% increase in new HIV diagnoses among the American Indian/Alaska Native population overall, and a rise of 58% among AI/AN gay and bisexual men. We urge for the Indian Health Service component of the EHE Initiative to be funded at $27 million.

CONCLUSION

The COVID–19 pandemic highlights the importance of preparing for infectious diseases outbreaks by fully funding programs that support public health services, infrastructure and workforce so that we are better prepared for the next pandemic. Thank you for your time and consideration of these important requests and for strengthening our nation's ability to end the HIV epidemic in the U.S. Please contact me or HIVMA's Senior Policy & Advocacy Manager, Jose A. Rodriguez, at JRodriguez@hivma.org, if you have any questions or need additional information. HIVMA is located at 4040 Wilson Boulevard Suite 300, Arlington, VA 22203.

[This statement was submitted by Marwan Haddad, MD, Chair-elect, HIV Medicine Association, MPH.]

PREPARED STATEMENT OF THE HIV + HEPATITIS 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 FY 2022 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.

This June 5th our nation commemorated the 40th anniversary of AIDS. Over the last four decades the U.S. has made great advances in HIV prevention, care, and treatment; but much work remains. While between 2015 and 2019 the U.S. saw slight decreases in the number of new HIV infections, disparities continue to exist, and some populations saw increases in infections. HIV continues to disproportionately impact Black and Latino gay men, Black women, people who inject drugs, and who live in the South. The Centers for Disease Control and Prevention (CDC) re-

ports that over half of all new HIV infections in 2019 were in the South. Recently, the Department of Health and Human Services released updated strategic plans to guide our nation in responding to the HIV and hepatitis epidemics, including for the first time ever calling for the elimination of viral hepatitis. In each of the plans, the need to address the syndemics of HIV and hepatitis is prioritized.

As our country continues to respond and recover from the COVID–19 pandemic, which has impacted HIV and hepatitis services, we know 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.

ENDING THE HIV EPIDEMIC IN THE U.S.

Over the past two years, Congress has appropriated over $400 million in new funding for the Ending the HIV Epidemic in the U.S. initiative, which sets the goal of reducing new HIV infections by 75 percent by 2025, and 90 percent by 2030. Priority jurisdictions have used initial funding to develop ending HIV plans with the help of community partners that build on existing HIV programs and utilize new innovations and strategies. Even while battling COVID, the Ryan White HIV/AIDS Program reports that in these priority jurisdictions, with the additional funding, they were able to bring nearly 6,300 new clients into the program and re-engage an additional 3,600 between March and August of 2020. In the community health centers funded by the EHE initiative, they were able to increase pre-exposure prophylaxis (PrEP) uptake from 19,000 in 2020 to nearly 63,000 people within 11 months.

We are pleased that President Biden has proposed to increase funding for the Ending the HIV Epidemic initiative by $267 million as part of his FY22 budget. Additionally, the Biden administration has proposed increases in other domestic HIV programs. Since many of these increases fall short of what was proposed last year and what is needed, we urge the Congress to do better and significantly increase funding for the Ending the HIV Epidemic in the U.S. initiative for FY2022 so that this important work can be properly ramped up. In particular we ask for increased funding for the following programs:

—CDC Division of HIV/AIDS Prevention for testing, linkage to care, and prevention services, including PrEP (+$196 m);

—HRSA Ryan White HIV/AIDS Program to expand comprehensive treatment for people living with HIV (+$107 m); and

—HRSA Community Health Centers to increase clinical access to prevention services, particularly PrEP (+$50 m)

The success of the EHE initiative rests upon our underlying public health prevention, care, and treatment programs at the CDC and HRSA. Congress must ensure that these are adequately funded to provide services in all areas of the country.

The Ryan White HIV/AIDS Program at the Health Resources and Services Administration provides medical care, medications, and essential coverage completion services to over 567,000 low-income, uninsured, and/or underinsured individuals with HIV. For over 30 years, the Ryan White program has pioneered innovative models of care which has resulted in 88 percent of Ryan White clients achieving viral suppression, a critical marker for decreasing new infections in the U.S. Currently Ryan White Programs, and particularly the AIDS Drug Assistance Programs (ADAPs), are facing increased demand as people have lost health coverage and incomes due to the economic impact of COVID–19, and state and local budgets have become increasingly stressed. Without increased funding some ADAPs may be forced to institute wait lists for medications or other cost containment measures. We urge Congress to fund the Ryan White HIV/AIDS Program at a total of $2.768 billion in FY2022, an increase of $345 million over FY2021 including an increase of $68 million for ADAPs for total funding of $968.3 million.

In addition, HIV+Hep opposes any efforts through the appropriations process to alter the intent of the program to use Ryan White-derived funds for activities outside the scope of the original intent of current legislative language.

The CDC Division of HIV Prevention funds state and local public health departments and community-based organizations to implement and enhance targeted, tailored, and high-impact prevention programs aimed at addressing racial and geographic health disparities. This includes HIV testing, condom distribution programs,

and other HIV awareness campaigns. CDC also funds our national surveillance system which is critical to identifying new HIV clusters and outbreaks and provides the data necessary to tailor resources and programming. Funding from the CDC also allows communities to focus on increasing access to and use of PrEP, which is critical to ending the HIV epidemic. Recent CDC data show that in 2019, nearly 285,000 or 23 percent of people eligible for PrEP were prescribed it, up from 3 percent in 2015. While this increase is moving in the right direction, some of the communities most in need of PrEP are not receiving it and we must continue building programs to provide outreach to communities and education about PrEP.

A holistic response to the HIV epidemic also depends on fully funding other priority programs at HHS, including the CDC's Division of School and Adolescent Health and STI Prevention, the Minority HIV/AIDS Initiative, AIDS Research at the NIH, the Title X Family Planning Program, and the Teen Pregnancy Prevention Program (TPPP).

VIRAL HEPATITIS

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 available data suggesting that more than 70 percent of new HCV infections are among people who inject drugs. 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. The number of acute hepatitis C cases reported in the U.S. has increased every year since 2012. CDC recently reported an increase of 63 percent in acute hepatitis C cases between 2015 and 2019, with 67 percent of the cases in 2019 associated with injection drug use.

CDC Division of Viral Hepatitis

The viral hepatitis programs at the CDC are severely underfunded, receiving only $39.5 million-far short of what is needed to build and strengthen our public health response and to eventually end hepatitis. States' ability to conduct enhanced HCV surveillance activities is severely hampered by a lack of funding. Additional resources would allow the CDC to enhance testing and screening programs, link people to treatment, conduct additional provider education, 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 $94.5 million over FY 2021 enacted levels.

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 $120 million, an increase of $107 million.

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 + Hepatitis Policy Institute.]

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 no less than $500 million for the Agency for Healthcare Research and Quality (AHRQ) and a minimum of $375.3 million for the National Institute for Occupational Safety and Health (NIOSH), including $34 million for the Education and Research Centers (ERCs), in fiscal year (FY) 2022.

AHRQ supports research to improve health care quality, reduce costs, advance patient safety, decrease medical errors, and broaden access to essential services. As the lead federal agency for funding health services research (HSR) and primary care research (PCR), AHRQ is the bridge between cures and care, and ensures that Americans get the best health care at the best value. The RAND Corporation released a report in 2020 as called for by the Consolidated Appropriations Act of 2018, which identified AHRQ as "the only agency that has statutory authorizations to generate HSR and be the home for federal PCR, and the unique focus of its research portfolio on systems-based outcomes (e.g., making health care safer, higher quality, more accessible, equitable, and affordable) and approaches to implementing improvement across health care settings and populations in the United States."

HFES requests a minimum of $500 million for AHRQ, which is consistent with the FY 2010 level adjusted for inflation and reflects the demonstrated needs of pandemic response. This funding level will allow AHRQ to rebuild portfolios terminated after years of cuts. AHRQ is the federal vehicle for studying and improving the United States healthcare system, and it needs the resources to meet its mission and this moment. Through this appropriation level, AHRQ will be better able to fund the "last mile" of research from cure to care.

Additionally, HFES requests $375.3 million for NIOSH, including $34 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, ERCs are responsible for supplying many of the country's OSH graduates who will go on to fill professional roles.

HFES strongly believes 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 3,000 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 health care sector to the ways we travel and to the hand-held devices we use every day.

CONCLUSION

HFES urges the Subcommittee to provide $500 million for AHRQ and $375.3 million for NIOSH, including $34 million for the Education and Research Centers (ERCs) in FY 2022. 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 Peter Hancock, DSc, PhD, President, and Steven C. Kemp, CAE, Executive Director, Human Factors and Ergonomics Society.]

PREPARED STATEMENT OF I AM ALS

Chairwoman Murray, Ranking Member Blunt thank you for the opportunity to submit written testimony. My name is Brian Wallach and I have enjoyed the opportunity to work with both of you and your colleagues in the Senate ALS Caucus over the past several years.

I am grateful for all you and your colleagues have done for the ALS community. Thanks to you and others like Senators Dick Durbin, Lisa Murkowski, Chris Coons, and Mike Braun, and our incredible ALS grassroots advocates, we have increased federal spending on ALS research by $83 million in just two years. And this past December, Congress overwhelmingly passed a bill to give ALS patients access to SSDI benefits upon diagnosis, averting bankruptcy for so many.

As a result of this work, the path towards ending ALS is clearer. The question now is when do we reach the end of that path and will any of those of us living with ALS now be here to see that day?

I desperately want to be here, but my body is failing. You can hear it in my voice and see it in the videos I post on Twitter. Odds are that unless something changes, I won't be. The average patient lives 2–5 years post-diagnosis and of those diagnosed in 2017 with me, four out of five-80%-are dead.

So I come with two urgent asks. Ones that if you make real will change my and millions of others' futures.

First, fund ARPA–H and include ALS among its core disease areas. During the 2020 campaign then-candidate Joe Biden promised ALS patient Ady Barkan that he would seek to create ARPA–H, modeled after DARPA, to solve issues relating to the diagnosis and treatment of disease. He also promised that ALS-along with cancer, diabetes and Alzheimer's-would be among the first diseases it tackled.

I was elated when President Biden's administration submitted a proposal to fund ARPA–H to Congress. I was devastated when I saw that only ALS was left out of the list of identified diseases it would target.

To cure ALS, we need an ARPA–H. We need both a focus on high risk/high reward research and to break down the antiquated, bureaucratic red tape facing ALS patients seeking promising therapies. Moreover, if we cure ALS, we can help unlock cures for Alzheimer's, Parkinson's, Frontotemporal Dementia and beyond.

Today, despite the increases in funding over the last 2 years, our government still spends less than $6,000 on ALS research per year per person in the U.S. living with ALS. You have the power to fix this by putting ALS back into ARPA–H.

Second, we need you to hold the FDA accountable for failing ALS patients by denying any type of approval for two promising therapies this year. On June 7th, we watched the FDA grant accelerated approval of aducanumab for the treatment of Alzheimer's disease and wondered why that same urgency has not been applied to ALS.

In September 2019, FDA released an updated Guidance for ALS Clinical Trials. It stressed the need for "regulatory flexibility in applying the statutory standards to drugs for serious diseases with unmet medical needs." The Guidance explicitly stated that "[w]hen making regulatory decisions about drugs to treat ALS, FDA will consider patient tolerance for risk and the serious and life-threatening nature of the condition in the context of statutory requirements for safety and efficacy."

The first two tests of FDA's promise of regulatory flexibility and urgency for ALS came this year with AMX0035, an oral medication, and NurOwn, a stem cell therapy. The Phase II/III trial for AMX0035 showed that AMX0035 slowed the progression of ALS and enabled patients on average to live 6.5 months longer. NurOwn's Phase III trial did not show the same overall benefit, but did show a "clinically meaningful" slowing of progression for a subgroup of ALS patients.

FDA's response: No approval for either therapy. No regulatory flexibility. No consideration of the terminal nature of ALS. No regard for the tens of thousands of patients, caregivers and advocates who signed petitions to the FDA pleading for access to these therapies.

Instead, the FDA reverted to the same inflexible position for both therapies: they asked each company to run another large, long placebo-controlled trial and then come back. Let me make crystal clear what these two decisions by FDA mean: at best these therapies won't be accessible to patients for 4 years. By then nearly every ALS patient alive today will be dead.

Why weren't these therapies approved? Both therapies showed efficacy for at least a subgroup of ALS patients. And if the concern was safety, both trials showed a strong safety profile-particularly in the context of a 100% fatal disease. Moreover, the denials deprived patients of the chance to access FDA-regulated drugs under the supervision of an ALS specialist. So, instead, patients are forced to try to replicate the formula for AMX0035 on their own and to travel abroad for risky stem cell procedures.

I've been told that the FDA has claimed to members of Congress and their staff that they are doing everything they can and that there was nothing else they could do with respect to these two therapies. This is simply not true or, if FDA actually believes this, they have provided Congress a clarion call to reform how FDA regulates treatments for diseases like ALS.

I am a former federal government employee. I come from a family of former and current federal government employees. I truly believe the FDA is filled with honorable, dedicated public servants. However, their actions here are impossible to square with their own Guidance. This is most clearly demonstrated by the fact that AMX0035 appears headed towards approvals in Canada and Europe based on the same data presented to FDA. FDA stands alone as an immovable obstacle.

I implore Congress to hold hearings on these denials to bring transparency and accountability to a process that has left the ALS community devastated.

In addition to hearings, I ask you to pass and fund 2 bills to ensure this does not happen again. Over the last year, the fight against COVID–19 showed how much regulatory flexibility FDA has when it wants to use it. Since FDA appears unwilling to use it to give ALS patients a chance to live, we have worked with members of Congress to reform how FDA approaches diseases like ALS.

The first, ACT for ALS, will, among other items, make a significant amount of funding available to establish expanded access programs. Programs that will make promising therapies available to ALS patients now while fueling additional research into a therapy's safety and efficacy.

The second, The Promising Pathways Act, will, among other things, allow for conditional approval of promising therapies after Phase II for life-threatening diseases like ALS. This would put us on par with Europe.

Today, the science needed to cure ALS is moving faster than ever and finally producing therapies that may be able to slow or stop this disease. This reality must be matched by a new regulatory approach that speeds promising therapies to patients. As I have outlined, despite programs aimed to do just that which have worked in other diseases, we do not have that approach for ALS today. It is our moral obligation to change this broken approach for all those facing ALS just as we did for HIV and cancer.

If we do, I will have a chance to see my daughters graduate from kindergarten, high school, and college.

You have the power to make that happen.

I thank you for having the courage to do so.

And I look forward to working with each of you to finally defeat ALS.

[This statement was submitted by Brian Wallach, Co-Founder, I AM ALS.]

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 clinicians specializing in infectious diseases prevention, care, research and education, I urge the Subcommittee to provide robust FY2022 funding for public health and biomedical research activities that save lives, contain health care costs and promote economic growth. IDSA asks the Subcommittee to provide $10 billion for the Centers for Disease Control and Prevention (CDC), $46.111 billion for the National Institutes of Health (NIH), $300 million for the Biomedical Advanced Research and Development Authority (BARDA) Broad Spectrum Antimicrobials and CARB–X programs and $200 million for the Strategic National Stockpile Special Reserve Fund program.

While we must continue to direct substantial resources to tackle the COVID–19 pandemic, we must also address other domestic and global infectious diseases threats and epidemics, including those for which progress has stalled and/or wors-

ened during the pandemic. For example, routine immunization rates have fallen, and access to care for diseases like HIV has been disrupted. In addition, high levels of antibiotic use likely exacerbated existing antibiotic resistance, deepening the need for antimicrobial stewardship, surveillance and new antimicrobial drugs. The COVID–19 pandemic has shown us all too clearly the fundamental importance of expanding the infectious diseases workforce, public health infrastructure and biomedical research enterprise necessary to successfully confront the panoply of infectious threats facing our increasingly interconnected world.

CENTERS FOR DISEASE CONTROL AND PREVENTION

Antibiotic Resistance Solutions Initiative (ARSI)

We urge $672 million in funding for the Antibiotic Resistance Solutions Initiative in FY2022. IDSA members see the impact that antimicrobial resistance (AMR) has on patients daily. Antimicrobial 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 expected to be the leading cause of death in the world.

We therefore recommend $672 million for the Antibiotic Resistance Solutions Initiative to achieve the goals outlined in the 2020–2025 National Action Plan for Combating Antibiotic-Resistant Bacteria. The ARSI is the cornerstone of the nation's efforts to detect, prevent, and respond to AMR. The program is also a critical building block of CDC's public health infrastructure that directly supports broader agency activities, including COVID–19 first responders, foodborne illness pathogen detection, sexually transmitted infections, health care associated infections and global health. Increased funding would help expand antibiotic stewardship across the continuum of care; double grant awards at the state and local level; expand the Antibiotic Resistance Laboratory Network globally and domestically to strengthen the identification, tracking and containment of deadly pathogens; support AMR research and epicenters; and increase public and health care professional education and awareness activities. Since FY2016, funding for the initiative has improved antibiotic use, increased state and regional laboratory capacity to rapidly detect resistant infections and enhanced tracking of health care-associated infections. However, many state laboratories still do not monitor for and report resistance data on pathogens of importance and the program will be unable to effectively address current and newly emerging threats and prepare for future challenges without a significant increase in funding in FY2022. Increased funding is vital to achieving the plan's goals, including a 20 percent decrease in health care-associated antibiotic-resistant infections and a 10 percent drop in community-acquired antibiotic-resistant infections by 2025.

Advanced Molecular Detection

Advanced Molecular Detection (AMD) strengthens CDC's epidemiologic and laboratory expertise to effectively detect and track pathogens, including how they mutate, to inform responses and improve clinical care of patients. AMD provides more rapid identification of pathogens which can positively benefit antimicrobial stewardship to improve patient outcomes and reduce AMR. Requested FY2022 funding of $60 million would further enhance federal, state and local laboratory capabilities and spur innovation, including through further integration of genomics and other advanced laboratory technologies into AMR surveillance. Increased funding would help CDC apply the work of SPHERES, a national genomics consortium led by AMD that coordinates large-scale, rapid SARS–CoV–2 sequencing across the U.S., to bolster AMR surveillance, detection and response.

National Healthcare Safety Network

FY2022 funding of $100 million for the National Healthcare Safety Network (NHSN) will enable the program to meet its current and projected demands. Requested funding would expand data collection on antibiotic use and resistance in health care facilities as outlined in the 2020–2025 National Action Plan for Combating Antibiotic-Resistant Bacteria. In 2020, many additional health care facilities began reporting COVID–19 data to NHSN, and new funding will help expand that reporting to include antibiotic use and resistance data. FY2022 funding would help achieve the National Action Plan goals for 75 percent of acute care hospitals and 25 percent of critical access hospitals reporting to the NHSN Antibiotic Resistance Option and 100 percent of acute care and 50 percent of critical access hospitals reporting to the NHSN Antibiotic Use Option. These data help measure and drive progress toward optimizing antibiotic use. Additionally, increased funding would

provide access to technical support for more than 65,000 staff at health care facilities who use NHSN.

CDC Center for Global Health

IDSA urges the Subcommittee to provide $857.8 million in FY2022 funding, including $456.4 million for CDC's Division of Global Health Protection. Public health experts address more than 400 diseases and health threats in 60 countries, including SARS–CoV–2. An emerging infection in any part of the world is just a plane ride away from the U.S. (or any other location). As highlighted by the COVID–19 pandemic, increased resources for this vital CDC program are needed to improve global capacity to prevent, detect and respond to health threats at their source before international spread. As a key implementor of the Global Health Security Agenda, the division works to improve health emergency preparedness and response, enhance infectious disease surveillance systems, strengthen laboratory capacity, train health care workers and disease detectives and build and support emergency operations centers in countries with limited public health capacities. The current COVID–19 tragedy in India and Brazil underscores the critical importance of global public health infrastructure. The program also works to address AMR by providing technical assistance to 30 countries, working to detect resistant threats; prevent and contain resistance pathogens; and improve antibiotic use. Other divisions in the CDC Center for Global Health are instrumental in providing technical assistance on HIV, tuberculosis (TB) and malaria and other parasitic diseases, and also ensuring access to essential immunization services for children in low- and middle-income countries. U.S. leadership of global health security efforts is essential, and the resources allocated to those efforts have been inadequate. Until all countries have laboratory monitoring and surveillance capacities and the trained staff and equipment necessary to detect and respond swiftly to emerging infectious threats, we all will remain vulnerable.

Elimination of Opioid Related Infectious Diseases

$120 billion in funding for the Opioid-Related Infectious Diseases program would allow CDC to address the significant and growing burden of the opioid epidemic by expanding surveillance for infectious diseases commonly associated with injection drug use, including HIV, viral hepatitis and infective endocarditis. CDC has found steep increases in multiple viral, bacterial and fungal infections due to injection drug use, and CDC estimates that individuals who inject drugs are 16 times more likely to develop an invasive Methicillin-resistant Staphylococcus aureus (MRSA) infection. We are very concerned about how the opioid crisis is driving higher rates of infectious diseases including hepatitis C, endocarditis, HIV, and pneumonia, as well as skin, soft tissue, bone, and joint infections. Support systems for individuals with substance use disorders are suffering disruptions due to the COVID–19 pandemic, which may be worsening the opioid epidemic and associated infectious diseases.

ASSISTANT SECRETARY FOR PREPAREDNESS AND RESPONSE (ASPR)

Biomedical Advanced Research and Development Authority (BARDA), Broad Spectrum Antimicrobials and Combating Antibiotic-Resistant Bacteria Biopharmaceutical Accelerator (CARB–X)

The BARDA Broad Spectrum Antimicrobials program and CARB–X leverage public/private partnerships to develop products that directly support the government-wide National Action Plan for Combating Antibiotic-Resistant Bacteria and have been successful in developing new FDA-approved antibiotics. To help achieve the plan's goals to accelerate basic and applied research for developing new antibiotics and other products, $300 million in FY2022 funding is needed. This funding will help prevent a situation in which we lose many modern medical advances that depend upon the availability of antibiotics, such as cancer chemotherapy, organ transplantation and other surgeries.

Project BioShield Special Reserve Fund (SRF), Broad Spectrum Antimicrobials

We recommend $200 million in funding for the Project BioShield SRF. The SRF is positioned to support the response to public health threats, including AMR. BARDA and National Institute of Allergy and Infectious Diseases efforts have helped 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 of drug development during which small biotech firms are particularly vulnerable. $200 million in funding would expand this approach to better support the antibiotics market.

NATIONAL INSTITUTES OF HEALTH

National Institute of Allergy and Infectious Diseases (NIAID)

$6.520 billion for NIAID, including $600 million for AMR research, would allow NIAID to address AMR while carrying out its broader role in supporting infectious diseases research, including emerging infectious diseases, HIV, TB and influenza. Increased FY2022 funding would strengthen investment in the biomedical research workforce, including training and efforts to support early-career physician-scientists and promote diversity, update the national clinical trials infrastructure to include community hospitals and enable access for underserved populations.

The COVID–19 pandemic has demonstrated the need to better prepare our biomedical research infrastructure to respond to emerging infectious diseases and future emergencies, including the need to strengthen and diversify the ID research workforce. High educational debt, low research salaries, and competing work-life demands have driven many promising researchers from the field. The current pandemic has reportedly increased interest in infectious diseases as a career, but translating increased interest into recruitment and retention remains a challenge. Infectious diseases as a specialty only filled 88% of positions and 75% of programs in the recent match; further, 80% of counties in the US do not have an ID physician. Strong NIAID support for career development through increased FY2022 funding and other initiatives is critical to maintaining and improving the pipeline of physician scientists committed to a career in ID. NIAID should use increased resources to provide additional K, T, and F awards, and Early Investigator Awards as well as new opportunities for community-based ID physicians to participate in clinical trials and other research to enhance recruitment, training and diversity of the physician-scientist workforce.

The COVID–19 pandemic has exposed systemic deficits that threaten our ability to combat future outbreaks and threats, such as AMR. FY2022 funding will allow NIAID to continue to respond to the pandemic and prepare for future outbreaks while carrying out its broader role in infectious diseases research. Such efforts include research on antimicrobial mechanisms of resistance, therapeutics, vaccines and diagnostics; development of a clinical trials network to reduce barriers to research on emerging and difficult-to-treat infections; and support for training more physician scientists and clinical investigators to improve research capacity, for example, as outlined in the 2020–2025 National Action Plan to Combat Antibiotic-Resistant Bacteria.

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 Barbara D. Alexander, MD, MHS, FIDSA, IDSA, President, Infectious Diseases Society of America.]

PREPARED STATEMENT OF THE INTEGRATIVE HEALTH POLICY CONSORTIUM

Thank you, Chair Murray and Ranking Member Blunt, for this opportunity to testify in support of programs at the Department of Health and Human Services under your Subcommittee's jurisdiction that are important to the members of the Integrative Health Policy Consortium (IHPC) (www.ihpc.org). Specifically, IHPC is writing to express its support for funding the National Center for Complementary and Integrative Health (NCCIH), a component of the National Institutes of Health (NIH), and the Federally Qualified Health Centers (FQHCs) program within the Health Resources and Services Administration (HRSA). In addition, our testimony respectfully asks the Subcommittee to support the inclusion of report language urging the Department of Health and Human Services (HHS) to implement recommendations issued by the HHS Pain Management Best Practices Inter-Agency Task Force.

The Integrative Health Policy Consortium (IHPC) IHPC is a broad-based coalition of organizations whose mission is to eliminate barriers to health. IHPC includes 26 organizations representing more than 650,000 state licensed, certified and/or nationally certified healthcare professionals, including medical doctors, registered nurses, doctors of chiropractic, naturopathic doctors, licensed acupuncturists, licensed massage therapists, and academic, research, clinical, and public education organizations. IHPC has championed the Congressional Integrative Health & Wellness Caucus and functions to support the federal agencies overseeing America's health and health re-

search needs. IHPC envisions a world with no barriers to health and is focused on promoting a healthier world that incentivizes health creation for all individuals, communities, and the planet.

NATIONAL CENTER FOR COMPLEMENTARY AND INTEGRATIVE HEALTH

IHPC appreciates the strong support that the Chair and Ranking Member have given the NIH. IHPC shares your enthusiasm for the agency's research and research training mission and encourages the subcommittee to continue prioritizing NIH funding. In addition, we urge the Subcommittee to provide the National Center for Complementary and Integrative Health (NCCIH) with similar, commensurate increases. With this additional support, NICCH could support its ongoing mission as well as embark fully on a new, promising research initiative, the Whole Health Perspective. This initiative would promote research looking at the interactions between systems in the body, such as connections between the brain and the heart, that predispose people to disease and expand our understanding of integrative health and pathways to improving health and preventing disease.

IHPC specially wants to draw attention to the importance of including all the regulated integrative health systems and professions in whole person research. One of the major lessons of the COVID–19 pandemic and the importance of optimal health is the need for each of the major systems as well as integrative protocols to be studied in real world environments to determine the whole person effect of regular care through specific approaches such as acupuncture, naturopathic medicine, chiropractic, homeopathy, holistic nursing, massage therapy, lifestyle and functional medicine approaches, direct entry midwifery, and traditional healing approaches from Native American and indigenous communities.

IHPC joins other organizations in asking the Subcommittee to provide NIH with $46.1 billion in FY 2022. This request, which is a $3.177 billion (7.4%) increase over the comparable FY 2021 funding level for the NIH, would allow for the agency's base budget to keep pace with the biomedical research and development price index (BRDPI) and allow meaningful growth of 5%. Further, such an increase would expand NIH's capacity to support promising science across all disciplines, particularly including the new Whole Health initiative underway at NCCIH. IHPC asks the subcommittee to provide NCCIH with at least a similar 7.4% funding increase in FY 2022.

FEDERALLY QUALIFIED HEALTH CENTERS

Federally Qualified Health Centers (FQHCs) are community-based health care providers that receive funds from the HRSA Health Center Program to provide primary care services in underserved areas. In recent years, especially with the onset of the nation's opioid crisis, FQHCs have emerged as a platform for Integrative Whole Health innovation and for the delivery of non-pharmacologic pain management services. During the COVID–19 pandemic, select FQHCs have expanded their services to deliver pain management services to an increased number of uninsured and underinsured individuals. To advance and expand the FQHC mission, IHPC endorses the recommendation issued by the National Association of Community Health Centers to provide community health centers with $2.2 billion in discretionary funding in FY 2022. Further, we respectfully request the Subcommittee to request a report from HRSA in FY 2022 regarding the inclusion of regulated complementary and integrative health professionals and services system wide, Medicare and Medicaid reimbursement for services within the FQHC system and barriers to access and reimbursement for non-pharmacologic pain management services; and possible solutions to the elimination of noted barriers.

HHS PAIN MANAGEMENT BEST PRACTICES INTER-AGENCY TASK FORCE

IHPC respectfully asks that the Subcommittee support the inclusion of proposed report language, urging HHS to facilitate adoption of recommendations from The Pain Management Best Practices Inter-Agency Task Force and launch a public awareness campaign to educate Americans about the differences between acute and chronic pain and the evidence-based non-opioid (non-pharmacologic) treatment options that are available. In 2019, this congressionally established task force issued a ground-breaking report regarding best practices for managing acute and chronic pain. Of note, the report underscores the philosophical and cultural shift to focus on addressing chronic and acute pain by using complementary and integrative health including non-pharmacologic approaches that have been proven effective and are widely supported by practitioners working in all healthcare settings. These treatment options include acupuncture, massage therapy, physical and occupational therapies, chiropractic, cognitive behavioral therapy, manipulative therapy, yoga, tai

chi, and meditation. If implemented, these recommendations will have profound public health and positive national economic impact on a significant percent of the U.S. population. The IHPC stands ready to assist the agency and the Congress in advancing this important public awareness.

Thank you for considering our views. The IHPC looks forward to working with you to enact the FY 2022 Labor, Health and Human Services and Education Appropriations bill and to help ensure our priorities are addressed in the final version of this important funding legislation.

Integrative Health Policy Consortium Partners for Health

American Holistic Nurses Credentialing Corporation (AHNCC) https://www.ahncc.org/	**Life University The Octagon** http://www.octagon.life.edu/	**American Nutrition Association Board of Certification Nutrition of Specialists (BCNS)** https://theana.org/certify
International Chiropractors Association (ICA) https://www.chiropractic.org/	**Alliance for Massage Therapy Education (AFMTE)** https://www.afmte.org/	**American Holistic Nurses Association (AHNA)** https://www.ahna.org/
Southern California University of Health Sciences (SCU) https://www.scuhs.edu/	**Integrative Medicine for the Underserved (IM4US)** https://im4us.org/	**American Association of Naturopathic Physicians (AANP)** https://naturopathic.org/
Palmer College of Chiropractic https://www.palmer.edu/	**Naturopathic Medicine Student Association (NMSA)** https://naturopathicstudent.org/	**National Center for Homeopathy (NCH)** https://www.homeopathycenter.org/
Council for Homeopathic Certification (CHC) https://www.homeopathicdirectory.com/	**American Academy of Medical Acupuncture (AAMA)** https://medicalacupuncture.org/	**Northwestern Health Sciences University, Center for Healthcare Innovation and Policy** https://www.nwhealth.edu/research/policy-in-action/
Institute for Natural Medicine (INM) https://naturemed.org/	**Upledger Institute** https://www.upledger.com/	**National Foundation for Integrative Medicine (NFIM)** https://nfim.org/
American Society of Acupuncturists https://www.asacu.org/	**Academy of Integrative Health and Medicine (AIHM)** https://aihm.org/	**American Massage Therapy Association (AMTA)** https://www.amtamassage.org/
Midwives of Alliance of North America (MANA) https://mana.org/	**National Association of Certified Professional Midwives** https://nacpm.org/	

[This statement was submitted by Margaret Erickson, PhD, RN, CNS, APRN, APHN-BD, Co-Chair, Integrative Health Policy Consortium.]

PREPARED STATEMENT OF INTERNATIONAL FOUNDATION FOR GASTROINTESTINAL DISORDERS

FISCAL YEAR 2022 L–HHS APPROPRIATIONS RECOMMENDATIONS

—At least $46.1 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).
—Please provide $10 billion for the Centers for Disease Control and Prevention (CDC).
—Please provide $5 million for the Chronic Disease Education and Awareness Program.

Chairwoman Murray, Ranking Member Blunt, and distinguished members of the Subcommittee, as you work with your colleagues to develop the FY2022 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.

CENTERS FOR DISEASE CONTROL AND PREVENTION

We greatly appreciate the support from the Subcommittee in creating the Chronic Disease Education and Awareness Program in FY2021. Patients with FGIMDs frequently suffer for years before receiving an accurate diagnosis, exposing them to unnecessary and costly tests and procedures including surgeries, as well as needless suffering and expense. Functional GI and motility disorders are among the most common digestive disorders in the general population. They affect an estimated 1 in 4 people in the U.S. and account for 40% of GI problems seen by medical providers. A CDC program focused on surveillance, provider education, and public awareness would increase diagnoses and improve patient outcomes. We ask that the Subcommittee provide $5 million for the Chronic Disease Education and Awareness Program in FY2022.

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% 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 four 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 seven 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 FY 2022. We look forward to continuing to work with you on these critical issues.

[This statement was submitted by Ceciel T. Rooker, President and Executive Director, International Foundation for Gastrointestinal Disorders.]

PREPARED STATEMENT OF THE INTERSTATE MINING COMPACT COMMISSION

We are writing in regard to the fiscal year 2022 Budget for the Mine Safety and Health Administration (MSHA), 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 for at least the last five fiscal years has included an amount of not less than $10,537,000 for state assistance grants. We are pleased to see that President Biden's fiscal year 2022 budget proposes to continue funding at this level. 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 important 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 26 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. We urge Congress to reject any attempt to diminish the funds available to states in the budget it adopts for fiscal year 2022 and future years. The budget that is adopted 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 2022 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 2022

—Provide $1.5 million for the IC Education and Awareness Program and the IC Epidemiology Study at the Centers for Disease Control and Prevention (CDC)
—Provide $46.1 billion for the National Institutes of Health (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 endo-

metriosis, 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 $1.5 million in fiscal year 2022 (FY2022) 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 FY2022.

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 $46.1 billion for NIH in FY2022. 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 doctor that specializes in IC that can help diagnose and treat. I can't stress enough how important finding the right doctor is. IC patients need a doctor 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 LEARNING AND EDUCATION ACADEMIC RESEARCH NETWORK

The Learning and Education Academic Research Network (LEARN), a coalition of 38 of the nation's leading research colleges of education across the country, advocates for the importance of research on learning and development. Education research provides the bedrock of knowledge used by our principals, teachers, counselors and professors to help preK–12 students and those seeking a postsecondary education succeed. With the staggering learning loss being experienced by students due to the COVID–19 pandemic, it is critical that Congress provides education research with the resources to guarantee that educational interventions are innovative, evidence-based and effective. LEARN urges the Subcommittee to meet the President's fiscal year (FY) 2022 budget request of 737.5 million for the Institute of Education Sciences (IES) overall with $267.9 million dedicated to Research, Development and Dissemination (RD&D). LEARN also requests that the Subcommittee provide $70 million for the National Center for Special Education Research (NCSER). In addition to requesting that the Subcommittee meet the President's FY2022 budget request of $1.94 billion for National Institute of Child Health and Human Development (NICHD), LEARN requests that the Subcommittee provide $2.21 billion for National Institute of Mental Health (NIMH) in FY2022.

While advocating for these increased resources for FY2022, we want to express our appreciation for the increases for IES that were made in FY2021. We would also like to thank Congress for the inclusion of $100 million for IES in the American Rescue Plan Act; this investment marks Congress' awareness of the importance of education research in addressing the nation's most difficult educational challenges. An increased investment in IES for FY2022 would allow for a more robust development, and dissemination of valuable education research to innovatively address the vast array of educational challenges posed before, during and after the COVID–19 pandemic.

INSTITUTE OF EDUCATION SCIENCES

The work of IES and its grantees can guide the nation's learning recovery so that we can exit the pandemic with a stronger, more equitable, educational system than we entered with. As the primary Federal agency charged with supporting research

for education practice and policy, IES is essential to developing a comprehensive, reliable evidence base, and ensuring that teaching and learning practices are grounded in scientifically valid research. Unfortunately, IES is only able to fund one out of every 10 applications it receives due to the limitations in its budget, despite a far greater percentage of such applications being rated excellent and worth of funding.

Without a critical examination of what works and what does not work to further knowledge, our education systems would be left to the same curriculum, instructional techniques and assessments, regardless of whether they spur student success. Examples of critical education research funded by IES include the development and adoption of a statewide approach to math instruction in one State that is now utilized in other States; the development and implementations of a reading curriculum now being adopted as a statewide literacy approach by a State legislature and improved instructional and behavioral practices for children with disabilities. Without continued support for general education research infrastructure, notable programs like these would not exist to address some of the nation's longest standing educational challenges and support the nation's most at-risk students.

The physical closure of schools and transition to virtual learning due to the COVID–19 pandemic has greatly disrupted education research at a time when it is more critical than ever before. Although IES grantees have adjusted their research where possible to remote and hybrid instruction, this pivot has also resulted in unanticipated costs, delays and cancellations; these increased costs are likely to persist through 2022. Nevertheless, IES funded work has provided insightful research findings and valuable tools for educators and caregivers throughout the pandemic. This includes a longitudinal study on the impact of COVID–19 on the educational attainment of economically disadvantaged undergraduates and an interactive tool guide on teaching math to young children at home. The work of IES and its grantees have already begun guiding the nation towards a strong and successful educational recovery.

The focus IES drives on education research is especially important today as our schools must ensure that efforts to reduce learning loss because of the COVID–19 pandemic are rooted in research and evidence-based practice. Given the importance of developing reliable evidence, LEARN is requesting that the Subcommittee meet President Biden's FY2022 request for $737.5 million for IES overall and $267.9 million for the Research, Development, and Dissemination (RD&D) line item within IES. These resources for the RD&D line item will build upon the critical resources provided in the American Rescue Plan Act for IES to further combat the negative learning outcomes resulting from the COVID–19 pandemic. The President's request for a 15 percent increase towards IES and a 35 percent increase for the RD&D line item is further evidence of the importance of supporting education research and evidence-based practices in response to the challenges of the COVID–19 pandemic.

In addition, we recommend that funding for research in special education, through the National Center for Special Education Research (NCSER), should be increased to $70 million. NCSER is the only Federal agency specifically designated to develop and provide evaluations for programs for students with disabilities, but currently has a budget that has remained relatively flat since FY2014. Research funded by NCSER provides special educators and administrators research-based resources that improve educational academic outcomes for children with or at risk of disabilities. During a time when special education students have been dramatically impacted by the change in schooling due to COVID–19, additional funding to NCSER is necessary to support data and evidence-based resources to guide the continued COVID–19 response and recovery for these students. Funding of $70 million would allow for a new competition in FY2022, allowing further resources to address COVID–19 learning issues.

NATIONAL INSTITUTES OF HEALTH

There are critical education research programs within the National Institutes of Health (NIH) that also need additional support. NICHD is essential to education research as it examines brain functions and the impact of different educational services on learning and development. LEARN supports an increase in NICHD funding to $1.94 billion. This increase will ensure that researchers can build on the knowledge already gained, evaluate what works best in treating developmental disorders and develop new research-based strategies to improve student's learning and development. Additionally, it will support NICHD's efforts to understand the effects of COVID–19 on key at-risk populations, including the cognitive development of children and adolescents.

LEARN also supports an increase in funding for NIMH to $2.21 billion. This increase will help further understanding of the behavioral, biological and environmental mechanisms necessary for developing interventions to reduce the burden of mental and behavioral disorders and optimize learning and development. The untraditional school year and strains of the COVID–19 pandemic has had a largely negative impact on the mental health of children and adolescents nationwide, it is important that research in this field is supported to address these challenges.

LEARN believes it is critical that evidence-based research is implemented and applied to schools nationwide as they work to address the myriad of educational challenges that existed prior, and were exacerbated, by the COVID–19 pandemic. As the nation looks towards recovery, IES and NIH must be at the forefront of any effort to ensure that Federal resources are going towards effective programming and interventions. The LEARN Coalition strongly believes that key investments in education research through IES and NIH will drive improvements in teacher and student performance in the coming years and allow for the beginning of a successful recovery from the COVID–19 pandemic. Thank you for your commitment to sustaining and strengthening the nation's education research infrastructure.

Respectfully submitted,

[Camilla P. Benbow, Ed.D., Co-Chair, Learning and Education Academic Research Network]

[Patricia and Rodes Hart Dean of Education and Human Development of the Peabody College of Education and Human Development, Vanderbilt University]

[Rick Ginsberg, Ph.D., Co-Chair, Learning and Education Academic Research Network, Dean of the School of Education, University of Kansas]

[Glenn E. Good, Ph.D., Co-Chair, Learning and Education Academic Research Network, Dean of the College of Education, University of Florida]

PREPARED STATEMENT OF THE LYMPHATIC EDUCATION & RESEARCH NETWORK

KEY RECOMMENDATIONS

—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 National Institutes of Health (NIH) with $46.1 billion for FY 2022 and advance lymphatic disease research by expanding resources and encouraging better coordination among relevant institutes and centers

—Provide the Centers for Disease Control and Prevention (CDC) with $10 billion for FY 2022 and enable $5 million for the Chronic Disease Education and Awareness Program.

Chairwoman Murray, Ranking Member Blunt and distinguished members of the Subcommittee, thank you for the opportunity to submit the priorities of the lymphatic diseases community you as you consider FY 2022 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 mil-

lion 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. We are currently isolated and alone.

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. 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 must be worn daily by patients.

FISCAL YEAR 2022 APPROPRIATIONS RECOMMENDATIONS

We have been hopeful with recent advancements, but more needs to be done. 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 $46.1 billion for NIH in FY 2022.

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 are grateful to the Subcommittee for continuing to support the establishment of 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. We ask that you continue to impress on NIH the critical need for this Commission and how they can work with relevant stakeholders such as ourselves. 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 $10 billion through FY 2022 and to increase funding to increase awareness, education, and surveillance of lymphatic diseases. We encourage the Subcommittee to support $5 million for the Chronic Disease Education and Awareness Program in FY2022 which 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 THE MARCH OF DIMES

MARCH OF DIMES: FISCAL YEAR 2022 FEDERAL FUNDING PRIORITIES

PROGRAM	FISCAL YEAR 2022 REQUEST
National Institutes of Health (total)	No less than $46,100,000,000
National Institute of Child Health and Development	No less than $1,708,021,938
National Institute of Environmental Health Sciences	No less than $874,961,000
National Children's Study Alternative (ECHO)	$180,000,000
Centers for Disease Control and Prevention (total)	**$10,000,000,000**
National Center for Birth Defects and Developmental Disabilities	$280,000,000
Emerging Threats to Moms and Babies	$100,000,000
Section 317 Immunization Program	$1,100,000,000
Newborn Screening Quality Assurance Program	$28,000,000
Polio Eradication	$176,000,000
Division of Reproductive Health	$102,500,000
Safe Motherhood Initiative	No less than $40,500,000
Preterm Birth	$2,000,000
Perinatal Quality Collaboratives	$30,000,000
Maternal Mortality Review Committees	No less than $30,000,000
Office on Smoking and Health	$310,000,000
National Center for Health Statistics	$200,000,000
Health Resources and Services Administration (total)	**$9,200,000,000**
Title V Maternal and Child Health Block Grant	No less than $750,000,000
Heritable Disorders	$28,883,000
Healthy Start	$145,000,000
Grants for Maternal Depression Screening and Treatment	$10,000,000
Maternal Mental Health Hotline	No less than $3,000,000
Title X Family Planning Program	$737,000,000
Office of the Secretary Health - Teen Pregnancy Prevention	**$150,000,000**
Agency for Healthcare Research and Quality (total)	**$500,000,000**

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 (FY) 2022 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 strongly supports President Biden's historic HHS budget proposal for FY 2022 which includes strong increases for critical programs supporting families, and we recommend the following 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 no less than $1.7 billion for NICHD's groundbreaking biomedical research activities in FY 2022. 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.

Additionally, now that the Task Force on Research Specific to Pregnant and Lactating Women (PRGLAC) has laid the foundation for addressing research on safe

and effective therapies for pregnant and lactating women in clinical trials by releasing recommendations in September 2018, as mandated by Congress in the 21st Century Cures Act (P.L. 114–255), and provided an additional implementation plan increased funding will allow for NICHD to more closely look at ways to include and integrate pregnant and lactating women in clinical trials. 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. We support the inclusion of this dedicated funding to address the nation's preterm birth crisis.

Surveillance for Emerging Threats to Mothers and Babies Initiative: March of Dimes recommends funding the Surveillance for Emerging Threats to Mothers and Babies Initiative Program (known as SET–NET) within the National Center for Birth Defects and Developmental Disabilities at Centers for Disease Control and Prevention (CDC) at $100 million. SET–NET was created during the Zika outbreak, which allowed CDC to create, a unique nationwide mother-baby linked surveillance network to monitor the virus' impact in real-time to inform clinical guidance, educate health care providers and the community, and connect families to care. Unfortunately, states were unable to sustain systems due to the program being chronically underfunded, and we were left without a national system to mobilize when COVID–19 struck.

Consequently, we have an incomplete picture on how to best care for mothers and babies with confirmed or suspected virus infection as the CDC currently only supports 29 state, local, and territorial health departments. The increased funding will allow for CDC to address these knowledge gaps and expand the initiative to provide real-time clinical and survey data from all 50 states, territories and jurisdictions on the impact of COVID–19 and new public health threats.

Perinatal Quality Collaboratives: PQCs are state or multistate networks working to improve the quality of obstetric care and improve outcomes. Currently, CDC funds 13 state-based PQCs that are implementing recommendations across health facility networks. However, many PQCs lack adequate resources to meet demands and reach their maximum potential. We request no less than $30 million to fully scale these programs in all states, an increase of $26.5 million.

Maternal Mortality Review Committees: Under the Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE MM) Program, CDC provides funding, technical assistance, and guidance to state maternal mortality review committees. These multidisciplinary committees identify, review and characterize maternal deaths and prevention opportunities. Currently, CDC has made 24 awards and supports 25 state agencies and organizations that coordinate and manage MMRCs. However, more standardized data collection is needed to help examine all the factors contributing to severe maternal mortality, preventable deaths, and poor birth outcomes. To this end, we request no less than $30 million, an increase of $15 million, to reach all 50 states, DC, and Puerto Rico and tribes with enhanced technical assistance to maximize MMRCs.

Newborn Screening: Newborn screening is one of our nation's most successful public health programs. Each year, nearly every one of the approximately 4 million infants born in the United States is screened for certain genetic, metabolic, hormonal and/or functional conditions. The early detection afforded by newborn screening ensures that infants who test positive for a screened condition receive prompt treatment, saving or improving the lives of more than 12,000 infants each year.

Both the Newborn Screening Quality Assurance Program at CDC and the Heritable Disorders program at Health Resources and Services Administration's (HRSA) have significantly improved the quality of newborn screening programs throughout the country. NSQAP works hand-in-hand with state laboratories by performing quality testing for more than 500 laboratories to ensure the accuracy of newborn screening tests. Where the Heritable Disorders program provides assistance to states to improve and expand their newborn screening programs and 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). To continue sustaining, improving, and enhancing these programs, March of Dimes urges funding of $28 million for NSQAP and $28.883 million for the Heritable Disorders program for FY22.

Grants for Maternal Depression Screening and Treatment: 1 in 5 women are affected by anxiety, depression, and other maternal mental health (MMH) conditions during pregnancy or the year following pregnancy. These illnesses are the most common complication of pregnancy and childbirth, impacting 800,000 women in the United States each year. Sadly, MMH conditions often go undiagnosed and untreated, increasing the risk of multigenerational long-term negative impact on the

mother's and child's physical, emotional, and developmental health, increasing the risk of poor health outcomes of both the mother and baby. Furthermore, women of color and women who live in poverty are disproportionately impacted by MMH conditions, experiencing them 2–3 times the rate as White women.

At the current funding level, only seven states have received grants to provide real-time psychiatric consultation, care coordination, and training for front-line providers to better screen, assess, refer and treat pregnant and postpartum women for depression and other behavioral health conditions. March of Dimes urges the Committee to provide $10 million in FY 2022 to add five programs and provide technical assistance to non-grantee states.

Maternal Mental Health Hotline: We thank the Committee for funding $3 million in FY21 to the new maternal mental health hotline. This funding will allow qualified counselors to staff a hotline 24 hours a day and conduct outreach efforts on maternal mental health issues. COVID–19 has exacerbated maternal mental health conditions at 3–4 times the rate prior to the pandemic and leaving these conditions untreated can have a long-term effects. We urge the Committee to provide $5 million to allow for the hotline to provide text messaging services, culturally-appropriate support, and continue public awareness efforts.

Conclusion: March of Dimes looks forward to working with you 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 maternal mental health that impacts mother, infants and families.

PREPARED STATEMENT OF MEALS ON WHEELS AMERICA

Dear Chair Murray, Ranking Member Blunt, and Members of the Subcommittee:

Thank you for the opportunity to submit testimony concerning Fiscal Year 2022 (FY22) 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 nationwide network of community-based senior nutrition providers and the individuals they serve, we are grateful for your ongoing support for the program, particularly in response to the COVID–19 pandemic. With Congress' help in securing much-needed emergency relief funding for the OAA network, local senior nutrition programs (e.g., Meals on Wheels) continue to serve on the front lines of the ongoing public health crisis, delivering essential nutrition assistance and so much more to older Americans. Despite the historic emergency supplemental funding and recent investments in annual appropriations, senior nutrition programs continue to be challenged by a soaring need for services which not only preexisted COVID–19 but have been rendered far worse as a result of the pandemic. For this reason, we request a total of $1,903,506,000 for the OAA Title III C Nutrition Program—Congregate Nutrition Services, Home-Delivered Nutrition Services, and Nutrition Services Incentive Program (NSIP)—in FY22. As programs will continue to serve a greater number of older adults through the new fiscal year and costs remain high, our specific appropriations requests are:

—$965,342,000 for Congregate Nutrition Services (Title III C–1)

—$726,342,000 for Home-Delivered Nutrition Services (Title III C–2)

—$211,822,000 for Nutrition Services Incentive Program (Title III)

While this FY22 request is double the FY21-enacted funding levels for the program, it reflects the amount necessary to maintain current levels of service, while enabling the network to expand and adapt to serve more seniors. As our country strives to respond, recover and rebuild from the health and economic crisis, these nutrition programs are a lifeline for millions of older adults and the services they provide must flex to meet the need.

Overseen by ACL's Administration on Aging and implemented at the local level through more than 5,000 community-based providers, the OAA Nutrition Program delivers nutritious meals, opportunities for social connection and safety checks to adults 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. Amid the pandemic, older adults face unprecedented demands on their physical and mental health, independence and financial well-being. The local providers that serve them are seeing a far greater demand for their services as operational expenses and/or overall costs to safely deliver meals continue to rise. Accordingly, additional federal funding and flexibility of use of OAA nutrition resources are needed for senior nutrition programs to adequately adapt and expand operations to meet the growing and evolving needs of the communities they serve.

Before the coronavirus pandemic, nearly 9.7 million (13%) older adults ages 60 and older were threatened by hunger (i.e., marginally food insecure)—5.3 million (7%) of which were food insecure or very low food secure.[1] Social isolation—which has been amplified amidst safety and social distancing measures—is yet another threat for the nearly 17.5 million (24%) seniors that lived alone in 2019.[2] One in five older adults reported frequent feelings of loneliness prior to the pandemic, and many more seniors have experienced feeling lonely or lack of social connection since then.[3] 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 adverse health effects. Despite the wide recognition of the relationship between healthy aging and access to nutritious food and regular socialization, millions of seniors were struggling to meet these basic human needs pre-COVID; and these issues have only been exacerbated as a result of the pandemic.

The OAA Nutrition Program is designed to reduce hunger, food insecurity and malnutrition, and to promote socialization and the overall health and well-being of older adults. Providers across the country have long played a pivotal role in supporting the independence and quality of life of the 2.4 million older adults they serve. Meals served by the program must also meet the dietary guidelines set by the OAA Nutrition Program and are often tailored to meet medical needs and cultural preferences. OAA services are targeted toward seniors with the greatest social and economic need-including those who are low-income; are a racial or ethnic minority; live in a rural community; have limited English proficiency; and/or are at risk of institutionalization.[4] For many program participants, the volunteer or staff member who delivers meals to their homes may be the only individual(s) she or he sees that day.

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, taking multiple prescription medications daily and/or having three or more chronic conditions. A significant number of those served belong to a racial and/or ethnic minority group, as 19% of participants are Black or African American, 7% are Hispanic or Latino, and 5% are Native American or Hawaiian or Pacific Islander. Additionally, among participants:

—35% live at or below the poverty level;

—25% live in rural areas;

—15% are veterans.[5]

A third (33%) of home-delivered meal recipients report not having enough money to purchase food.[6] 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.[7] Additional research has found home-delivered meal program participants experience less healthcare utilization and lower expenditures than the non-

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[1] J. Ziliak & C. Gundersen, The State of Senior Hunger in America 2018: An Annual Report, prepared for Feeding America, 2020. https://www.feedingamerica.org/research/senior-hunger-research/senior.

[2] U.S. Census Bureau, American Community Survey 2018, available on the Administration for Community Living Aging, Independence, and Disability Program Data Portal (AGID), 2020. https://agid.acl.gov/CustomTables/.

[3] AARP, Loneliness and Social Connections: A National Survey of Adults 45 and Older, 2018. https://www.aarp.org/research/topics/life/info-2018/loneliness-social-connections.htm.

[4] Administration for Community Living (ACL), State Program Reports 2019, available on AGID, 2021. https://agid.acl.gov/CustomTables/.

[5] 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, 2017. https://acl.gov/sites/default/files/programs/2017-07/AoA_outcomesevaluation_final.pdf.

[6] ACL. National Older Americans Act Participants Survey (NPS), 2018, available on AGID Custom Tables and NPS Data Files, 2020. https://agid.acl.gov/.

[7] Meals on Wheels America. More Than a Meal Pilot Research Study, report prepared by K. S. Thomas & D. Dosa, 2015, https://www.mealsonwheelsamerica.org/learn-more/research/more-than-a-meal/pilot-research-study.

participant controls, suggesting the program's potential to reduce costs among patients with high-cost or complex healthcare needs.[8]

Additionally, the OAA Nutrition Program is a true public-private partnership that provides critical support and resources to local community-based organizations. By serving seniors in their homes and communities, local programs generate a powerful social and economic return on investment for older adults and taxpayers alike. They leverage funds granted to states through the OAA to offer nutrition and social services with the help of millions of volunteers, who provide innumerous in-kind contributions to support daily operations. In the aggregate, funding from the OAA accounted for 40% of the total amount spent to provide over 223 million congregate and home-delivered meals in 2019, based on the latest available data.[9] As public spending on healthcare rises each year—largely attributable to a rapidly growing senior population with complex health needs and disproportionate risk to severe illness and complications due to COVID–19—it is imperative that we invest in these cost-effective programs that safely promote health and independence and reduce costly healthcare utilization among many of our country's most at-risk seniors. To further underscore, Meals on Wheels can serve a senior for an entire year for approximately the equivalent cost of one day in the hospital or 10 days in a nursing home.

Prior to the pandemic, federal funding for the senior nutrition network was not keeping pace with increasing demand, rising costs and inflation, leaving a huge gap between seniors served and those in need of services but not receiving them. Nationally, the OAA Nutrition Program network served 17+ million fewer meals in 2019 than in 2005—a 7% decline—despite the population of adults 60 and older growing 53% over that same period.[10] Further illustrating the need for more funding, a 2015 Government Accountability Office study estimated that 83% of low-income, food insecure seniors do not receive the congregate or home-delivered meals that they likely needed.[11] Among Meals on Wheels America members surveyed in 2019, nearly half of all local programs reported maintaining an active waiting list due to insufficient resources, and 85% of programs surveyed saw unmet need for services in their communities at that time.[12] The emergency funding provided through COVID–19 relief legislation not only enabled programs to provide services for those individuals in their communities who have long been eligible and underserved but also helped address a huge influx of older adults newly in need of nutrition services because of the pandemic. An increase in FY22 appropriations is needed to ensure that these individuals can continue to receive the nutritional and social support unique to the OAA Nutrition Program that helps them remain healthier and independent at home and out of far more costly institutional or healthcare settings.

With the onset of the pandemic in March 2020, as mentioned above, the Meals on Wheels network faced an unprecedented surge in demand as the number of older adults sheltering in place increased and congregate centers shifted ways of operating—including transitioning congregate services to fully home-delivered or to grab-and-go and curbside pick-up alternatives, as well as offering virtual socialization activities and wellness checks over the phone. Most Meals on Wheels programs overcame significant challenges to continue and then rapidly scale their operations to serve more older Americans in need. In a survey conducted in November 2020 on behalf of Meals on Wheels America, programs reported delivering an average of 100% more home-delivered meals at their pandemic peak than they served before.[13] At that time, programs also reported serving home-delivered meals to 84% more clients on a weekly basis, and four out of five local programs agreed that these "new clients are here to stay."

Despite the incredible response from the senior nutrition network to quickly scale services, barriers remain in addressing the full demand. According to the November 2020 survey, 88% of Meals on Wheels programs reported increased costs due to the necessary purchase of personal protective equipment (PPE) and safety supplies,

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[8] Berkowitz et al. Meal Delivery Programs Reduce the Use of Costly Health Care in Dually Eligible Medicare and Medicaid Beneficiaries. Health Affairs (Vol. 37, No. 4), 2018. https://doi.org/10.1377/hlthaff.2017.0999.

[9] See note 4 above.

[10] ACL. State Program Reports 2005–2019, available on AGID, 2021. https://agid.acl.gov/CustomTables/.

[11] U.S. Government Accountability Office (GAO). Older Americans Act: Updated Information on Unmet Need for Services, 2015. https://www.gao.gov/products/GAO-15-601R.

[12] Meals on Wheels America. More Than a Meal Comprehensive Network Study, research conducted by Trailblazer Research, 2019. www.mealsonwheelsamerica.org/learn-more/research/more-than-a-meal/comprehensive-network-study.

[13] Meals on Wheels America. COVID–19 Impact Survey, research conducted by Trailblazer Research, November 2020.

meal production expenses and/or labor needs. Local programs reported that costs are expected to remain high, and nine in 10 Meals on Wheels programs reported unmet need for home-delivered meals in their community. Nearly a third of programs said they would need to, at minimum, double their home-delivered efforts to fill the gap in their community, as many reported increased numbers of seniors forced to go on waiting lists. More than 15 months into this public health crisis, local programs are continuing to deliver these life-saving services at high rates and have cited funding as the primary factor impacting their ability to serve individuals most directly affected by the pandemic. Without additional funding through the OAA, many nutrition providers will not be able to support their current client base, much less expand to reach more seniors who need services but are not receiving them.

We understand the difficult decisions you face with respect to annual appropriations bills and other budgetary challenges as Congress works to mitigate the impacts of the global pandemic and recover from this prolonged national emergency. However, to address the current level of nutrition services needed in communities, increased federal funding through the regular appropriations cycle is critically needed for the next fiscal year and beyond. With approximately 12,000 individuals turning 60 every day, the requested appropriations increase will help provide the levels needed for community-based nutrition programs to reach eligible older adults, especially as the demand for these essential services continues to rise.

As the Subcommittee develops its FY22 Labor-HHS-Education appropriation bill, we request you provide a minimum of $1,903,506,000 for the OAA Nutrition Program so that local community-based Meals on Wheels programs can ensure the health, safety and social connectedness of our nation's seniors, build the capacity of OAA programs and services, and bridge the growing gaps and unmet need for services in communities nationwide. Thank you for your leadership, support and consideration. We look forward to working together to ensure that no senior in America is left hungry and isolated.

[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 $475 million for NLM in FY22, a 3% (+$12.9 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. As NLM works to achieve key objectives of its Strategic Plan—to accelerate data powered discovery and health, reach new users in new ways, and prepare a workforce for a future of data-driven research and health, it also supports NIH-wide efforts to answer the call to respond to national priorities, close the gap in health disparities, and capitalize on fundamental investments. NLM accomplishes this through effective preservation of valued scientific and data resources, judicious investments in extramural and intramural research, informed stewardship of Federal resources, and innovative partnerships to align priorities and leverage investments across HHS, the Federal government, and the biomedical research community.

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.

Leveraging NIH Investments in Biomedical Research

NLM's budget supports information services, research, and programs that sustain the nation's biomedical research enterprise. In FY22 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 is unique because it stimulates and supports innovative research in data science and information management that transcends specific disease areas and data types.

NLM plays a critical role in NIH's data science and open science initiatives leading 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 FY 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 upload a total of 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. 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 32 million references to the biomedical literature, is the world's most heavily used source of bibliographic information with almost 3.3 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 6.8 million biomedical journal articles, including those produced by NIH-funded researchers. On a typical weekday more than 3.5 million users download articles from PubMed Central.

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.

Disseminating Clinical Trial Information

ClinicalTrials.gov, the world's largest clinical trials registry, now includes more than 370,000 registered studies and summary results in all 50 states and in 219 countries for more than 48,000 trials. More than 158,000 users access this vital information each day. 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 health care 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. The NLM coordinates an 8,000-member Network of the National Library of Medicine (NNLM), including 7 Regional Medical Libraries that receive NLM support, 125 resource libraries connected to medical schools, and more than 5,000 libraries located primarily in hospitals and clinics. Through the NNLM, 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.

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. Together, NLM and NIH have built the NNLM All of Us Community Engagement Network (CEN). The CEN focuses on NNLM's mission to improve the public's access to health information and provide awareness of All of Us to communities that are Underrepresented in Biomedical Research by partnering with libraries across the United States. The CEN is designed to leverage the mission of the NNLM to help libraries in supporting the health information needs of their users.

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. From the beginning, NLM has been at the forefront of providing people with information on COVID–19 . Our frontline health care providers use NLM's databases to access the latest research datasets, literature publications, and scientific information about Covid–19. NLM has responded 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 has been:

—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.
—Creating BI SARS–CoV–2 Resources, a portal of literature, gene sequence data, and clinical resources related to the virus that causes COVID–19.
—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 FY 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.

Closing the Gap in Health Disparities

The National Library of Medicine supports NIH's efforts to close the gap in health disparities and improve the diversity of the biomedical information science workforce. Their work supports our mission and core values to make MLA and AAHSL more diverse and inclusive organizations. NLM accomplishes this by:
—Providing open access to scientific literature through PubMed and PubMed Central make scientific literature accessible, lading to biological discoveries and providing the foundation to developing clinical guidelines that inform health care. Resources include PubMed Special Query for Health Disparities and Minority Health Information Resources.
—Utilizing the Network of the National Library of Medicine to provide equal access to biomedical information and improves the public's access to information. NNLM supports events including the recent DEI webinar series "Nine Conversations that Matter to Health Sciences Librarians" as well as NNLM Reading Clubs on Disability Health, LGBTQ Health, Racism and Health and Diversity in Medicine.

—Funding grant programs that support research to advance health equity and grants to reduce health disparities research supplements to promote diversity in health research and leveraging health information technology to address minority health and health disparities.
—Raising awareness and sparking conversations about the intersection of society and ethical considerations in biomedical research and technology through the annual NLM Science, Technology, and Society lecture series.

We look forward to continuing this dialogue and thank you for your efforts to support funding of at least $475 million for NLM in FY22, with additional increases in future years.

PREPARED STATEMENT OF THE METAVIVOR RESEARCH AND SUPPORT, INC.

FISCAL YEAR 2021 APPROPRIATIONS RECOMMENDATIONS

—Please provide the National Institutes of Health (NIH) with an increase of at least a $3.2 billion for FY 2022 to bring total agency funding up to a minimum of $46.1 billion annually.
—Please support establishment and adequate funding for the new Advanced Research Projects Agency for Health (ARPA–H) at NIH as proposed in the Administration's Budget Request to Congress to facilitate robust scientific progress on cancers.
—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 FY 2021 Senate LHHS Appropriations Bill).

Chairwoman Murray, Ranking Member Blunt, 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 FY 2022 appropriations for medical research and public health. The community is deeply grateful for the sustained investment in NIH, and emerging calls for a robust and comprehensive effort to enhance cancer research. Please maintain the commitment to supporting innovative medical research and providing adequate resources to public health programs moving forward, for FY 2022.

ABOUT METAVIVOR

My name is Jamil Rivers. I had a typical family before my diagnosis of "de novo" metastatic breast cancer. I was 39 years old, married, with three children and a full-time job. We were very active and always doing something. I have a big, tight-knit family and we love to travel. I had just changed jobs and we moved into a new house. I never missed a beat—and then my husband was diagnosed with stage-one colon cancer. I became his caregiver. It was in 2017, and everyone got sick in the wintertime like we always do. We had colds and were coughing, but my cold didn't go away. I also had this pain and this pinch, like I had pulled a muscle on my right side. When I went to the doctor about my cold and cough, they had prescribed me antibiotics. I also asked for an ultrasound because appendicitis runs in my family. The results showed that I had lesions in my liver. I had no other symptoms and no other pain, but further testing showed I had stage IV "de novo" metastatic breast cancer. It was the most shocking news ever.

The breast cancer had spread to my liver, my spleen, lymph nodes, lungs, bones, my abdomen and my chest wall. I was devastated. I'm blessed with this beautiful family and my kids are really young. At the time they were only 5, 6 and 16 years old. Why would God bless me with this beautiful family and then strip me from them? I couldn't wrap my brain around the fact that my husband and I could both have a serious health issue. It just wasn't a possibility.

"Who is going to take care of our kids?" That was the first thing I thought about in the midst of my devastation. But after that, I realized I had to survive for them;

I have to be here for them. I wanted my kids to know that I did everything I could possibly do in my power to be here for them. I had to process my diagnosis so I could focus on my health. You never think this could happen to you but it did. It happened to me.

I'm the type of person who, when a challenge is brought to me, I figure out how to execute it and get it done. I basically had to figure out. I empowered myself and armed myself with as much knowledge, information, resources and support as possible. My mission was survival.

I'm my kids' mom and no one else can be. I'm the breadwinner in my family and everyone is also on my benefits. It was imperative that I keep my job and do well at my job so I could continue to take care of them. I started chemotherapy right away because, on paper, I was literally dying. The kids had to see me lose all of my hair and be really tired. That's when I started researching what else I could do in terms of integrative therapy to help me manage the side effects of the chemo in order to still work, be active and take care of my kids the same way I always had.

Now, my husband is in recovery and after 1 year of chemotherapy, my tumors have shrunk to the point where they're a microscopic size so you can't see them on a scan... also known as "no evidence of disease". I'm still working, taking care of the kids and involved in their school activities. I want to soak in every waking second with my family.

I'm not giving up anytime soon.

Through my advocacy, I have tried to help bring more attention to metastatic breast cancer, the need for more research funding and investment towards metastatic breast cancer. I now serve as Board President of METAvivor and work alongside others to push this important work forward. 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 $18 million but we need more...stage IV metastatic cancer needs more research.

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.

Sarah, Oregon

My name is Sarah Wald. I live in Eugene, Oregon. I am a professor at the University of Oregon and a parent. I'm also living with metastatic breast cancer. I was diagnosed with metastatic breast cancer just over two years ago. It was a denovo diagnosis. This means I was Stage IV at diagnosis. It was not a recurrence. I have no family history of breast cancer. I saw my doctor annually for breast exams and planned to start mammograms at forty. I had no symptoms at diagnosis. I felt healthy. I biked 50 miles the weekend after I found what felt like an immobile small grape in my breast. I called my doctor the morning after I found the lump and took the first available appointment. She got me in for a mammogram and ultrasound the day I saw her. It was already too late. There were breast cancer cells in my bones.

I don't know how to explain to you what it is like to find out you are dying of a terminal disease in your thirties. I don't know how to explain to you what is like to feel healthy and be looking forward to the future with your family and then to be told that you will almost certainly be dead in the next few years. There is nothing I want more than to live. I want every day of life that I can have. I want every extra week I can spend with my family. I want to see the flowers come in and bloom every spring. We need money for research. I was shocked to find out how little money actually goes to metastatic breast cancer research when it is metastatic

breast cancer that kills. For those of us living with the disease, it is a race against time to find new treatments that will give us those extra months and those extra days. New research and new treatments make a difference. For the past two years, my cancer has been controlled by a treatment that first received FDA approval in 2015. My second line of treatment will contain a drug that received FDA approval after my diagnosis in 2019. The research you fund today might be the research that lets me see another birthday, mine or my child's. We need to find out how to stop breast cancer from metastasizing and treat it when it does. I don't want anyone else to go through what I am enduring. Please support funding more research for stage IV metastatic breast cancer.

[This statement was submitted by Jamil Rivers, Board Chair, METAvivor Research and Support, Inc.]

PREPARED STATEMENT OF THE MICHELSON CENTER FOR PUBLIC POLICY

The Michelson Center for Public Policy (MCPP) thanks the Subcommittee for its long-standing bipartisan leadership in support of the National Institutes of Health (NIH). Robust support for science and innovation is critical if we are to advance public health, sustain U.S. leadership in medical research, and remain competitive in today's innovation economy.

It is now estimated that the COVID–19 pandemic will cost the U.S. economy more than $16 trillion.[1] The NIH's fiscal year (FY) 2021 budget was just 0.25 percent of that. The NIH is the world's largest funder of medical research and the basic, clinical, and translational research that it funds is the very fuel that feeds the American engine of discovery and drives innovation in pharmaceuticals and biotechnology. More importantly, NIH research saves lives and improves wellbeing for millions worldwide. Now is the time to vaccinate the economy and bolster our ability to respond to the emerging public health threats of tomorrow by continuing to invest heavily in biomedical research with transformative potential. MCPP urges the Subcommittee to provide $100 billion for NIH in FY 2022.

MCPP is a 501(c)(4) social welfare organization that propels legislative change through meaningful collaboration with elected officials, government agencies, and civic leaders to achieve positive outcomes in medical research, education, equity, and animal welfare. The Michelson Center for Public Policy is an affiliated but separate organization from the Michelson Philanthropies network of foundations (Michelson 20MM Foundation, Michelson Found Animals Foundation, and Michelson Medical Research Foundation) and complements the Michelson Philanthropies' thought leadership and expertise with bold and effective advocacy.

MCPP's founder and co-chair is physician, inventor, and philanthropist Gary Michelson, M.D. He is committed to using his platform to advocate for robust investment in biomedical research, disruptive innovation that can deliver more treatments and cures, and support for the next generation of researchers.

Through the Michelson Medical Research Foundation, Dr. Michelson makes grants to support high-quality, cutting-edge medical research because a single breakthrough could benefit the lives and health of hundreds of millions. But philanthropy cannot do it alone. Truly transformative medical advances are seeded by robust investment in the NIH and these investments have exponential returns for the economy, jobs, tax revenues and—most importantly-humankind.

MCPP is thankful for the strong bipartisan support that the Subcommittee leaders, Chairwoman Rosa DeLauro and Ranking Member Tom Cole, have shown in providing the NIH with six consecutive funding increases during this time of constrained budgets. These increases have helped the NIH regain ground from the years of largely flat funding in inflation-adjusted dollars. However, we must do more.

The Biden Administration has proposed to fund the NIH at $51 billion in 2022, which is a good start, but not nearly enough. This is precisely the right time to be bold and go bigger. For the NIH to invest adequately in risky research with the most promise for transformative advances—the very type of research that enabled the unprecedented COVID–19 vaccine development we saw over the past year-it needs twice that.

We cannot afford to be modest in our efforts. No one deserves to fall ill and die, or to helplessly watch as their child, parent or spouse suffers because we failed to do the work right now to save them. We must dramatically increase the NIH's budg-

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[1] https://news.harvard.edu/gazette/story/2020/11/what-might-covid-cost-the-u-s-experts-eye-16-trillion/.

et, so that a lack of funding is not the reason why patients go untreated and diseases remain a threat to public health.

The COVID–19 pandemic has shown that the NIH cannot only rely on incremental annual increases to its base budget to meet the next public health challenge. A fraction of the resources put into combating the pandemic should have been invested in the NIH years ago. With impacts like $16 trillion from one pandemic, we need more than inflationary increases to NIH each year to keep pace and inoculate the country against the next public health crisis.

Investing in the NIH is an investment in our national security. The investments that protect our nation's health and wellbeing should be protected in the same manner as investments in our national defense.

Not only is NIH research essential to advancing health and national security, it also plays a key economic role. Funds provided to NIH are not costs, but instead generate remarkable rates of economic return and even greater returns on our health and wellbeing. In FY 2020, NIH invested $34.65 billion, or almost 80 percent of its budget, in the biomedical research industry across the country. This investment supported more than 536,338 jobs nationwide and generated nearly $91.35 billion in economic activity across the U.S.[2] Just one NIH-funded medical research program, The Human Genome Project, directly generated more than a trillion dollars for the US economy—a 178-fold return on investment—and has paid for itself many times over in industry tax revenues returned to the government.[3]

MCPP is enthusiastic about the Biden Administration's proposal to establish a new Advanced Research Projects Agency for Health (ARPA–H). As proposed, ARPA–H could drive innovation and accelerate the development of innovative therapeutics, treatments, and cures for chronic conditions such as cancer, diabetes, and Alzheimer's Disease. Too often, research supported by the NIH results in incremental advancements and not the transformative scientific breakthroughs that only come from robust investment in high-risk high-reward research. MCPP is committed to supporting innovative ideas that can accelerate the pathway to cures. Standing up an entity like ARPA–H that is focused on high-risk high-reward research and accelerating the timeline from idea to clinical application is the exact thing our nation needs to leverage the lessons learned from the COVID–19 pandemic and apply them to other pressing public health challenges.

A crucial component of ensuring that the NIH is equipped to meet the health challenges of the future is supporting the next generation of scientists. Early career researchers in the biomedical sciences face many struggles as they move toward independence. Lack of independent funding opportunities and tenure-track faculty positions place many early career researchers in a cycle of training positions that may hinder growth, innovation, and scientific independence. In addition, the NIH funding ecosystem is harmfully "hypercompetitive." In 2020, only one out of every five applicants was ultimately awarded NIH funding, and the resulting grant was almost always less than the amount requested to effectively perform the research. This system especially disadvantages early career investigators, squandering the potential of scientists with groundbreaking and innovative ideas.[4] Furthermore, among early career researchers, women, parents, and those from underrepresented backgrounds in STEM bear a disproportionate amount of this burden. MCPP urges the Subcommittee to build NIH's ability to devote more of its annual budget to programs that support early career researchers, with the goal of attaining ten percent of the agency's overall budget invested in the most promising young investigators conducting highly innovative research with truly transformative potential.

MCPP thanks the Subcommittee for its important work dedicated to ensuring the health and security of the nation, and we appreciate this opportunity to urge the Subcommittee to continue the success of NIH by providing at least $100 billion in FY 2022. This is the minimum amount needed to transform our nation's investment in life-saving medical research, enhance NIH's ability to support highly innovative and groundbreaking research, and expand support for young investigators.

We have a once-in-a-lifetime opportunity to pave the way for future medical advances to benefit humankind. Let's seize it.

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[2] NIH's funding information and economic impact data comes from United for Medical Research's 2021 State-By-State Update, https://www.unitedformedicalresearch.org/wp-content/uploads/2021/03/NIHs-Role-in-Sustaining-the-U.S.-Economy-FINAL-3.23.21.pdf.

[3] https://www.nih.gov/about-nih/what-we-do/impact-nih-research/our-society.

[4] https://nexus.od.nih.gov/all/2018/05/04/the-issue-that-keeps-us-awake-at-night/.

PREPARED STATEMENT OF THE MIDWEST URBAN STRATEGIES

Dear Chairman Murray and Ranking Member Blunt:

Midwest Urban Strategies (MUS) represents a coordinated effort on behalf of 13 Department of Labor urban workforce development boards to connect traditional workforce development practices with economic development. Our member 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. The economic recession and recovery caused by COVID–19 is unlike any other period is our nation's history. MUS members, along with local workforce development boards across the country, immediately adapted to continue to provide critical supports and services to job seekers and businesses throughout the pandemic. Our methods may have changed given the circumstances, but the impact of our work persisted, no matter the obstacle.

As the Senate Appropriations Committee considers the Fiscal Year (FY) 2022 Labor-HHS Appropriations Bill, we urge you to support further federal investment into WIOA and fully fund the law beyond its FY2020 authorized levels. We strongly support the proposed funding levels in President Biden's FY 2022 Budget as it recognizes that 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).

Additional federal resources for WIOA programs lead to more job training, education, skills development and innovative, proven practices like industry-based sector partnerships, career pathways, and apprenticeships. MUS works collaboratively in our region and across the country to advance these best practices. Workers and entire industries have been severely disrupted as a result of COVID–19 and these strategies will need to be implemented seamlessly to respond. The established local workforce system is well-positioned to enhance efforts for an equitable recovery; low wage, low skill workers and minority populations were hit hardest by COVID–19. The federal funding structure, which allows these funds to be invested locally, provides for intentional investments to help those most in need.

Local workforce development leaders engage directly with businesses to keep individuals employed and design training/education programs to prepare the workforce for the future. We continue to work with unemployed individuals to re-connect them to the workforce and identify and evaluate other opportunities; recent BLS data suggests nearly 41% of those unemployed have been unemployed for at least 27 weeks (long-term unemployed).[1] Business services, especially for small and medium-sized enterprises, have been critical during the COVID–19 pandemic as employers sought to maintain payrolls and find workers as businesses began to re-open. Increased federal appropriations are greatly needed to address this unprecedented health, economic, and social destabilization.

The Fiscal Year 2022 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 FY2022 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

—$692,370,000 for Wagner-Peyser (FY2021 Enacted)

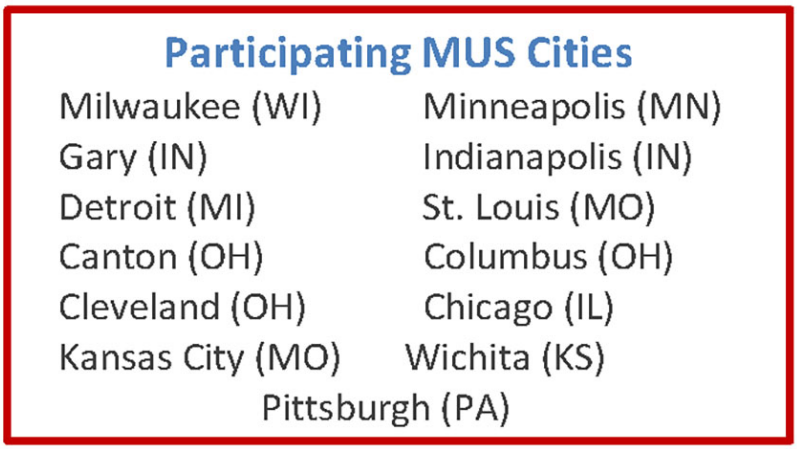
Title IV—Department of Education

—$3,675,021,000 for Vocational Rehabilitation Services (FY2021 Enacted)

This training, support and business partnership is vital to our country's economic prosperity. For further information, please contact Tracey Carey.

[1] https://www.bls.gov/charts/employment-situation/unemployed-27-weeks-or-longer-as-a-percent-of-total-unemployed.htm.

Sincerely.



[This statement was submitted by Tracey Carey, Executive Director, Midwest Urban Strategies.]

PREPARED STATEMENT OF THE MOORE CENTER FOR THE PREVENTION OF CHILD SEXUAL ABUSE

The Moore Center for the Prevention of Child Sexual Abuse at the Johns Hopkins Bloomberg School of Public Health (Moore Center) welcomes the opportunity to submit this statement for the record about the importance of federal investment in child sexual abuse prevention research. The Moore Center was founded in 2012 on the premise that child sexual abuse is a preventable, not inevitable public health problem. Our mission is to create, through rigorous science, a public health approach to preventing child sexual abuse. Together with many stakeholders in the child welfare community, the Moore Center requests that Congress appropriate $10 million for child sexual abuse prevention research at the Centers of Disease Control and Prevention's National Center for Injury and Violence Prevention, Division of Violence Prevention in FY 2022.

Child sexual abuse and the damage it causes to children, adults, families, and communities too often makes headlines. Astoundingly, approximately 13 percent of all children will become victims of the crime. Child sexual abuse is associated with serious mental and physical health problems that shorten the lifespan and reduce its quality. Effects include increased risk for post-traumatic stress system disorder, substance use disorders (including opioid abuse), HIV, heart disease, and suicide. Given this, it is no surprise that our 2018 study found that the economic burden of child sexual abuse was $9.3 billion in 2015, and costs each victim more than $280,000 in earning and other losses over their lifetime.[1]

The COVID–19 pandemic has further underscored the need for effective prevention programming. The National Center for Missing and Exploited Children reported an almost 100 percent increase in online enticement reports and a 63 percent increase in CyberTipline reports between January and September 2020, compared to the same months in 2019. Additionally, the International Criminal Police Organization reported increased consumption of child sexual exploitation and abuse materials among several member countries during the pandemic. In addition to increased online offending, data from US and UK Stop it Now! helplines and websites indicate a surge in requests for help by people concerned about their own sexual thoughts and behaviors, particularly stepfathers with sexual thoughts about their stepdaughters. These increases are likely due to steep pandemic-related job losses and work-from-home/learn-from-home policies that leave at-risk men who were previously managing their urges with too much time, too much access to children, and

[1] Letourneau, Elizabeth J., et al. "The Economic Burden of Child Sexual Abuse in the United States." Child Abuse & Neglect, vol. 79, 2018, pp. 413–422., doi:10.1016/j.chiabu.2018.02.020.

too little structure. We expect risk for online and intra-familial offending will remain high until pre-pandemic employment and in-school education levels are regained.

The federal government rightly funds treatment and other services for crime victims, including victims of child sexual abuse, and funds criminal justice efforts to detect, prosecute and hold accountable those who commit child sexual abuse. Indeed, the federal government annual spends approximately $529,000,000 solely to incarcerate people with sex crimes against children in federal facilities. Yet 95 percent of all sex crimes are committed by people with no prior sex crime convictions. As important as victim and criminal justice efforts are, they do little if anything to prevent harm from occurring in the first place. An inadequate focus on preventing child sexual abuse stands in stark contrast to robust federal efforts that address all other forms of child victimization as preventable public health problems and not solely criminal justice programs. For decades, we have supported the development, validation, and dissemination of programs such as home visitation that effectively prevent child physical abuse and neglect, as well as school-based programs that effectively prevent peer-on-peer bullying, teen dating violence, and suicide. The lack of similar strategies to prevent child sexual abuse is primarily due to the failure to fund similar research in this space.

In the absence of validated prevention efforts, organizations and individuals that work with children have had to develop and implement idiosyncratic and untested prevention efforts. Youth serving organizations, schools, religious groups, sports clubs, after-school programs, child care settings, hospitals, and other youth-focused organization have to create and recreate their untested prevention strategies. Indeed, most states mandate that child sexual abuse curricula be implemented in K–12 schools, yet few such programs have been tested for their effectiveness. There is no way to tell if any given prevention effort might be effective, ineffective, or even harmful to children in the absence of evaluation.

The FY 2019 appropriations bill directed the CDC to release a report on the current state of child sexual abuse prevention research. The report, released in December 2019, outlines significant gaps in existing research efforts, which include the need to: improve surveillance systems and data collection; increase the understanding of risk and protective factors; and, strengthen, develop and disseminate evidence-based prevention policies, programs and practices.

In FY 2020 $1 million was allocated to the CDC's Division of Violence Prevention, which funded two grants to study adult child sexual abuse perpetration prevention. The Moore Center was a recipient of one of these grants, which is being used to conduct research to validate our Help Wanted intervention, an online prevention program designed to provide individuals with sexual interest in younger children with the support and resources to maintain their commitment to non-offending. Virginia Commonwealth University was the recipient of the other grant, which will be used to evaluate Praesidium's Armatus(r) Learn to Protect program, a program focused on the prevention of school employee-perpetrated child sexual abuse, misconduct, and exploitation of students.

In FY 2021 child sexual abuse prevention research received a $500,000 increase. In response, the CDC published a funding opportunity announcement for proposals to evaluate approaches on primary prevention of child sexual abuse perpetrated by youth or adults. The Moore Center was very appreciative for this increase and recognizes the difficulty that the budget caps created for giving programs funding increases; however, it is critical that additional funding is allocated in FY 2022 to address the aforementioned research gaps identified by the CDC. We believe that a $10 million appropriation would allow for meaningful advances to be made in the successful prevention of child sexual abuse.

We want all American children to grow up free from abuse; federal investment in child sexual abuse prevention research is needed to make this wish a reality. The foundation and philanthropic community currently supporting prevention research and evaluation cannot continue to fund it alone. We urge you to include $10 million for research on the primary prevention of child sexual abuse at the CDC as funding priority for FY 22.

We look forward to working with the committee on efforts to protect our children from child sexual abuse and hope that you will consider the Moore Center a resource in the future. Thank you in advance for your time and consideration.

[This statement was submitted by Elizabeth J. Letourneau, Ph.D., Director, Moore Center for the Prevention of Child Sexual Abuse.]

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 (LHHS) Appropriations Subcommittee regarding our request for Fiscal Year 2022 report language for a Work-based Learning Coordinators Demonstration Program funded at $5,000,000 at the Department of Labor's Employment and Training Administration.

NAF's educational design promotes open enrollment in our career academies and allows students of all backgrounds and capabilities to participate. The design is replicable, sustainable, and cost-effective, and because it integrates within public schools, supports lasting systemic reform and equity nationwide. NAF transforms the learning environment to include STEM-infused, industry-specific curricula and work-based learning experiences. NAF serves more than 117,000 students in 34 states, Washington D.C., Puerto Rico, and the U.S. Virgin Islands. NAF is focused on helping to eliminate systemic, educational, and professional barriers faced by students of color.

Economic upheaval from the pandemic will negatively affect the young people entering the workforce at a time when communities need talented workforce to aid in the recovery. It is even more challenging for students of color and from low-income communities with systemic inequities who will face lower earnings, less overall wealth, and greater economic consequences.

Public secondary education institutions play a critical role in preparing youth for future success through initiatives like career and technical education programs, access to local colleges, and work-based learning opportunities with employers. As a principal public institution that young adults go through before becoming adults, the secondary education system plays a significant role in setting up the next generation for success in the workforce. Work-based learning programs ensure a connection between schools and the working world, whether it's preparing students to enter existing jobs, encouraging entrepreneurial endeavors, or serving as a foundation for career opportunities after post-secondary education.

Work-based learning is the continuum of activities both in classroom learning and the actual workplace setting that leads students to gain real world experience. It also has proven economic benefits for Black and Latinx students and young people from families with low incomes. Through work-based learning, virtual and in-person, students can better identify their career interests and aptitudes, understand the education and training they need to achieve their aspirations, and build their professional and support networks.

The most effective work-based learning experiences provide sustained and meaningful interaction between a student and employer partner. This would include career preparation activities such as internships, apprenticeships, and mentorship programs. While less intensive activities—such as guest speakers, mock interviews, and worksite tours—are important to help students with career awareness and exploration and to introduce employers to the concept of work-based learning, the more time—and resource-intensive activities like internships are where students gain the most insight into the working world and are able to hone their professional skills.

When created with intentional student learning outcomes and ownership by all stakeholders, work-based learning can shape students' aspirational opportunities by helping them explore potential careers of interest; build student skills; and help level the playing field by exposing students to networking opportunities to build a diverse professional network, which research indicates is particularly transformative for students of color and those from low-income households.

Further, 80% of jobs are filled through personal and professional connections. Work-based learning helps students build these relationships and expand their networks beyond their immediate communities. The relationships with adults nurtured through work-based learning opportunities are also shown to be long-lasting, positively benefiting students up to a decade later. Young people deserve an education that builds workforce-ready skills, helps them create social capital, and connects them to opportunity. This is true in "normal" economic times and even more critical during a downturn.

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 grad-

uate from high school than their non-NAF counterparts. NAF academy students have a 99% graduation rate.

Educators often have the challenge of finding time to plan and implement work-based learning due to their lack of staffing capability to this particular initiative. With so many demands on school staff, work-based learning is seen as supplementary and not a priority. Administrators and teachers who have accountability testing requirements also push back on the amount of time this strategy requires outside of the classroom. These educators may lack the capacity to meaningfully engage employers and develop sustainable relationships.

Work-based learning coordinators can bridge the divide between school and community employers. The coordinators support work-based learning programs by assisting schools and districts with strategic program planning, coordinating work-based learning activities, and building relationships with employer partners to increase access to internships and other career-focused activities.

NAF encourages schools and communities to have work-based learning coordinators as we have seen it make a difference in the quality and quantity of experiences for students. NAF urges the subcommittee to support and advocate for the inclusion of the following report language in the Fiscal Year 2022 Appropriations bill.

Research shows that participation in work-based learning during high school has a positive impact on students, including completing high school, and helps them secure higher-quality jobs, boosting equity and economic opportunity. To build upon Congress' request of the Department in Fiscal Year 2021 to encourage local secondary education authorities be included on local workforce development boards, the Committee recommends $5,000,000 in Fiscal Year 2022 for the first year of a five-year demonstration program to provide full-time, work-based learning coordinators in underserved communities with an already proven track record for secondary career and technical education. Work-based learning coordinators to conduct outreach, engagement, recruitment and coordination of work-based learning activities, including, but not limited, to paid internships or pre-apprenticeships for high school students, with local community employers, especially with in-demand industries of information technology, health sciences, and engineering. The work-based learning coordinators may be employed by the local education agency, local workforce development board or local workforce development agency, a group of employers, or a consortium of eligible entities. In making grant awards, the Committee directs the Secretary to ensure to require a plan for evaluations in each individual grant proposal, including types of work-based learning opportunities completed, demographics of participating students, and students' post-secondary career plan, as well as to conduct a national assessment of all grantee proposals once complete.

CONCLUSION

Though our world is changing rapidly, and we face unprecedented challenges; we have an opportunity to pave the way for a stronger and more equitable economy. Work-based learning, including paid internships, is a proven, effective way to ensure high school students are college, career, and future ready and prepared to meet the demands of an evolving economy. NAF appreciates the opportunity to share its expertise; and thanks you for your consideration of this important request.

PREPARED STATEMENT OF THE NATIONAL ALLIANCE FOR CAREGIVING

Chair Murray and Ranking Member Blunt, and members of the Subcommittee, thank you for your tireless efforts during the COVID–19 pandemic to ensure that older adults, people with disabilities, and their caregivers across the nation could access the supports and services that they needed to survive. As you know, during our historic collective crisis, Older Americans Act programs that provide community-based care and services to millions of older adults, caregivers, and people with disabilities each year, became part of the lifeline that empowered many to stay safely in their homes. Other vital federal programs provided critical support for caregivers, who became increasingly isolated during one of our nation's most challenging periods. Your Subcommittee's work saved lives and helped to ensure quality care for millions of people. We are grateful to you and your staff for all you have done.

As we move into the next phase of the pandemic and recovery, we submit our funding requests for FY 2022 with the sincere hope that programs supporting family caregivers will again emerge as a priority for the Subcommittee. The needs of caregivers in your states and across the nation, including mid-career Americans who are juggling children and aging parents, have only become more pronounced. Many have left the workforce altogether because they needed more support. In the wake of emergency investments that responded to a historic increase in the needs of older

adults and caregivers during the pandemic, federal investments cannot simply return to normal.

We urge congressional appropriators to embrace, at a minimum, many of the recommendations included in the FY 2022 Biden Administration budget. However, for key, national caregiver support programs, we ask that you consider going above the Administration's request and fund these programs at levels that sufficiently recognize the immense challenges that caregivers of all ages and demographics faced during the global crisis. Therefore, we ask that you consider the following appropriations requests which fall under the Administration for Community Living (ACL) and the Administration on Aging (AoA):

—$334,000,000—Older Americans Act Title III E, National Family Caregiver Support Program (NFSCP), including $400,000 for the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Council

—$21,600,000—Older Americans Act Title VI, Native American Caregiver Support Services

—$14,200,000—Lifespan Respite Care Program

—$5,000,000—Care Corps Community Care Corps Grants

—$35,000,000 Alzheimer's Disease Program Initiatives (ADPI):

In addition, we ask that you provide $20,000,000 for the BOLD Infrastructure for Alzheimer's Act initiatives under the Centers for Disease Control and Prevention. These funding requests align with those of national coalitions that focus on caregiving, including. the Leadership Council of Aging Organizations (LCAO), Leaders Engaged in Alzheimer's Disease (LEAD), and the Eldercare Workforce Alliance (EWA).

I submit these requests and this testimony as the President and Chief Executive Officer of the National Alliance for Caregiving (NAC). NAC's mission is to build partnerships in research, advocacy, and innovation to make life better for family caregivers. Our work aims to support a society which values, supports, and empowers family caregivers to thrive at home, work, and life. As a 501(c)(3) charitable nonprofit organization based in Washington, D.C., we represent a coalition of more than 60 non-profit, corporate, and academic organizations; nearly 40 family support researchers with expertise in pediatric to adult care to geriatric care; advocates who work on national, state, and local platforms to support caregivers across over 30 states. In addition to our national work, NAC leads and works closely with peer organizations in countries such as Australia, Canada, Denmark, Finland, France, Hong Kong, India and Nepal, Ireland, Israel, Japan, New Zealand, Sweden, Taiwan, and the United Kingdom. You can learn more about NAC and our work at www.caregiving.org.

Background: For the purposes of this testimony, the term "caregiver" is defined as it is in the RAISE Family Caregivers Act. A caregiver is "an adult family member or other individual who has a significant relationship with, and who provides a broad range of assistance to, an individual with a chronic or other health condition, disability, or functional limitation."[1] Many on this committee have been personally impacted by family caregiving. We appreciate your leadership and that of your colleagues in the Senate and House who have spoken openly, and candidly, about the realities of caregiving.[2] Those experiences, along with 53 million other Americans who support a friend or family member, form the backbone of our long-term care systems.

Family caregiving is a public health issue. In a nationally representative research study NAC conducted with AARP and released last year, we identified some of the common issues facing caregivers today.[3] Just in the last five years, 9.5 million more people have taken on caregiving, and we anticipate additional caregivers because of the coronavirus pandemic. Compared to 2015, family caregivers have faced more confusing care pathways and face a "ripple effect" on their mental health, physical health, and financial health. About 1 in 5 (18%) of caregivers feel financial strain due to caregiving. Caregivers often must work less, spend more money out-of-pocket, and save less for retirement. More people are caring for someone for up to five years when compared to five years ago—and these caregivers are more likely to care for

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[1] From P.L. No: 115–119, available at https://www.congress.gov/bill/115th-congress/house-bill/3759. In research and in advocacy, "caregiver" may be described as: informal caregiver, care partner, caretaker, and related terminology. In an international context, the term "carer" is often used. It should be noted that an estimated 1.4 million children in the U.S. are unpaid caregivers (NAC and United Hospital Fund, Young Caregivers in the U.S. (2005) at https://www.caregiving.org/data/youngcaregivers.pdf).

[2] See Congressional Stories of Family Caregiving (November 2017), https://www.caregiving.org/wp-content/uploads/2018/02/GSA-Congressional-Stories-of-Caregiving-briefing-paper.pdf.

[3] National Alliance for Caregiving and AARP Public Policy Institute, Caregiving in the U.S. 2020 (May 2020), Caregiving in the U.S. 2020—NAC/AARP Research Report

someone with multiple care needs. Yet we know from economic analysis that when supported, family caregivers can improve health outcomes for individuals, reduce health care costs, and improve population health.

Investing in supports and services for caregivers makes sense. Even modest investments could add an additional $1.7 trillion to the U.S. GDP by 2030.[4] New analysis from BlueCross BlueShield[5] likewise anticipates that supporting caregivers can improve population health and reduce costs. Without support, caregivers who were also commercially insured beneficiaries faced worse overall health, and a higher prevalence of cost-driving health conditions including anxiety, major depression, adjustment disorder, behavioral health disorders, and hypertension. Given the macroeconomic impact of investing in family caregivers, we respectfully request that this committee prioritize the following FY 2022 federal investments in this essential population.

OAA Title III E-National Family Caregiver Support Program:

We request $334,000,000 for the Older Americans Act's (OAA) Title III(e), National Family Caregiver Support Program (NFCSP), which is a critical cornerstone to supporting the dignity and independence of older adults, adults with disabilities, and the friends or family who provide care to them. NFCSP offers an entry point for identifying caregiver needs and can help to address the need for caregiver education, respite, and support. Since 2000, the program has provided grants to states and territories to help older adults and people with disabilities stay in the home as long as possible. The NFCSP offers five core services including information about available services to caregivers; assistance to gain access to services; individual counseling, organizational of support groups, and caregiver education; respite care, to allow caregivers to take a break; and other important supplemental services. The NFCSP remains the only nationally administered program to provide supports and services to caregivers of older adults and people with disabilities.

Within the National Family Caregiver Support Program, we ask you to continue—at a minimum—funding the important and groundbreaking work of the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Council. The Administration requested $400,000 for this ongoing work in their FY 2022 budget request, which would allow the RAISE Family Caregivers Council to work toward fulfilling its mission to develop a national strategy to address the needs of family caregivers of all ages and circumstances.

OAA Title VI C-Native American Caregiver Support Services:

Title VI of the OAA provides grants to eligible Tribal organizations to promote the delivery of home and community-based supportive services (HCBS), including nutrition services and support for family and informal caregivers, to Native American, Alaskan Native, and Native Hawaiian elders. During the COVID–19 crisis, we witnessed tragic devastation among tribal elders and their families. Therefore, we ask you to fund vital caregiver support programs at $21,600,000, which would fully double the investment in these programs and continue important support for tribal caregiving communities still recovering from the ravages of the pandemic.

Lifespan Respite Care Program:

The Lifespan Respite Care Program, administered through the Administration for Community Living, provides short-term care that offers individuals or family members temporary relief from the daily routine and stress of providing care. The program strengthens family stability and maintains family caregiver health and well-being by providing often desperately needed respite to exhausted and at-risk caregivers. Additionally, respite care proved through this program can save additional federal dollars by helping to delay, or altogether avoid, out-of-home placements or hospitalizations. Only 14 percent of family caregivers report having used respite care service, despite nearly 38 percent feeling respite would be helpful. We urge your Subcommittee to adopt the President's budget request of $14,200,000 for this vital program.

Community Care Corps Grants:

Within ACL's program portfolio, we urge you to continue to fund the important work of the Community Care Corps Grant program at $5,000,000. The Community

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[4] AARP. The Economic Impact of Supporting Working Family Caregivers (2021), available at https://www.aarp.org/content/dam/aarp/research/surveys__statistics/econ/2021/longevity-economy-working-caregivers.doi.10.26419-2Fint.00042.006.pdf, https://doi.org/10.26419/int.00042.006.

[5] See, BlueCross BlueShield. The Impact of Caregiving on Mental and Physical Health (9/9/20), last accessed 5/25/21, https://www.bcbs.com/the-health-of-america/reports/the-impact-of-caregiving-on-mental-and-physical-health.

Care Corps supports innovative local models in which trained volunteers assist family caregivers or directly assist older adults or adults with disabilities in maintaining their independence. These volunteers provide critical non-medical support and companionship to supplement their other caregiving options and relieve over-burdened family caregivers and help meet the growing demand for services from a large and growing aging and disability population.

Alzheimer's Disease Program Initiatives (ADPI) and BOLD Act Initiatives:

Within both the Administration for Community Living and the Centers for Disease Control and Prevention, there are two important programs that support those caring for Alzheimer's disease and related dementias (ADRDs). ADPI supports HCBS for people living with ADRD and their caregivers through grants to states, communities, and Tribal entities. To support the important work of ADPI, we hope your committee will support a $35,000,000 FY 2022 funding request. Within CDC, the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act Initiatives establish an effort within the Centers of Excellence in Public Health Practice dedicated to promoting Alzheimer's disease management and caregiving interventions. We encourage your Subcommittee to include $20,000,000 to support the BOLD Initiatives.

In closing, these vital federal efforts and programs that support millions of family caregivers across the country have a profound impact on the quality of life. They can reduce caregiver depression, anxiety, and stress, enabling caregivers to provide care longer and thereby avoiding or delaying the need for costly hospital and institutional care. On behalf of myself, the National Alliance for Caregiving, other national aging and disability advocates, and countless caregivers across the country, I implore you and your Subcommittee to support FY 2022 funding levels for these programs that recognize and respect the immense contribution of caregivers to society. Thank you again for all you have done and will do for older adults and individuals with disabilities and their caregivers.

[This statement was submitted by C. Grace Whiting, J.D., President and CEO, National Alliance for Caregiving.]

Prepared Statement of the National Alliance for Eye and Vision Research

EXECUTIVE SUMMARY

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 ophthalmic/optometric professional societies, patient and consumer groups, private funding foundations, and industry. NAEVR is immensely grateful to 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 (FY) 2016 through FY2021. The $12.85 billion NIH increase in that timeframe has helped the agency regain ground lost after a decade of effectively flat budgets.

This past investment in NIH has not only improved our understanding of fundamental life and health sciences but also prepared the nation to combat unprecedented health threats, including the COVID–19 pandemic, and promoted ever-evolving medical advances. To maintain this momentum in FY2022, NAEVR strongly supports the NIH program funding level of $51.95 billion as proposed by President Biden, including no less than $46.1 billion for NIH's base program level budget [absent proposed funding for the Advanced Research Projects Agency-Health (ARPA–H)], an increase of at least $3.177 billion or 7.4 percent (as compared to the Administration's proposed $45.45 billion NIH base funding level, which is a $2.51 billion or 5.9 percent increase), to enable NIH's base budget to keep pace with the Biomedical Research and Development Price Index (BRDPI) and allow for 5 percent growth. This increase is necessary to support promising science across all Institutes and Centers (ICs), ensure continued Innovation Account funding established through the 21st Century Cures Act for special initiatives, and support early-stage investigators.

NAEVR also urges one-time emergency funding for federal research agency "research recovery" investment to enable NIH to mitigate the pandemic-related disruptions without foregoing promising new science. NAEVR supports the bipartisan Research Investment to Spark the Economy (RISE) Act (H.R. 869/S. 289) which includes $10 billion for NIH (although at the Subcommittee's May 26, 2021, hearing NIH Director Francis Collins, MD, PhD estimated that the pandemic shutdown re-

sulted in a $16 billion loss to its biomedical enterprise). Though pandemic-related lab closures impacted all researchers, the situation was especially acute for early-stage investigators. NAEVR's educational foundation Alliance for Eye and Vision Research (AEVR) documented this impact in a September 2020 video discussion engaging 22 Emerging Vision Scientists who described the chilling effect on their research, collaborations, training, and overall career pathway (a journal article version of this discussion will be published on July 1, 2021, in JAMA Ophthalmology),

NAEVR also urges Congress to fund the National Eye Institute (NEI) at $900 million, a $64.3 million or 7.7 percent increase over FY2021 that reflects both biomedical inflation and growth as compared to the Administration's $858.4 million funding level, a $22.83 million or 2.7 percent increase. Despite NEI's total $160 million funding increases in the FY2016–2020 timeframe, its enacted FY2021 budget of $835.7 million is just 19 percent greater than the pre-sequester FY2021 funding of $702 million. Averaged over those nine fiscal years, the 2.1 percent annual growth rate is still less than the average annual biomedical inflation rate of 2.7 percent, thereby eroding purchasing power. In fact, NEI's FY2021 purchasing power is less than that in FY2012.

The NEI currently faces an increasing burden of vision impairment and eye disease due to an aging population, the disproportionate risk/incidence of eye disease in fast-growing minority populations, and the impact on vision from numerous chronic diseases (such as diabetes) and their treatments/therapies. Especially with the COVID–19 pandemic, the NEI faces additional challenges, as both the working age population and students have relied almost exclusively on electronic communications devices and e-learning platforms which can increase the rates of myopia, dry eye, eye strain, and other vision disorders.

Maintaining the momentum of vision research is vital to vision health, as well as to overall health and quality of life. Since the US 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.

NEI-FUNDED RESEARCH SAVES SIGHT AND RESTORES VISION

The past federal investment in vision research has led to major advances in the prevention of vision loss as well as the restoration of vision.

Audacious Goals Initiative: The NEI has been at the forefront of regenerative medicine with its Audacious Goals Initiative (AGI), which launched in 2013 with the goal of restoring vision. Engaging a broad constituency of scientists from the vision community and numerous other disciplines, 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. 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.

Retinal Diseases: The NEI has been at the forefront of research into retinal diseases. NEI-funded researchers helped show that a protein called Vascular Endothelial Growth Factor (VEGF) stimulates abnormal blood vessel growth that occurs in the advanced stages of the "wet" form of Age-related Macular Degeneration (AMD) and Diabetic Retinopathy. Food and Drug Administration (FDA)-approved anti-VEGF drug therapies that slow the development of blood vessels in the eye delay vision loss and may improve vision for patients. The NEI has funded comparison trials of anti-VEGF drugs to provide eye care professionals and patients with the information they need to choose the best treatment options.

With respect to the "dry" form of AMD, known as geographic atrophy and the leading cause of vision loss among individuals age 65 and older, 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. 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.

Genetics/Genomics: The NEI has been at the forefront of genetics/genomics and gene therapy approaches to various vision disorders—both common and rare. The causes of AMD and glaucoma remain elusive—although most cases are not inherited, genetics does play a role. While NEI-funded researchers have identified many genetic risk factors for AMD and glaucoma, further study of these genes is helping to elucidate the biology of these disease and holds promise for improved therapies.

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.

Front-of-Eye Research: The NEI has launched an Anterior Segment Initiative (ASI) in order to capitalize on research opportunities at the front of the eye. The ASI is addressing clinically significant, quality-of-life problems such as ocular pain and Dry Eye Disease (DED), especially in terms of pain and discomfort sensations, as well as disruptions in the tearing process. Using multi-disciplinary approaches, the ASI plans to elucidate relevant anterior segment innervation pathways that contribute to normal or abnormal functioning of the neural circuits related to the ocular surface.

CONGRESS MUST ROBUSTLY FUND THE NEI AS IT ADDRESSES THE INCREASING BURDEN OF VISION IMPAIRMENT AND EYE DISEASE

NEI's FY2021 enacted budget of $835.7 million is less than 0.5 percent of the $177 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 $2.53 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/]

A May 2021 JAMA Ophthalmology article reported that more than 7 million people in the U.S. are living with uncorrectable vision loss, including more than 1 million with blindness. Of those living with vision loss and blindness, nearly 1 in 4 are under the age of 40, while 20 percent of all people aged 85 and older experience permanent vision loss. More females than males experience permanent vision loss or blindness, and the Hispanic and African American populations experience a higher risk of vision loss. This study's research methods allowed for a broader analysis of populations in the U.S. (including individuals under age 40) than that used in previous national estimates of vision loss and blindness. [doi:10.1001/jamaophthalmol.2021.0527]

In an August 2016 JAMA Ophthalmology article, AEVR reported from a national attitudinal survey 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. [doi:10.1001/jamaophthalmol.2016.2627]

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 supports the President's request for $51.95 billion in NIH funding but urges the Subcommittee to appropriate no less than $46.1 billion for NIH's base program level and $900 million for the NEI. NAEVR also supports one-time emergency "research recovery" investment to mitigate the pandemic-related disruptions without foregoing promising new science.

NAEVR thanks the Subcommittee for the opportunity to submit this written testimony, especially as it continues to grapple with the long-term challenges 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

Madam Chair and Members of the Subcommittee, I am pleased to present the views of the National Alliance for Public Charter Schools on the fiscal year (FY) 2022 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 $440 million for FY 2021. The CSP plays a critical role in expanding educational opportunities for families and in improving educational outcomes nationwide. As the Subcommittee considers the FY 2022 Labor, Health and Human Services, Education and Related Agencies appropriation, we request an increase in funding for the CSP to at least $500 million.

We support the Administration's proposed investments in programs that will benefit all public school students, including the Title I program and the Individuals with Disabilities Education Act. These increases, along with the other COVID relief funds, will help charter schools, like other public schools, address the many challenges they face after the pandemic-related shutdowns. At the same time, we were disappointed to see that the Administration's budget proposal called for flat funding of the CSP. The CSP is the only source of federal funding to support the growth of high-quality charter schools in the communities that need them most. Given charter schools' history of educating students with disadvantages in diverse situations, a $60 million increase for the CSP will deliver outsized returns.

THE OPERATION OF CHARTER SCHOOLS DURING THE PANDEMIC

The COVID–19 pandemic has been extremely challenging for charter schools, just as for all other public schools. Most had to pivot quickly from on-site instruction to distance learning, ensure that teachers had the skills and knowledge to deliver online instruction effectively, overcome disparities in student access to technology, and address many other challenges. Fortunately, charter schools are used to innovating and adapting to meet changing needs, and in this time of crisis they were able to leverage their autonomy effectively. A recent report released in partnership with Public Impact found that small charter networks and single-site charter schools (which together account for 65 percent of all charter schools) were more likely than district schools to set expectations that teachers would engage in real-time synchronous instruction, check in regularly with students, and monitor attendance. Parents have responded accordingly: an April 2021 survey of more than 2,700 parents nationwide found that 65 percent believe that choices like charter schools and learning pods would be "extremely or very effective" in helping students in their state. Parents want more opportunities for their kids, and charter schools are one critical way of providing them.

UNDERSTANDING CHARTER SCHOOLS AND THEIR ACCOMPLISHMENTS

In recent years, and notwithstanding charter schools' achievements and significant efforts to meet the needs of students during the pandemic, we have seen a number of misconceptions emerge about charter schools. To be clear, charter schools are public schools, supported by taxpayers, and open to all students, without entrance requirements. The CSP is the only federal K–12 program that requires its recipients to be open enrollment. Each State decides who may authorize charter schools and how schools will be held accountable for meeting the goals laid out in their charters. And charter schools, as public schools of choice, are ultimately accountable to parents: if a charter school is not delivering for families, it will not remain open. Moreover, while charter schools typically have more flexibility than district schools—such as to set curriculum, hire teachers and staff, and adapt to meet the needs of their students—they are required to meet the same academic testing and Title I accountability requirements as other public schools.

Most importantly, although there is some variety in charter school performance, in the main they are delivering. 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.

More recently, a 2020 study from the Program on Education Policy and Governance at Harvard University found greater academic gains for students in charter schools than for students in traditional public schools who took the reading and math assessments administered by the National Assessment of Educational Progress (NAEP) in fourth and eighth grade between 2005 and 2017. African Amer-

ican and low-income students attending charter schools were almost 6 months ahead of their peers in reading and math compared with students in traditional public schools over the 12-year span of the study. This was the first nationwide study to compare student achievement trends over time between sectors rather than effectiveness at a single point in time.

THE IMPORTANCE OF THE FEDERAL CHARTER SCHOOLS PROGRAM

First authorized in 1994 through the bipartisan efforts of President Bill Clinton and Congressional leaders, the CSP was originally created to support the start-up costs of new schools. Since then, the program has enjoyed strong support from Presidents and Members of Congress from both parties, and has expanded to address the changing needs of the movement.

Since its inception, Congress has appropriated some $6.3 billion for the CSP. To put that number in context, it amounts to less than 2 percent of the appropriation for ESEA Title I LEA Grants over that same time period. This modest investment has helped the number of charter schools grow from only a handful in the early 1990s to around 7,500 schools and campuses today that serve around 3.3 million public school students. CSP has made many of those schools possible by supporting non-sustained start-up costs not covered by per-pupil funding-such as 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. The majority of all charter schools, therefore, have needed CSP grants to open.

The CSP makes it possible for new charter schools to open to address changing community needs. One such school—Lumen High School in Spokane, WA—received a 2020 subgrant from the Washington State Charter Schools Association, a 2019 State Entity CSP grant recipient. Lumen is a dual-generational school designed to meet the layered need of teen parents. It offers childcare and early childhood education, incorporates parenting skills in the curriculum, and offers critical wrap-around services to eliminate barriers that might keep parenting teens from accessing education. When the COVID–19 pandemic struck, Lumen's founding Executive Director was offered the chance to delay opening for a year but chose to put the needs of her community first and open in the midst of the pandemic because, as she explained, "our students need school now." Increased CSP funding makes it possible for schools like Lumen to open in the communities that need them most.

Charter school enrollment has grown rapidly, but it has not kept up with family demand. Surveys indicate that some 3.3 to 3.5 million additional students would attend a charter school if space were available to them. Many of those are students who currently attend schools identified as in need of support and improvement under Title I, that is, schools that are not meeting State performance targets. The increase we recommend would enable the creation of charter schools to serve more of the students and families who want them.

FISCAL YEAR 2022 REQUEST

As previously noted, our request for FY 2022 is $500 million-a $60 million increase that would be a wise investment. Within the account, funds should be allocated to programs with floors and ceilings so that the Department can shift funds according to the needs of the field from one year to the next. $500 million would provide sufficient funding for new grants to States and CMOs and thus enable those entities to support the creation of new charter schools. This would reduce wait lists and provide high-quality educational options to more families, particularly those in communities that have been hit hard by the pandemic and where the learning needs are greatest. It will also help ensure funds are available for states that have recently strengthened their charter school laws, including Iowa, Wyoming, and West Virginia.

Finally, our request would help charter schools access appropriate facilities. Charter schools generally have not had the same access to funding sources that support the facilities needs of other public schools, such as municipal bonds, property tax revenues, and State school facilities programs. This forces schools to scrape by in buildings not designed for learning, use funds that should have been available for instruction to cover facility needs, or simply not open at all. The two small facilities programs included in the CSP—Credit Enhancement for Charter School Facilities and the State Facilities Incentive 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 charter schools over the last quarter century. Our schools' enrollments continue to climb, and more and more studies have found that charter schools are succeeding: they increase achievement and meet the other needs of a diverse and often historically underserved student population. This success could not have been achieved without the CSP. We ask that you continue that support and accept our recommendation for $500 million for FY 2022.

[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

Chairwoman Murray, Ranking Member Blunt and Members of the Subcommittee, on behalf of the National Alliance on Mental Illness, thank you for the federal investments in mental health crisis response that you have supported and made possible so far. I appreciate the opportunity to discuss NAMI's priorities, many of which we share, as evidenced by the hearing this Subcommittee held last week on building a robust crisis response system. Without personnel who are trained to handle mental health emergencies, and without the infrastructure in place, the default response to many people in crisis is a law enforcement response, which often ends in trauma or tragedy. In fact, one in four fatal police shootings are of people with mental illness, with one in three being people of color. The lack of effective crisis response also burdens emergency departments (EDs) that are ill-equipped for mental health crises, despite the fact that one of every eight ED visits is related to a mental health or substance use disorder. But as you said in your statement, Madame Chairwoman, there is something we can do about it. Thank you for your leadership.

NAMI is grateful that Congress passed the bipartisan National Suicide Hotline Designation Act of 2020, which created 988 as a three-digit mental health and suicide crisis line that will go live nationwide by July 16, 2022. This alternative to 911 gives communities the opportunity to transform care by developing 988 crisis response systems with the core elements described in SAMHSA's National Guidelines for Crisis Care: 1) crisis call centers, 2) mobile crisis teams, and 3) crisis receiving and stabilization programs. Crisis call center hubs, staffed by people well-trained in crisis response, can assist the vast majority of people calling with a behavioral health crisis. For those who need more, mobile crisis teams provide an in-person response and are able to effectively de-escalate the majority of behavioral health crises and connect people to follow-up services. In situations where needs are more acute, crisis receiving and stabilization services provide safe, therapeutic settings that reduce reliance on ED visits and can avoid the need for hospitalization.

While there is a clear vision for successful 988 crisis response systems, few systems meet the standards needed to realize this vision. Currently, National Suicide Prevention Lifeline (Lifeline) call centers rely on a patchwork of inadequate funding, leaving insufficient capacity to meet current needs, let alone the increased demand that will be spurred by the adoption of 988. There is growing availability of mobile crisis teams, but demand still far outstrips supply, particularly for children and adolescents. There is a dearth of crisis stabilization programs nationwide, and widespread shortages of behavioral health professionals to staff crisis response systems.

Robust federal investment is required to realize the promise of 988 to deliver a mental health response to mental health crises. Some states are adopting 988 user fees, but those fees are minimal and will support only a portion of 988 crisis system costs. Medicaid rarely covers the full costs of the core services—and it does not cover services for people who are not Medicaid-eligible. Without federal support, communities will be unable to develop and sustain a crisis infrastructure that ensures a mental health response will be available for mental health crises.

To help communities develop capacity for the critical first element of a 988 crisis system, crisis call center response, NAMI strongly recommends including $240 million in FY2022 for the National Suicide Prevention Lifeline. This recommendation is based on an initial analysis from Vibrant Emotional Health, the current administrator of the Lifeline. This will provide needed funding to expand capacity for 988 calls, chats, and texts, including implementing technology, enhancing standards and training, and providing nationwide back-up for local call centers.

In FY2021, this Subcommittee included an additional $35 million in the Mental Health Block Grant to fund a 5% set-aside for Crisis Care Services. While this was a valuable start and we are grateful for this investment that is helping states develop crisis services, especially mobile crisis teams, the need is substantial. That is

why NAMI is requesting a 10% set-aside for crisis services in FY2022 to provide critical funds to both start up crisis services and to support the many costs of crisis care that are not covered by Medicaid or insurance plans.

NAMI is also requesting $12.5 million for the SAMHSA Strengthening Community Crisis Response Systems program. When someone experiences a mental health crisis, they often wind up in hospital emergency departments (EDs) where they frequently end up waiting in hallways, sometimes for days, before being admitted to an inpatient or residential facility. This practice, referred to as "ED boarding," is harmful to patients and strains already-burdened EDs. The $12.5 million we are requesting will help communities reduce the traumatic practice of ED boarding by providing intensive crisis services, such as crisis receiving and stabilization programs, and by implementing databases of beds at inpatient and residential behavioral health facilities that help reduce the wait for intensive treatment.

These three programs, while important, are only part of realizing the promise of a successful crisis response system. And while some of the needed investments fall outside this Subcommittee's jurisdiction, I believe it is important to give you the full picture of what is required to effectively implement a comprehensive 988 crisis response system over the next several years.

Whether through the annual appropriations process, broader efforts to upgrade our country's infrastructure, or other means, Congress must invest $10 billion over the next 10 years in 988 infrastructure in three key areas: 1) Supporting capital projects and operations, 2) Increasing the behavioral health workforce, and 3) Ensuring Medicare, Medicaid, and TRICARE coverage. I would like to give you a quick overview of what is needed in each area.

First, supporting 988 capital projects and operations. To build a mental health crisis system that relies on well-equipped 988 call centers as the first point of contact, federal support of the national Lifeline should be supplemented by federal authorization and funding, based on SAMHSA's projections, to support operations at 180+ local Lifeline call centers across the country. This will ensure that people get connected to services when and where they need them.

In addition, communities need support for capital expenses to expand crisis services, such as mobile crisis team vans, facilities for crisis receiving and stabilization and peer respite programs, and call center infrastructure. Congress should expand funding and broaden the uses of the Health Resources and Services Administration's (HRSA) current Capital Development Grants to include crisis system infrastructure.

Second, increasing the behavioral health workforce. As the Subcommittee knows, behavioral health workforce shortages pose challenges for health systems, including crisis response. Congress can help by significantly expanding behavioral health workforce training programs, including HRSA's Behavioral Health Workforce Education and Training (BHWET) and Graduate Psychology Education (GPE) programs, as well as SAMHSA's Minority Fellowship Program (MFP). In addition, to help recruit and retain skilled staff, HRSA's National Health Service Corps Loan Repayment Program criteria must be expanded to include crisis call centers, mobile crisis teams, crisis receiving and stabilization programs, and Certified Community Behavioral Health Clinics.

Third, ensuring Medicare, Medicaid, and TRICARE coverage of crisis services. It is also vital that Medicare, Medicaid, and TRICARE cover mobile crisis and crisis stabilization services. Together, these programs cover tens of millions of people, many of whom will experience mental health and suicidal crises and deserve an appropriate response. Peer support specialists in particular play critical roles in crisis services yet are not covered providers under Medicare. That must change. Finally, to maximize access to behavioral health crisis services, Congress should make permanent the current flexibilities for Medicare coverage of telehealth behavioral health services.

It is NAMI's priority to ensure that an effective 988 crisis response system infrastructure is developed across the country and we are grateful for this Subcommittee's support. We recognize that it is also important to invest in research and a wide range of prevention, intervention, and recovery programs at SAMHSA, including Certified Community Behavioral Health Clinics, that help people get on a path of recovery. To that end, we urge your consideration of the Mental Health Liaison Group (MHLG) recommendations for FY2022 appropriations. NAMI also offers our strong support for the President's FY2022 proposed budget of $1.6 billion for the community mental health block grant and $1 billion to increase mental health professionals in schools.

Thank you for this opportunity and for the leadership you have demonstrated in advancing mental health care. I look forward to working with you to put in place the infrastructure to support a 988 crisis response system and transforming mental health care in America.

[This statement was submitted by Angela Kimball, National Director of Advocacy & Public Policy, National Alliance on Mental Illness.]

PREPARED STATEMENT OF THE NATIONAL ALLIANCE TO END SEXUAL VIOLENCE

The National Alliance to End Sexual Violence (NAESV) is the voice in Washington for the 56 state and territorial sexual assault coalitions and 1500 local programs working to end sexual violence and support survivors. The programs included in the Violence Against Women Act (VAWA) are a vital part of local programs' work to support survivors and end sexual violence. This testimony focuses specifically on the Rape Prevention & Education Program (RPE), a VAWA program located at the Centers for Disease Control, Injury Center, and the need to increase funding for the program from $51.75 million to $100 million in FY 22 as recommended by the President's budget and include report language requiring the collaboration with state sexual assault coalitions in the program. We are grateful to the committee for the $1 million increase for RPE in FY 21, however, increased funding is desperately needed.

RPE formula grants, administered by the CDC Injury Center, provide essential funding to states and territories to support rape prevention and education programs conducted by rape crisis centers, state sexual assault coalitions, and other public and private nonprofit entities. In the past few years, demand for programs funded by RPE have skyrocketed, the evidence base has progressed significantly, the current appropriation is very nearly the authorized level, and further investment in the program is desperately needed. The #MeToo movement, the national focus on campus sexual assault, and high-profile cases of sexual violence in the media have increased the need for comprehensive community responses to sexual violence but have also increased the demand for prevention programs beyond providers' capacity.

According to the National Intimate Partner and Sexual Violence Survey (CDC, 2015 national data):

—21% of women and 3% of men reported completed or attempted rape ever in their lifetime.

—Among victims of rape, 43% (11 million) of females and 51% (1.5 million) of males reported it occurred for the first time between the ages of 11–17.

If our children are to face a future free from sexual violence, RPE must be increased. The RPE program prepares everyday people to become heroes, getting involved in the fight against sexual violence and creating safer communities by engaging boys and men as partners; supporting multidisciplinary research collaborations; fostering cross-cultural approaches to prevention; and promoting healthy, non-violent social norms, attitudes, beliefs, policies, and practices.

We know RPE is working.

A 2016 study conducted in 26 Kentucky high schools over 5 years and published in American Journal of Preventive Medicine found that an RPE-funded bystander intervention program decreased not only sexual violence perpetration but also other forms of interpersonal violence and victimization.

"The idea that, due to the effectiveness of Green Dot, ... there will be many fewer young people suffering the pain and devastation of sexual violence: This is priceless." Eileen Recktenwald, Kentucky Association of Sexual Assault Programs

Across the country, states and communities are engaged in cutting-edge prevention projects:

—Connecticut's Women & Families Center developed a multi-session curriculum addressing issues of violence and injury targeting middle school youth.

—Oklahoma is working with domestic violence and sexual violence service agencies, public and private schools, colleges and other community-based organizations to prevent sexual violence.

—Alaska's Talk Now Talk Often campaign is a statewide effort developed in collaboration with Alaskan parents, using conversation cards, to help increase conversations with teens about the importance of having healthy relationships.

—Kansas is looking closely at the links between sexual violence and chronic disease to prevent both.

—Maryland's Gate Keepers for Kids program provides training to youth-serving organizations to safeguard against child sexual abuse.

—Missouri is implementing "Green Dot" bystander education statewide to reduce the rates of sexual violence victimization and perpetration.

—North Carolina was able to ensure sustainability of its consent-based curriculum by partnering with the public-school system to implement their sexual violence prevention curriculum in every 8th grade class.

—Washington is implementing innovative skill building projects that amplify the voices of historically marginalized communities, such as LGBTQ youth, teens with developmental disabilities, Asian American & Pacific Islander teens, & Latino parents & children.

Why increase funding for RPE?

The societal costs of sexual violence are incredibly high including medical & mental health care, law enforcement response, & lost productivity. 2017 research sets the lifetime economic burden of rape at $122 million per victim and also reveals a strong link between sexual violence and chronic disease.

The national focus on campus and military sexual assault as well as high profile cases of sexual violence in the media have increased the need for comprehensive community responses to sexual violence but has also increased the demand for prevention programs beyond providers' capacity.

A Missouri program reported: "The demand for our services has increased about 18% both in 2014 and in 2015. Increased awareness and increased need (crime) are most likely contributors to this trend. There are limited resources available for prevention education. In addition, new government requirements/laws, such as with Title IX and PREA, have contributed to referrals to our organization. Our organization always works to increase support from local resources, but funding is extremely competitive and limited."

A Massachusetts program reported: "With Title IX in the news, requests for prevention education have increased...We are saying no to many requests for education because of capacity issues. We are unable to build and sustain relationships with other underserved communities because of a lack of capacity."

A Nebraska program reported: "I am hugely dismayed at the lack of funding for prevention...It's noble to provide direct services to victims of sexual violence, but if we don't provide prevention monies, then we are just a band-aid. It's terribly frustrating."

Funded involvement of state sexual assault coalitions is imperative for the success of RPE.

RPE was first authorized in the original 1994 version of the Violence Against Women Act (VAWA) and has been reauthorized subsequently with each iteration of VAWA. RPE was the brainchild of National Alliance to End Sexual Violence (NAESV) founder, Gail Burns-Smith, as a coordinated federal response to the prevention of sexual violence. While funding goes to state health departments, the original intent of the RPE program was to fully involve state sexual assault coalitions and rape crisis centers as leaders in this work because of their vast experience in addressing sexual violence. Over the years, the level of involvement of state coalitions has varied between states and has ebbed and flowed. At the same time, there are states in which the state sexual assault coalition has never been meaningfully involved in RPE.

During 2019, NAESV met with state sexual assault coalitions and conducted two membership surveys. While some state coalitions continue to have good and strong working relationships with their state health departments and feel positively about how RPE is being administered, based on our research, over half of the state sexual assault coalitions are dissatisfied or very dissatisfied with how RPE is being administered. This past year, there have been changes in some states that have resulted in both concerns about state approaches to RPE and elimination of some state sexual assault coalitions involvement in RPE-funded prevention work. Our research also found that:

1. One in four coalitions expressed a concern about lack of sexual violence expertise in the administration of RPE at the state level.
2. 30% of coalitions have concerns about lack of collaboration and leadership.
3. Over 60% of coalitions thought there was too little involvement of community based sexual assault programs in the work of RPE.

NAESV has concluded, with the complete consensus of state sexual assault coalitions, that enough states are having a problem to warrant a legislative solution. Communities deserve the best, most well-informed prevention efforts especially in this era where demand and interest in sexual violence prevention is so high. We know, with the funded involvement of state sexual assault coalitions and increased funding, RPE can be an even more powerful tool in ending sexual violence. The field looked to other successful national formula grants designed to address violence against women as a guide in developing a legislative proposal. The STOP and Sexual Assault Services (SASP) Programs at the Department of Justice Office on Violence Against Women (OVW), designed to provide a criminal justice and survivor services response respectively, both include language to require meaningful collabo-

ration as well as funding to state sexual assault coalitions. We suggest following the success of these grant programs to also ensure the meaningful, funded involvement of state sexual assault coalitions in the prevention of sexual violence.

We recommend the following report language:

"The Committee believes significant involvement of state sexual assault coalitions and underserved communities is critical to ensure rape prevention education dollars are spent on the most impactful programs. So in granting funds to states, the Director of the National Center for Injury Prevention and Control shall set forth procedures designed to ensure meaningful involvement of the State or territorial sexual assault coalitions and representatives from underserved communities in the application for and implementation of funding."

Funding History: In the 2013 reauthorization of Violence Against Women Act, Congress cut authorization for RPE from $80 to $50 million. In FY 17, the program was funded at $44.4 million, a $5 million increase from FY 16. In FY 18 & FY 10, RPE was funded in the omnibus at $49.4 million. In FY 20, RPE was funded at $50.75 million. In FY 21, RPE was funded at $51.75 million.

Please increase funding for RPE to $100 million and include report language requiring the funded collaboration of state sexual assault coalitions in the RPE program.

Please feel free to contact me with any additional questions at terri@endsexualviolence.org.

[This statement was submitted by Terri Poore, Policy Director, National Alliance to End Sexual Violence.]

PREPARED STATEMENT OF THE NATIONAL ALOPECIA AREATA FOUNDATION

THE FOUNDATION'S FISCAL YEAR 2022 L–HHS APPROPRIATIONS RECOMMENDATIONS

—At least $46.1 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)

—Please provide $10 billion for the Centers for Disease Control and Prevention (CDC).

—Please provide $5 million for the Chronic Disease Education and Awareness Program.

Chairwoman Murray, Ranking Member 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 FY2022 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 6.9 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 6.9 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

"There is a chance you could lose all your hair." That was the last thing anyone ever wants to hear. I will never forget standing in the shower in November 2015 with my hands full of hair and in complete disbelief. Was this really happening to me? I felt as though my identity was being ripped away from me as every strand of hair fell out of my head. My hair was my identity. Who would I be without it? How was I going to live like this for the rest of my life?

I lost all of my hair on my entire body including eyebrows and eyelashes within four weeks and I was diagnosed with the autoimmune disease called alopecia areata. For the next year, I did everything in my power to grow my hair back from every topical cream to medicines that compromised my immune system to weekly steroid injections into my scalp. This was the worst pain I had ever experienced in my life but I would do anything to grow my hair back.

Nothing was working. I had to stop as my mind, body, and soul couldn't take it anymore.

I don't know what was worse, the treatments or the stares I would receive out in public as everyone thought I was going through treatment for cancer. I wanted to blend in with society so badly, but wigs were so expensive. I refused to look at myself in the mirror because I hated the reflection. I wore a hat everywhere I went even to bed until the lights were turned off to take it off and I wouldn't take any pictures, especially during the holidays because I was ashamed of my appearance. I wanted my life back so I could be a good mom to my daughters and just enjoy life. Alopecia areata is not just cosmetic, it takes an emotional toll as it caused severe anxiety and depression that I continue to deal with years later. I was very fortunate to have the unconditional support of my parents who helped me to purchase wigs so I could feel somewhat normal again; however, there are too many people with alopecia areata who do not have the luxury of support that I was blessed with. Your support would impact people's lives immensely.

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 Jeanne Rappoport, Acting Chief Executive Officer, National Alopecia Areata.] Foundation.]

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION FOR STATE COMMUNITY SERVICES PROGRAMS

As Board President 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 2022 appropriation level of $800 million for CSBG and an increase in client eligibility to 200% of the Federal Poverty Level. The current 200% eligibility established under the Coronavirus Aid, Relief, and Economic Security (CARES) Act will expire at the end of Fiscal Year 2021, creating a steep drop-off of services for many vulnerable families during a critical time of recovery. These funding and eligibility levels will empower States and local communities with the resources they need to lead the fight against poverty through innovative, effective, and locally tailored anti-poverty programs that help individuals, families, and communities achieve economic security.

NASCSP is the member organization representing the State CSBG Directors in all 50 states, the District of Columbia, and three U.S. territories on issues related to CSBG and economic opportunity. NASCSP provides training and technical assistance to empower State Offices in implementing program management best practices and in developing 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 supplemental funding through the CARES Act and the increase to CSBG in the FY 2021 Labor-HHS Bill.

CSBG is a model example of a successful Federal-State-Local partnership, a fact I can personally attest to having worked for more than 15 years in the Arkansas State CSBG office. I worked closely with the local Community Action Agencies and with federal OCS and ACF staff. The CSBG network leverages federal and non-federal funds to support a range of essential services and activities that improve the lives and communities of Americans. These activities are incredibly important to vulnerable individuals and families, especially during times of crisis. CSBG is in every state and county, from the most urban counties to the most rural ones, where CSBG furthers the critical goals of economic security, social mobility, and racial justice. I will highlight three main points in my testimony:

1. The structure of CSBG empowers States and local communities to take the lead on poverty, giving States wide discretion to tailor funding to their unique economic and social conditions.
2. CSBG creates impact in communities across the country by leveraging additional private, local, state, and federal investments to fight poverty, serving as the national human services infrastructure by weaving together and coordinating private and public antipoverty efforts.
3. The robust local, state, and federal accountability measures of the CSBG Performance Management Framework are uniquely comprehensive when compared to other federal programs, preventing service duplication and fostering continuous improvement.

Structure

Proponents of state and local anti-poverty efforts often highlight their ability to tailor services, asserting that state and local leaders are best equipped to tackle the challenges facing their communities. CSBG is a block grant administered and managed by states, who administer and distribute funds to a nationwide network of more than 1,000 local CSBG Eligible Entities, also known as Community Action Agencies or CAAs. The CSBG network forms the bedrock of the human services infrastructure that uplifts urban, rural, and suburban communities across the United States. In some rural counties, the CAA is the only human services organization addressing poverty and uplifting low-income families in the community.

State offices distribute funds to Community Action Agencies, who utilize CSBG funds to address their specific local needs, often in one or more of these core domains: 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 requires that these services

are shaped by a community needs assessment performed at least every three years, ensuring programs are tailored and responsive to unique community needs, rather than a one-size-fits-all solution. The needs assessment prevents service 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 and viewpoints are accurately reflected in organizational priorities. In addition to low-income representation, Community Action boards are also comprised of local elected officials or their representatives and community stakeholders including local businesses, other assistance organizations, professional groups, and community organizations. This unique tripartite structure assures the needs of a community are identified and met with the available resources necessary to maximize outcomes and impact. The tripartite structure of Community Action boards calls on all sectors of society to join in the shared fight against poverty.

State Offices are charged with providing the oversight and support necessary for effective administration of CSBG at the local and state levels. States provide training and technical assistance to build the capacity of local CAAs; ensure compliance with federal and state requirements; and serve as important partners in the development of statewide linkages and coordination to combat state causes and conditions of poverty. The structure of CSBG empowers states and locals to work collaboratively, maximizing impact for America's communities.

Impact

CSBG is a positive federal investment in a national system to address poverty that produces concrete results. Federal CSBG dollars are used to build, coordinate, support, and strengthen anti-poverty infrastructure across our communities. In Fiscal Year 2018,[1] for every $1 of CSBG, CAAs leveraged $8.27 from non-federal sources. Leveraging funds allowed CAAs to expand highly successful and impactful programs. Including all federal sources, non-federal sources, and volunteer hours valued at the federal minimum wage, the CSBG Network leveraged $21.97 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 for low-income families and their communities. The CSBG network served more than 10.2 million people with low incomes in Fiscal Year 2018. A robust appropriation will expand impact and foster innovation within the network Below is a snapshot of some quantitative impacts of CSBG:

—915,230 households improved their energy efficiency and/or energy burden in their homes.
—594,718 low-income seniors (65+) achieved or maintained an independent living situation.
—253,422 children and youth who are achieving at a basic grade level (academic, social and other school success skills.
—78,713 adults who improved their education levels.
—55,684 unemployed adults who obtained employment up to a living wage.
—18,090 unemployed adults who obtained employment with a living wage or higher.

Looking beyond the data, we see that the CSBG Network is delivering innovative, comprehensive, and effective programs across the country that uplift individuals, families, and their communities:

—*Disaster Response and Recovery in Oregon:* In September of 2020, Oregon residents in Douglas and Josephine counties already experiencing a surge in COVID–19 cases were faced with the additional threat of unprecedented wildfires. Evacuating families struggled to find adequate shelter and consistent access to food as the fires raged across multiple impacted counties. Already familiar with serving local low-income communities, the United Community Action Network (UCAN) immediately began providing disaster relief. UCAN partnered with FEMA, local public health departments, and emergency response centers to help homeless or unsheltered individuals and families find safety. Unable to cook while evacuating, families utilizing food assistance relied on expensive prepared meals which quickly drained their resources. Despite the extreme circumstances, UCAN continued to provide food, hygiene products, and social services wherever space was available, including parking lots and outside gas stations. While the wildfires stoked confusion and separated families, UCAN connected those who were displaced and supplied cellphones so those affected could contact loved ones. UCAN was instrumental in organizing the

[1] FY 2018 data is the latest publicly available from the Office of Community Services (OCS) within the Department of Health and Human Services (HHS).

emergency response, providing critical resources, and reconnecting those separated by disaster.

—*Vaccination Coordination & Education in Wisconsin:* In coordination with Wisconsin's Vaccination Task Force, the Wisconsin Department of Children and Families and the Wisconsin Community Action Program Association (WISCAP) are training case managers to help Wisconsin residents to navigate the COVID–19 vaccination process. Trainings cover vaccine scheduling through the 2–1–1 Wisconsin phone service, a framework for discussing vaccine confidence, and a review of wrap-around services available to compliment vaccination. Through this coordination, Wisconsin is leveraging the 2–1–1 service as a referral source for hyper-local, trusted community member-driven vaccination education. Wisconsin's CSBG network also applied for a COVID–19 Outreach Grant to better assist BIPOC and rural, low-income people with vaccine hesitance or barriers to access like transportation. This coordinated effort helped all programs leverage vaccine rollout funding to create a broader reach within local communities, increase access to vaccines, and ultimately save lives.

—*Flexible & Bundled Services in Michigan:* Michigan's Bureau of Community Action and Economic Opportunity (BCAEO) began organized discussions around new services as soon as the CARES Act was first introduced. Working regionally with local CAAs as well as with Governor Whitmer's taskforce, BCAEO developed contracts and procedures to expand services as soon as CARES funding was available. Expanding their nutrition programs, local agencies created online grocery stores so families with medical, religious, or cultural dietary restrictions could choose foods for delivery. CAAs also delivered quarantine-boxes, packages of food and hygiene supplies that allowed residents to shelter in place before making long-term preparations. Agencies partnered with struggling local farmers to provide fresh produce while also fully retaining their staff during lockdowns by moving them to food warehouse & delivery positions. At the same time, Michigan CAAs utilized supplemental funding to provide more than 2,200 people with internet-connected devices to access remote education, employment opportunities, telehealth, and other critical online resources.

Accountability

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, CSBG state offices gather and document outcomes for the CSBG Annual Report. Within this reporting mechanism, National Performance Indicators are used across the network to track and manage progress, empowering CAAs have the data they need to improve services and innovate delivery. The ROMA system engages 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 continuously high-quality delivery of programs and services.

In closing, we ask the committee to fund CSBG at no less than $800 million for FY 2022 and to increase client eligibility to 200% of the Federal Poverty Level, ensuring that this nationwide network with a nearly 60-year record of success continues to positively impact the lives of vulnerable Americans. The structure of CSBG empowers States and local agencies to address poverty in their communities, while prioritizing the voices of people with low incomes in determining solutions. CSBG is committed to the comprehensive accountability mechanisms of the Performance Management Framework, ensuring effective and responsible stewardship of funds at the Federal, State, and local level. CSBG is producing tangible results, serving millions of vulnerable Americans each year and empowering communities, families, and individuals to achieve economic security, social mobility, and racial justice. NASCSP looks forward to working with Committee members to ensure CSBG continues to help families achieve these outcomes, strengthening our communities and providing our most vulnerable neighbors with security, dignity, and justice. Thank you.

Respectfully submitted.

[This statement was submitted by Beverly Buchanan, Board President, National Association for State Community Services Programs.]

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF COUNCILS ON DEVELOPMENTAL DISABILITIES

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 $89 million, the level included in the President's FY22 budget request, for the DD Councils within the Administration for Community Living (ACL) in the Labor-HHS-Education appropriations bill for Fiscal Year (FY) 2022. We also respectfully request that the following report language be included in the Fiscal Year 2022 Labor, Health and Human Services, Education Appropriations bill:

> *Technical Assistance*.—The Committee provides not less than $700,000 for technical assistance and training for the State Councils on Developmental Disabilities. Such technical assistance should be provided by an organization with long-standing experience providing technical assistance to the national network of state developmental disabilities councils or similar Developmental Assistance and Bill of Rights Act national programs. In addition, the agreement encourages ACL to consult with the appropriate Developmental Disabilities Act stakeholders prior to announcing opportunities for new technical assistance projects and to notify the Committees prior to releasing new funding opportunity announcements, grants, or contract awards with technical assistance funding.

Funding for the DD Councils has obtained broad bicameral support from members of Congress. This funding request also has broad support from the disability community. The Consortium for Citizens with Disabilities, the largest coalition of national organizations working together to advocate for people with disabilities, submitted a support letter to this committee dated April 26, 2021.

Authorized by the Developmental Disabilities Assistance and Bill of Rights Act (DD Act), DD Councils work collaboratively with the University Centers for Excellence in Developmental Disabilities, and the Protection and Advocacy program for Developmental Disabilities, 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] Appointed by Governors, and consisting of at least 60 percent of people with DD and their families, DD Councils assess problems or gaps in the I/DD system and design innovative solutions that make real changes to social systems such as employment, transportation, education, healthcare, housing and more, to fully integrate people with I/DD into society.

The request for an increase in funding for FY2022 is informed by the tragedy and lessons learned from last year's COVID–19 pandemic and the spotlight it placed on circumstances of everyday living for people living with intellectual or developmental disabilities (I/DD) that present obstacles. For decades since the passage of the DD Act and later the Americans with Disabilities Act, the whispered concerns about the dangers of living with I/DD in isolation and stripped of critical supports were realized when the pandemic hit. Several studies showed a link between having an I/DD and a greater risk of contracting and dying from COVID–19, with one study finding having an intellectual disability was the strongest independent risk factor for presenting with a Covid–19 diagnosis and the strongest independent risk factor other than age for Covid–19 mortality. The Centers for Disease Control and Prevention identified social factors which increased the risk of COVID–19 transmission including: relying on direct support workers and families, difficulties understanding information and preventative measures, and difficulty communicating symptoms of the illness. The circumstances of simply living with I/DD means that people are struggling to simply live, not only during pandemics but every day of their lives. For example, it is true that relying on direct support workers and families is an obstacle to surviving COVID, but it is also an obstacle to obtaining employment, accessing transportation, and most activities people without disabilities take for granted.

The DD Councils support innovative programs to promote self-determination and create systemic pathways to independent living to keep people with I/DD safe during public health emergencies and to help them live their fullest lives in the community long after the pandemic. DD Councils direct resources through partnerships with local non-profits, businesses, and state and local governments, to overcome obstacles to community living for people with I/DD. States and territories rely on DD Councils to turn fragmented approaches into innovative and cost-effective strategies

[1] 42 U.S.C. 15001(b).

to increase the percentage of individuals with I/DD who become independent, self-sufficient and integrated into the community. Examples of DD Council projects include: partnerships to increase competitive and integrated employment, campaigns promoting access to qualified direct support workers, programs for successfully transitioning to independent living, advocacy for access to affordable housing, training to 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 emerging issues. Every DD Council pivoted during COVID–19 to meet immediate and critical needs. For example, in response to the hardship that COVID–19 has placed on people's ability to stay connected and engaged, the Washington State Developmental Disability Council invested in grants including: providing laptops and prepaid data cards for internet access for those without technology; promoting healthy living during COVID; and combating social isolation. At the same time, their longer-term plans were implemented. For example, as part of their five-year plan, the Missouri Developmental Disabilities Council identified affordable and accessible housing is an essential need for people with I/DD. The council supported community initiatives that resulted in persons with developmental disabilities having opportunities for housing including the Missouri Inclusive Housing Development Corporation (MoHousing).

Thank you for consideration of our request.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF DRUG COURT PROFESSIONALS

Chairwoman Murray, Ranking Member Blunt, and distinguished members of the subcommittee, I am honored to have the opportunity to submit my testimony on behalf of this nation's nearly 4,000 treatment court programs and the 150,000 people the programs will connect to lifesaving addiction and mental health treatment this year alone. Given the overlapping crises of substance use and the COVID–19 pandemic, I am requesting that Congress provide funding of $105 million for the Drug Treatment Court Program at the Department of Health and Human Services, Substance Abuse and Mental Health Services Administration for fiscal year 2022.

I serve as a superior court judge in Lewis County, Washington, where, for the entirety of my tenure as judge, I have presided over our county's treatment court programs, including drug courts. I have never participated in a more effective approach to promoting public health while also remaining steadfast to the promise of the justice system to protect public safety. Strong empirical evidence shows time after time that treatment courts not only reduce crime, but also save lives and families by connecting participants to evidence-based treatment services and recovery support.

Participants like Brant. Before coming to our program, he spent much of his life cycling in and out of the justice system because of an addiction that began in his early twenties. By the time he came to our program, he had been to jail seven times, with more on the horizon unless something changed. Our treatment court program provided the accountability and treatment that Brant needed to change.

In our program, Brant, like the rest of our participants, was assessed and given an individualized treatment plan designed by substance use treatment professionals using evidence-based methods, including medication-assisted treatment where appropriate. Together, in concert with the multidisciplinary treatment court team who ensured Brant received the services and accountability he needed to succeed, we set a goal of recovery for him, not another costly and ineffective stint behind bars.

Today, Brant is not only living that goal, he's doing what he can to help others achieve the same. He works for an organization that conducts outreach to vulnerable populations with substance use disorders and helps them get their lives back on track, with a special focus on homeless veterans. He also serves as the president of the nonprofit organization that helps support the Lewis County Drug Court, ensuring the lifesaving work of our program continues well into the future.

I have worked in treatment courts since 2004, when I helped launch Lewis County's adult drug court as chief criminal deputy in the prosecutor's office. Subsequently, as the chief criminal deputy of neighboring Thurston County, I supervised our adult drug court, mental health court, and veterans court units. Since then, I have watched many of the most helpless individuals in our justice system overcome their substance use or mental health disorder, regained their lives, and became productive citizens. Most go on to raise families, begin growing careers, and help others

in the similar difficult positions they once found themselves in. Without hesitation, I credit the treatment court model for the health and safety of these individuals.

Lewis County is a rural, relatively quiet part of southwestern Washington. But we are not immune from the grips of the twin crises currently gripping the nation from coast to coast: the substance use epidemic and the ongoing effects of COVID–19, including isolation and economic devastation. Treatment courts, such as adult drug courts, veterans treatment courts, family treatment courts, and others, offer a public health and public safety response to these crises by expanding and enhancing substance use treatment capacity to serve more individuals in their communities.

With overwhelming empirical evidence showing their effectiveness, it is easy to see that treatment court programs across the country merit continued funding. The Government Accountability Office finds the drug court model reduces crime by up to 58%. Further, the Multi-Site Adult Drug Court Evaluation conducted by the Department of Justice confirmed drug treatment courts significantly reduce both drug use and crime, as well as finding a cost savings averaging $6,000 for every individual served. Additional benefits include improved employment, housing, financial stability, and reduced foster care placements.

Brant is not alone in his success. Treatment courts in this country have connected 1.5 million people who have lifesaving mental health and substance use disorders with treatment options best suited to them. Together, the court team offers the tools to overcome substance use disorder and past trauma to create meaningful, healthy relationships.

Continued support from the Drug Treatment Court Program at the Department of Health and Human Services ensures the nearly 4,000 treatment courts in the United States today provide critical treatment services to save lives and reunite families. But we know there are many more who still need this opportunity. I strongly urge this committee to recommend funding of $105 million to the Drug Treatment Court Program in fiscal year 2022, so treatment courts in Washington and beyond can continue providing lifesaving substance use treatment services.

[This statement was submitted by Hon. Andrew Toynbee, Judge, Superior Court of Lewis County, Washington, Chehalis, Washington.]

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF EMERGENCY MEDICAL TECHNICIANS

Thank you, Chairwoman Murray, Ranking Member Blunt, and distinguished members of the Subcommittee. My name is Bruce Evans, and I am the President of the National Association of Emergency Medical Technicians (NAEMT). I am also a fire chief leading a fire-based EMS organization in a super rural area of Southwest Colorado—12,000 residents in 264 square miles.

Founded in 1975 and over 70,000 members strong, NAEMT represents our nation's frontline EMS practitioners, who provide critical, lifesaving services to communities nationwide, especially in rural, frontier, and other hard-to-reach areas. On behalf of our organization, thank you for your ongoing support of EMS professionals. NAEMT would like to offer our views on the Subcommittee's FY 2022 bill. At the outset, we write to ask the subcommittee to provide robust funding for the SIREN Rural EMS Equipment and Training Assistance (REMSTEA) program within the Department of Health and Human Services' (HHS) Substance Abuse and Mental Health Services Administration (SAMHSA).

This testimony is submitted just a few weeks after the 46th Annual EMS Week, which occurred from May 16—May 22, 2021. The goal of EMS Week is to thank paramedics, EMTs, and the entire EMS workforce for their services and sacrifices. However, EMS professionals do not just want a pat on the back—like the rest of our members, I am writing to continue to raise public awareness about the critical funding shortfall of EMS in the communities we serve. This urgent request aligns with the spirit of EMS Week.

Passed in the 2018 Farm Bill, the SIREN/REMSTEA grant program supports rural public and nonprofit EMS agencies in their efforts to complete their mandate to provide critical emergency medical care to all of the residents in the communities they serve. The grants help rural EMS agencies train and retain staff and purchase equipment, among filling other needs. Community demands keep growing: each year, fire departments and EMS agencies respond to more than 20 million calls for emergency services. While the COVID–19 pandemic exacerbated the plight of these agencies, EMS practitioners and agencies were facing severe challenges before the virus' outbreak. This can be attributed, in part, to greater distances between health care facilities and low reimbursement rates. The most pressing impact is the decline

of available medical care in rural communities, which has heightened the need for already-stretched EMS agencies to perform these lifesaving services. Again, this foreboding and bleak landscape existed even before the onset of the pandemic, which has strained the social safety net that EMS professionals provide.

COVID–19 made an already growing problem much worse. In FY2020 and FY2021, your Committee provided $5 million and $5.5 million for SIREN grants, respectively. However, the program requires a substantial increase in funds to make sure our personnel have the equipment and training they need. Social distancing and "stay-at-home" protocols because of the pandemic complicated income streams for these agencies. Many rural EMS agencies rely heavily on community fundraising efforts, such as bingo, raffles, and community barbeques. At the same time, support from localities whose tax revenue base has dramatically declined, further hindering EMS agencies' ability to fill their coffers. Beyond smaller revenue streams, costs have gone up, especially as EMS agencies have been paying higher prices for personal protection equipment (PPE) throughout the pandemic.

Rural EMS organizations, like mine in Colorado, have disproportionately suffered from shrinking revenue streams and increased demand before the pandemic and now, especially as it relates to synthetic opioid overdoses, which have skyrocketed and do not seem to be slowing down. Ambulance crews that support the most far-flung areas of our country are running out of money and personnel. Because of the especially demanding work that rural EMS organizations shoulder, they are struggling to stay afloat at a much higher rate than their more urban counterparts. This challenge is not limited to one region of the country; rather, rural EMS organizations across the board are more likely to shut their doors, leaving their residents without reliable access to local ambulance service. Ultimately, without the support this grant program provides, many more local EMS operations will likely have to close their doors.

The result is, unfortunately, predictable: increasing workforce shortages as EMS personnel become increasingly burnt out, face shrinking compensation, and are constantly exposed to unpredictable and dangerous environments. In short, more money is needed to bring more people aboard to ensure that our professionals are provided a safe, healthy, and respectful work environment, and that their EMS agency can effectively serve their communities. The enhanced funding for the SIREN/REMSTEA program will go to good use, especially as our country and economy recover from the economic and health care crisis brought on by the pandemic.

Beyond the demonstrated need, EMS personnel made good use of the funds allocated under the FY2020 and FY2021 spending bills. For FY2020, SAMHSA awarded REMSTEA grants ranging from $92,000 to $200,000 to approximately 27 EMS agencies across the country for recruitment and training purposes. In December 2020, SAMHSA announced the potential to grant awards to another 27 rural EMS applicants. Rural EMS agencies are in dire need for additional support—we can assure you that our organization's members will not leave money allocated by Congress on the table.

On behalf of our 70,000 members who live and work in every state across our country, thank you again for supporting our brave men and women who provide important roles in the health care ecosystem. SIREN/REMSTEA grants will certainly help them do their jobs to their fullest ability.

[This statement was submitted by Bruce Evans, MPA, NRP, CFO, SPO, President, National Association of Emergency Medical Technicians.]

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF NUTRITION AND AGING SERVICES PROGRAMS

Our ask for FY 2022 is for a minimum total of $1.9 billion for the three Older Americans Act (OAA) Title III–C Nutrition Programs, divided approximately as follows:

—Congregate Nutrition Services (Title III C–1)—$965 million
—Home-Delivered Nutrition Services (Title III C–2)—$726 million
—Nutrition Services Incentive Program (NSIP) (Title III)—$211 million

We can more than justify the need for this funding level. It is important to understand the reality of how the pandemic impacted these programs. The OAA nutrition programs endured a wholescale conversion of the operations because of the COVID–19 pandemic. Before the pandemic, according to the Administration for Community Living's AGID database, more than twice as many older adults were served in the congregate program as in the home-delivered nutrition program. The pandemic caused the transition of almost all congregate program participants to the home-delivered nutrition program.

This conversion resulted in programs encountering immediate increases in costs for food, transportation and personnel, since many relied on older volunteers who were unable to continue their work. Price increases have been particularly felt in those transportation costs, including gasoline prices. Programs went from serving hundreds of participants per day in one location to getting meals to hundreds of individual locations. Gasoline prices have shown a 49.6 percent increase over the last year, including a 9.1 percent increase between just April and May.

Further, in addition to providing additional funding during the pandemic, Congress also has approved some needed flexibilities to allow these programs to seamlessly convert. The most impactful of these was an updated definition of "homebound," allowing any older adult forced to shelter in place to be eligible for a home-delivered meal, overriding any previous state restrictions. This has led to tremendous increases in demand. In fact, a survey conducted by Meals on Wheels America showed an average of 95 percent increase in demand in the early months of the pandemic, including 80 percent of surveyed programs reporting doubling of requests for home-delivered meals. While demand has stabilized to some extent, it remains at a national average of a 60 percent increase over pre-pandemic levels. Local programs also reported that operating costs will likely remain high for the foreseeable future, and nine in 10 home-delivered meals programs reported continued unmet need for home-delivered meals in their community. Nearly a third of these programs said they would need to nearly double or more than double their home-delivered efforts in the future to serve this unmet need.

This is perhaps the greatest justification for this funding. We do not want to see older adults crashing into and falling over this "cliff" of funding running out while the need for service continues. We do not want to have our dedicated personnel in the field be forced to remove older adults in need from their programs, knowing what the health consequences would be.

This funding request is premised on the fact that while the pandemic may be easing, it is not over by any means. Without question, the emergency funding provided to this nutrition network has been used. These funds we request will absolutely also be used.

It should also be noted that nutrition programs were creative and innovative in their use of emergency funds, establishing partnerships with restaurants, food delivery services, drop-ship services and the like in order to stretch their funding as far as it would go. But public-private partnerships do involve resources from both sides. Supporting our funding request for FY 2022 will allow these innovations and partnerships to continue and expand.

Another justification for this funding request must be what it can do to help alleviate the three evils of hunger, food insecurity, and malnutrition in older adults. We have documented information on major increases in food insecurity during the pandemic. We were also acutely aware that even before the pandemic, one in two older adults were at risk of or were already malnourished. The provision of a daily meal to an older adult in a homebound setting can often be the main source of their nutrition for that given day. Said another way, if you remove that meal, that older adult simply may not eat at all.

A continued investment in the OAA nutrition programs allows us an important intervention for those older adults who are socially isolated. Funding provided during the pandemic went well beyond just providing a meal. Our nutrition network responded by developing critically important programs to maintain contact with older adults who suddenly found themselves not being able to have their normal daily socialization at their congregate program. They provided telephone reassurance calls as well as higher-tech approaches to maintaining contact such as virtual book clubs, exercise classes, and nutrition education. These services, like the food provided, need to be continued in the year ahead.

We were also especially pleased that the American Rescue Plan Act included funding to allow the aging network to assist in the effort to get older adults vaccinated. At the time FY 2022 begins, we will be entering flu and pneumonia season. We need to ensure that we continue to provide the aging network with resources to aid older adults in getting the vaccines they need to prevent these illnesses.

In addition, we are all striving for the day when congregate nutrition sites, senior centers and adult day centers that provide meals can reopen. Of course, this can only be done with proper regard for health and safety rules and ordinances. NANASP and our colleagues at the National Council on Aging are surveying our members to find out what costs facilities will incur both to open and remain open. The results are concerning—many programs are reporting $15,000 in costs or more per facility—and these expected costs go outside of most budgets. We hope that this funding can be significant and flexible enough to allow some to be used to facilitate

reopening and/or that funding for these facilities be included in any major infrastructure bill Congress may produce with the President.

Finally, we implore this Subcommittee to think about what has unfolded in the past year with respect to different funding sources. Aging network programs must report their spending of regular FY 2021 funding as well as four streams of emergency funding and expected FY 2022 funding. We strongly request that you communicate through this legislation that while accurate reporting is necessary and important, steps should be taken by the Administration to ensure that the reporting process is as simplified as possible to ensure that programs are not spending much of their limited staff hours and resources on this onerous task.

Next year, this wonderful Older Americans Act nutrition program will celebrate its 50th anniversary. Without question, its 49th year has likely been its toughest. Yet the fact that the OAA nutrition program went seamlessly through an unexpected full-scale conversion speaks volumes about the dedication of nutrition service providers, who deserve our sincere thanks. They pivoted and persevered despite their personal struggles and fears about the virus. While not technically first responders, they were first to respond to one critical need for older adults—nutrition. In short, they always have the best interest of the older adults they serve front and center, as has this Subcommittee. We ask for you to keep this interest in mind again in this incredibly challenging time so we can be prepared for the final phases of the pandemic and all the related downstream issues there may be.

In closing, in the words of a program director from a recently-published *New York Times* article on OAA nutrition programs:

> "[Program administrators] worry that if Congress doesn't sustain this higher level of appropriations, the relief money will be spent and waiting lists will reappear.
> 'There's going to be a cliff,' Mary Beals-Luedtka [director of the area agency on aging serving northern Arizona] said. 'What's going to happen next time? I don't want to have to call people and say, 'We're done with you now.' These are our grandparents.'"

Prepared Statement of the National Association of Secondary School Principals

The National Association of Secondary School Principals (NASSP) appreciates the opportunity to submit the following testimony for the record to the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies. As the premier national organization and voice for middle level and high school principals, assistant principals, and other school leaders, NASSP seeks to transform education through school leadership, recognizing that the fulfillment of each student's potential relies on great leaders in every school committed to the success of each student.

As you develop the fiscal year (FY) 2022 appropriations bill for the U.S. Departments of Labor, Health and Human Services, Education, and Related Agencies, NASSP encourages you to help every American student achieve success and be ready for college, career, and life by prioritizing funding for Supporting Effective Instruction State Grants, the School Leader Recruitment and Support program, the Literacy for All, Results for the Nation (LEARN) program, and Student Support and Academic Enrichment grants.

NASSP urges the subcommittee to allocate $3.00 billion for the Supporting Effective Instruction State Grants program, Title II, Part A (Title II–A) of the Every Student Succeeds Act (ESSA). This program provides states and school districts with formula funding that ensures that educators, principals, and school leaders receive the professional learning and leadership skills needed to support every student.

Research continues to show that Title II–A's investments in educators pays significant dividends in terms of improving educational practice and increasing student achievement. School districts use Title II–A funding to implement ESSA's rigorous definition of professional development that embodies the important transition from scattershot, one-off professional development workshops and sessions to collaborative, ongoing, job-embedded professional learning such as coaching, mentoring, and professional learning communities (PLCs). Research supports the positive effect of the kinds of professional development defined in ESSA. For example, key studies show that coaching helps teachers improve their practice faster. A 2018 meta-analysis, which examined 60 rigorous studies of coaching, found large positive effects of coaching on teachers' instructional practices. Across 43 studies, researchers found that coaching accelerates the growth that typically occurs as one moves from novice to veteran status. Additionally, multiple researchers have documented that teachers

who collaborate in PLCs to continuously improve their practice and their students' learning experiences have a measurable positive impact in schools. A 2009 study that took place in New York City documented student achievement gains across grade levels when teachers engaged in purposeful, content-focused interactions.

Title II–A's support for principal and school leader professional learning is also critical, as research shows a strong correlation between high-quality principals and student achievement and teacher retention. A March 2021 Wallace Foundation paper stated that a review of two decades of evidence—including six quantitative, longitudinal studies involving 22,000 principals—found that "principals have large effects on student learning, comparable even to the effects of individual teachers. A separate 2016 review of 18 studies meeting ESSA's Tiers I–III evidence standards concluded that "school leadership can be a powerful driver of improved education outcomes." This research buttresses earlier studies that concluded that principals are second only to teachers as the most important school-level determinant of student achievement. Other research suggests that schools led by high-quality principals have lower teacher turnover rates.

While the federal government's investment in Title II–A has proven to be much needed and welcome, the COVID–19 pandemic laid bare the need for higher levels of support for our nation's educators. A significant increase to $3.00 billion for Title II–A will provide schools and districts with crucial funds to address new and existing challenges induced or exacerbated by the pandemic. A larger investment in Title II–A will help accelerate student learning, curb teacher and principal shortages by recruiting new individuals into the educator workforce, provide supports to keep educators in the profession, keep class sizes low, and provide mental health and wellness support to our nation's educators as they reenter classrooms full time for the upcoming school year.

NASSP urges the subcommittee to support our nation's school leaders through renewed funding for the School Leader Recruitment and Support Program (SLRSP). Authorized under ESSA and funded at $14.5 million in FY 2017, SLRSP is the only federal program specifically focused on investing in evidence-based, locally-driven strategies to strengthen school leadership in high-need schools. Unfortunately, this program has received no funding in the last several fiscal years. Recently though, President Joe Biden released his FY 2022 budget, where he called for the program to receive $30 million, a number that NASSP requests this committee support.

SLRSP empowers states and school districts, individually or in partnership with nonprofits or institutions of higher education, to accelerate the recruitment, preparation, support, and retention of dynamic school leaders who have a measurable, positive effect on student achievement in high-need schools. Through this program, aspiring principals gain access to high-quality preparation programs, sitting principals receive critical professional development supports, and thousands of teachers—along with hundreds of thousands of students—have the opportunity to work and learn in schools where school leaders have the tools to help them maximize their potential. Funding SLRSP at $30 million will allow proven programs to train more principals to lead during this critical time, provide additional support to current principals, and ultimately lead to better support for teachers and students.

As we continue working with states, districts, and schools on how best to serve students and teachers as schools begin close out the current school year and look toward the next, it is important we recognize that investments in school leadership are critical to addressing learning loss and meeting students' social and emotional learning needs. Additionally, investments in leadership are extremely cost effective when you consider that investing in one principal is actually an investment in the 25 teachers and 500 students they, on average, support. A recent report from The Wallace Foundation states, "Principals really matter. Indeed, it is difficult to envision an investment with a higher ceiling on its potential return than a successful effort to improve principal leadership."

While investments in school leadership will have a significant impact on addressing lost instructional time for students, additional investments in critical programs will also be necessary to help student achievement. That is why NASSP also calls for the subcommittee to provide $500 million for the LEARN program, which builds on the success of the Striving Readers Comprehensive Literacy (SRCL) program.

Research has already started to highlight the pandemic's impact on students' literacy skills. McKinsey & Company found that students taking formative assessments in 2020 learned only 87% of the reading that grade-level peers would typically have learned by the fall. Students lost the equivalent of one-and-a-half months of learning in reading on average, but in schools that predominantly serve students of color, the learning loss was especially acute. The LEARN program builds on the success of the SRCL program where states implementing comprehensive literacy

plans have seen significant improvements in English language arts achievement in districts and schools serving disadvantaged students.

Eleven states (Georgia, Kansas, Kentucky, Louisiana, Maryland, Minnesota, Montana, North Dakota, New Mexico, Ohio, and Oklahoma), the Bureau of Indian Education, and four territories received SRCL grants in 2017, and an additional 13 states (Alaska, Arkansas, California, Georgia, Hawaii, Kentucky, Louisiana, Minnesota, New Mexico, Ohio, Rhode Island, and South Dakota) received grants in 2019 under the now-named Comprehensive Literacy State Development program. With these grants, states are able to support high-quality professional development for teachers, principals, and specialized instructional support personnel to improve literacy instruction for struggling readers and writers, including English-language learners and students with disabilities.

The literacy skills our students need today are much more complex than they were 50 years ago. Creating a globally competent workforce depends on students using their reading and writing skills to develop important abilities in areas such as math, science, technology, and manufacturing. Yet despite the fundamental importance of reading and writing, only 35% of fourth-grade students and 34% of eighth-grade students performed at or above the proficient level in the reading assessment of the National Assessment of Educational Progress—the Nation's Report Card.

Of the more than 523,000 students who leave U.S. high schools each year without a diploma, many have low literacy skills. Research clearly demonstrates that a high-quality, literacy-rich environment beginning in early childhood is one of the most important factors in determining school readiness and success, high school graduation, college access and success, and workforce readiness.

A strong federal commitment to literacy is imperative. LEARN supports states in a comprehensive, systemic approach to strengthen evidenced-based literacy and early literacy instruction for children from early learning through high school and supports district capacity to accelerate reading and writing achievement for all students.

Lastly, NASSP urges the subcommittee to allocate $2.00 billion for the Student Support and Academic Enrichment (SSAE) grant program authorized by Title IV–A of ESSA for FY 2022. This would be a $780 million increase over the FY 2021 enacted level. Title IV–A is a flexible grant that supports state and district efforts to: 1) support safe and healthy students by providing comprehensive mental and behavioral health services and implementing violence prevention programs, trauma informed care, school safety trainings, and other evidenced-based initiatives; 2) increase student access to a well-rounded education, such as STEM, computer science and accelerated learning courses, career and technical education, physical education, music, the arts, foreign languages, college and career counseling, effective school library programs, and social and emotional learning; and 3) provide students with access to technology and digital learning materials and educators with professional development and coaching opportunities necessary to effectively use those resources.

Over the last four fiscal years, on a bipartisan basis, Congress has provided a $4 billion investment for Title IV–A, which has allowed districts to meaningfully invest in programs that provide direct educational services and equitable supports to students. Its flexibility has allowed districts to provide funding for critical programs that support educators, school leaders, and students. As district leaders continue to leverage the flexibility of the SSAE grants, they are eager to plan for the continuance and/or expansion of existing programs and services, and to create new programs.

To address unprecedented interruptions to learning caused by COVID–19, we call on Congress now to go beyond what was authorized in ESSA by providing $2 billion for the SSAE block grant. This will allow additional school districts, especially in rural areas, to make investments in not just one, but all three areas that this grant supports. Right now—more than ever—districts need the continued investments in the Title IV–A program. This pandemic has made clear that districts face a wide range of unique challenges, whether it's ensuring all children have access to technology for remote or blended learning or the ability to provide mental health supports from afar. As school systems prepare for the return to classrooms next school year, they will need the flexibility of Title IV–A funds to provide social and emotional learning programs, engaging well-rounded classes like music and physical education, and active learning opportunities enabled through technology.

NASSP thanks you again for the opportunity to share these thoughts and information with you, and also thanks you for your continued work to support our nation's students and educators. To discuss this testimony further or if you have any questions, please contact NASSP's senior director of federal engagement and outreach, Zach Scott, at scottz@nassp.org.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF STATE HEAD INJURY ADMINISTRATORS

On behalf of the National Association of State Head Injury Administrators (NASHIA), thank you for the opportunity to submit testimony regarding the fiscal year 2022 appropriations for federal programs that impact approximately 2.87 million Americans who are treated annually in emergency department visits and hospitals for a traumatic brain injury (CDC, 2014). To address their needs, NASHIA is requesting increased funding for programs authorized by the Traumatic Brain Injury (TBI) Program Reauthorization Act of 2018 and administered by the U.S. Department of Health and Human Services' (HHS) Administration for Community Living (ACL) and the Centers for Disease Control and Prevention's National Center for Injury Prevention and Control (NCIPC). We also support additional funding for the ACL's National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) program authorized by the Workforce Innovation and Opportunity Act (WIOA) of 2014, and which funds TBI Model Systems and TBI research. NASHIA is requesting:

—$12 million additional funding for the ACL TBI State Partnership Grant Program to provide funding to all states, territories and District of Columbia;
—$6 million additional funding for the ACL TBI Protection & Advocacy Grant Program to increase the amount of the awards; and
—$5M additional funding for the CDC's NCIPC to establish and oversee a National Concussion Surveillance System as authorized by the TBI Program Reauthorization Act of 2018.

NASHIA is also requesting a funding increase of $6.6 million to expand the NIDILRR TBI research capacity through the TBI Model Systems (TBIMS):

—To increase the number of TBIMS from 16 to 18 ($1 million each), while increasing per center support by $200,000;
—$1 million to expand TBIMIS collaborative research projects from 1 to 3; and
—$100,000 to increase funding for the National Data and Statistical Center in order to gain information for valuable research.

Each year, a substantial number of Americans are injured due to motor vehicle crashes, falls, military-related injuries, violence, industrial injuries, sports-related injuries and other injuries that cause cognitive, emotional, physical, sensory and health-related problems resulting in unemployment and loss income; homelessness; incarceration; and institutional and nursing home placement due to lack of community alternatives. While recent trends have noted the increasing number of Americans with TBI-related disabilities among older adults due to falls, the COVID–19 pandemic is raising alarms regarding those who are infected who may experience hypoxia due to the deprivation of oxygen, resulting in brain damage that may necessitate the need for rehabilitation to regain functioning and ongoing supports should functioning not be restored. In addition, the increased risk of domestic and intimate partner violence during the time of the "stay at home" orders put people at risk for sustaining a brain injury from the abuser hitting the head, slamming the head against the wall or from near strangulation. As we emerge from the pandemic, the impact on both those at risk for a brain injury and for those with a brain injury will certainly become more apparent.

This year has been especially challenging for individuals with brain injury and their families. States have reported that brain injury program participants have cancelled services due to the fear and anxiety that COVID–19 has caused them. At the same time, providers have experienced loss of income as the result of not being able to perform contractual duties due to the restrictions. As a result, states have witnessed increased anxiety and self-isolation among individuals with brain injury. Thus, the federal funding requested is critical to assist states with issues that emanate from the pandemic, as well as to address the increased number of brain injuries due to an aging population and other factors.

ADMINISTRATION FOR COMMUNITY LIVING—TBI ACT PROGRAMS

The ACL TBI State Partnership Grant Program is the only program that assists states in building and expanding service capacity to address the complex needs associated with brain injury that generally require the coordination of multiple systems (e.g., medical, rehabilitation, education, vocational, behavioral health, Medicaid) and payers (e.g., insurance, Workers' Comp, state and federal programs). Twenty seven states are ending their grant activities. We are requesting additional funding so that all states, territories and District of Columbia may receive funding to address gaps in services within their states.

These grants also help to carry out the ACL priorities to increase direct services, including home and community-based services; accelerating COVID–19 recovery; supporting caregivers; and advancing equity.

ACL TBI STATE PROTECTION & ADVOCACY (PATBI) PROGRAM

The ACL Federal Protection and Advocacy TBI (PATBI) program is a formula grant that provides $4 million total in funding for the 57 P&As in the United States, its territories and the Native American Protection and Advocacy Project in order to provide: (1) information, referrals, and advice; (2) Individual and family advocacy; (3) legal representation; and (4) specific assistance in self-advocacy. The requested amount will increase the amount awarded to state and PATBI grantees.

CENTERS FOR DISEASE CONTROL AND PREVENTION—NATIONAL CENTER ON INJURY PREVENTION AND CONTROL

CDC's National Injury Center initiated a pilot study as a first step in implementing a national surveillance system to determine the extent of mild brain injury or concussions in this country. Most individuals with a concussion are treated in an emergency department or physician's office and may not be reported in other data systems that capture the number of Americans who are hospitalized with moderate to severe TBI. Subsequently, Congress included $5 million authorization to implement the National Concussion Surveillance System within the TBI Program Reauthorization Act of 2018.

Last year, the Government Accountability Office (GAO) issued a Report to Congress that found that data on the overall prevalence of brain injuries resulting from intimate partner violence are limited and that such data is needed to better understand the problem to ensure that resources are targeted appropriately to address these issues. In 2013, the Institute of Medicine (IOM) and the National Research Council released an extensive report on sports-related concussions in children and teens and also examined sports-related concussions among military dependents, as well as concussions in military personnel ages 18 to 21 that result from sports and physical training at military service academies or during recruit training. The report noted that limited data is available and recommended that CDC oversee a national surveillance system to accurately determine the incidence of sports-related concussions.

We strongly support funding to implement a national surveillance system to help states, federal and national partners with needed data to address prevention, identification, and treatment for concussions.

ACL'S NATIONAL INSTITUTE ON DISABILITY, INDEPENDENT LIVING, AND REHABILITATION RESEARCH (NIDILRR)

NIDILRR supports innovative projects and research in the delivery, demonstration, and evaluation of medical, rehabilitation, vocational, and other services designed to meet the needs of individuals with TBI through TBI Model Systems grants. Each TBI Model System contributes to the TBI Model Systems National Data and Statistical Center (TBINDSC), participates in independent and collaborative research, and provides valuable information and resources. This research is critical to help TBI providers to better deliver services that result in good outcomes.

In closing, NASHIA, as 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. Federal funding is critical to help states in that endeavor, including data and research to support an effective delivery system. We urge you to consider increasing funding for the ACL TBI Program (state and protection & advocacy grant programs), for the ACL NIDILRR program to expand TBI research, for CDC to establish a National Concussion Surveillance system.

Thank you for your continued support. Should you wish additional information, please do not hesitate to contact: Susan L. Vaughn, Director of Public Policy at svaughn@nashia.org, or Becky Corby, NASHIA Government Relations at rcorby@ridgepolicygroup.com.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF STATE LONG-TERM CARE OMBUDSMAN PROGRAMS

Chairman Murray and Ranking Member Blunt, I present this testimony on behalf of the nearly 74,000 residents in Washington State's long-term care facilities and

in collaboration with the National Association of State Long-Term Care Ombudsman Programs (NASOP). Thank you for your past support of State Long-Term Care Ombudsman Programs (SLTCOPs) and the at-risk individuals that they serve, particularly in the CARES Act. As you know, our work to serve the residents of long-term care facilities under the terrible cloud of the COVID–19 pandemic has been extremely challenging. We are emerging from this period facing many crises in facilities across the nation, but we are determined to protect the rights of residents, resolve their complaints and service problems, and work with facilities to improve the quality of care, the roles in which we ombudsmen have been entrusted.

I submit this statement and the funding recommendations for the Fiscal Year 2022 for SLTCOPs administered through the Administration for Community Living, Department of Health and Human Services, to include:

—$65 million to support our work with residents of assisted living, board and care, and similar community-based long-term care settings as these are less regulated and residents often need greater advocacy;

—$70 million for our current core obligation to respond to tremendous need, ensuring residents have regular and timely access to our program; and

—$20 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.

Let me explain why our program is requesting this funding. I will start by letting you know why we ombudsmen are so passionate about our work. Our mission is to protect the health, safety, welfare, and rights of our nation's older adults and individuals with disabilities living in nursing homes and assisted living facilities. We protect the residents' rights to be treated as individuals with autonomy, choice, independence, and access to quality health care. We believe that in a just society, all people would have their needs met. 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. Increased consistent funding is needed for the SLTCOP to support the critical role ombudsmen play in the care infrastructure, specifically the long-term care and community-based care infrastructure funded in part by Medicaid and Medicare.

Two years ago, volunteers in Washington donated approximately 32,860 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 programs across the nation, we are not able to keep up with consumer needs and growing costs. One of the key areas of need right now is the direct result of the covid–19 pandemic. The advocacy and protections our programs provide are necessary to address the trauma and impact that residents, family members, and staff have experienced during the pandemic. Many ombudsman programs, due to the risks, have lost paid staff and volunteers who need to be replaced.

The pandemic put all ombudsmen on high alert. The Washington State LTCOP responded swiftly to the needs of residents and their families by adapting our methods, and developing ways to reach into facilities that were in "lockdown". We distributed nearly 70,000 post cards and notes to long-term care residents and their families informing them about the program, and Residents Rights. Through private donors and a grant from Washington State, we delivered approximately 800 Amazon Fire Tablets to adult family homes to help residents "stay connected" with their family, friends, and communities. We advocated on behalf of residents and their families through participation in multiple stakeholder meetings, educating and informing journalists, providing testimony, and working with our state legislature to pass meaningful legislation (HB1218). The State LTCOP created a mental health and spiritual counselor referral list to address the loss and grief, and the trauma experienced by long-term care residents. We organized a new resident-only advisory council to the State LTC Ombuds, giving voice to the thousands of long-term care residents who were voiceless during the pandemic. These are just a few examples of the work conducted during the COVID–19 crisis which is not yet over.

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 $65,000,000 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. We rarely are able to get to the growing number of assisted living facilities, which depending on the state are called board

and care and other names. Nationally, for example, while assisted living beds have grown to more than 57,000 in the years 2013 to 2018, we have about 2,000 fewer volunteers and only 71 more paid ombudsmen over that five-year period.

Home and Community based service options continue to grow in number, but there is no expansion in ombuds services. Increases in long-term care residents is a key factor and challenge to providing our cost saving advocacy services. Washington State has demonstrated leadership by reducing Medicaid costs, while excelling in consumer options outside of expensive nursing homes. 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 threaten the health and wellbeing of people in our care. These challenges 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 of their rights.

Our second request is for $70,000.000, 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 our family members and neighbors in long-term care, our work saves Medicare and Medicaid funds by avoiding costs associated with poor quality care, unnecessary hospitalizations and expensive procedures and treatments. Furthermore, nationally in 2019, more than 5,947 volunteers donated their time. Ombudsman staff and volunteers investigated 198,502 complaints made by residents, relatives, friends, and volunteers. Ombudsmen were able to resolve or partially resolve 71.5 percent—or an ombudsman resolved nearly 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 me, 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 of the LTC Ombudsman Program (the Institute of Medicine, and the Bader Report) have recommended that best practice be to employ one full-time paid 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 suffered a significant loss of volunteers during the pandemic. We weren't able to cover every facility before the pandemic and things are worse now. Nearly half of the facilities in our state never receive routine visits by an ombuds, and visitations are the hallmark activity of the Program—vital to building trust and effectiveness. We are so busy responding to complaints that we are not able to conduct regular outreach or build presence in all facilities. We are overwhelmed with complaints about involuntary, and unlawful discharges, also known as, "resident dumping" which is harmful to residents, and costly. Long-term care providers recognize the value and benefit of the LTC Ombudsman program trainings, and consultation services, which often address problems before they escalate.

Third, we request $20,000,000 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, except for $4 million in the Coronavirus Response and Relief Supplemental Appropriations Act of 2021. 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.

Demand for our services is growing. The number of complex and very troubling cases that ombudsmen investigate has been steadily increasing. As more residents are vaccinated and facilities "re-open" ombudsmen are returning to in-person visits. What we see is concerning and disturbing when it comes to poorer staffing levels and the impacts of social isolation. 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. Om-

budsmen are needed now more than ever in nursing homes, assisted living, and similar care facilities.

In order to improve advocacy and services available to residents, our office and NASOP respectfully request the aforementioned funding levels. Just think how much more we could accomplish if we had the resources to meet the demand.

We appreciate that the Leadership Council of Aging Organizations has written in support of these requests.

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 COLLEGE ATTAINMENT NETWORK

Dear Chair Murray and Ranking Member Blunt,

Thank you for your continued leadership in past funding cycles to reinforce investments in the federal programs that support students in their pursuit of higher education. Today, we write to respectfully request that federal student aid funding be a high priority for the Subcommittee. Without the statutory discretionary spending caps for Fiscal Year 2022, we hope that total discretionary funding can rise to provide strong support for our nation's higher education system and students.

With this goal in mind for FY22, NCAN recommends these specific funding levels for the U.S. Department of Education programs:

—NCAN recommends the requisite funding in FY22 so that the maximum Pell Grant award can be increased to $12,990, double the current maximum award.
—Supplementary Educational Opportunity Grant funding of $1.061 billion.
—Federal Work-Study funding of $1.48 billion.
—TRIO program funding of $1.316 billion.
—GEAR UP funding of $435 million.
—$200 million increase in administrative funding for federal student aid management.

Additionally, we request that the Corporation for National and Community Service receive $1.21 billion in funding for FY22—and that the AmeriCorps program, that allows some college access programs to provide near-peer mentors for their students, receive $501 million in funding.

The National College Attainment Network (NCAN), founded in 1995, represents more than 600 members across the country that all work toward NCAN's mission to build, strengthen, and empower communities and stakeholders to close equity gaps in postsecondary attainment for all students. Collectively, we are committed to college access and success so that all students, especially those underrepresented in postsecondary education, can achieve their educational dreams. NCAN's members span a broad range of the education, nonprofit, government, and civic sectors, including national and community-based nonprofit organizations, federally funded TRIO and GEAR UP programs, school districts, colleges and universities, foundations, and corporations.

Drawing on the expertise of our hundreds of organizational members in every U.S. state, NCAN is dedicated to improving the quality and quantity of support that underrepresented students receive to apply to, enter, and succeed in postsecondary education. Students of color, students from low-income backgrounds, and those who are the first in their family to attend college experience disproportionately lower rates of postsecondary success. For example, a low-income student is 29% less likely to enroll in postsecondary education directly after high school than a high-income student. Ultimately, only 35% of low-income high school students obtain a postsecondary credential by age 26, compared to 72% of high-income students.

The federal investments that would most bolster the goal of closing attainment gaps include the following:

PELL GRANT INVESTMENTS

NCAN recommends that the maximum Pell Grant award be increased to $12,990, double the current maximum award. The Pell Grant has served as the cornerstone of financial aid for students from low-income backgrounds pursuing higher education since its creation in 1972. This need-based grant provides crucial support for around 7 million students each year, or about one-third of undergraduates. Without this need-based grant funding, an even smaller portion of students from low-income backgrounds would be able to access higher education. Congress has recognized the importance of the Pell Grant over the past five years by investing in annual increases of, on average, about $140 to the maximum award.

Given that the previously required automatic inflationary increases have expired, these annual investments by Congress have been essential for the nation's students who do not have the means to pay for college from falling farther behind in their pursuit of higher education. Even with these investments, the purchasing power of the Pell Grant for a four-year college degree from a public institution is holding at a historic low of 29% of the cost of attendance. At its peak in 1975–76, the maximum Pell Grant award covered more than three-fourths of the average cost of attendance—tuition, fees, and living expenses—for a four-year public university.

To address the long-term purchasing power of the Pell Grant, and to have the Pell Grant be increased so that it covers at least half of the cost of a four-year public higher education, the maximum award should be doubled.

In President Biden's budget for FY22, the administration has requested that Congress consider a Pell Grant increase of $1,875, through discretionary and mandatory funding, to bring the maximum award to $8,370 for the 2022–23 award year. If Congress adopted the President's request, raising the maximum Pell Grant to $8,370, its purchasing power would significantly increase to 36%. NCAN applauds this historic investment, referred to in the budget as a "down payment on the President's commitment to doubling the grant in future years." NCAN encourages Congress to consider a plan for future increases that would achieve a doubling of the Pell Grant, such as is outlined in the bicameral Pell Grant Preservation and Expansion Act of 2021—which would achieve this goal, over a five-year timeframe.

To reach this goal, NCAN requests the requisite funding in FY22 so that the maximum individual Pell Grant award can be increased to $12,990, double the current maximum award.

FAFSA SIMPLIFICATION

In President Biden's budget for FY22, the administration requests a $200 million increase in administrative funding for federal student aid management. These funds are necessary to help with the implementation of the FAFSA Simplification Act and FUTURE Act—two laws that will achieve the goal of simplifying the Free Application for Federal Student Aid (FAFSA) process, a top priority for NCAN. With the Office of Federal Student Aid announcing a phased implementation plan for FAFSA simplification, to take full effect one year later than originally anticipated, NCAN supports this funding request to ensure that the timeline is not further delayed. The urgency for students to access need-based aid has only grown since passage of the legislation.

CAMPUS-BASED AID

As low-income students piece together resources from a variety of sources to support their postsecondary education pursuits, every dollar and type of aid is significant. For most low-income students, the Supplemental Educational Opportunity Grant (SEOG) and Federal Work-Study help to fill unmet need in their financial aid packages.

The SEOG program should be increased for FY22 so that institutions of higher education to support a greater percentage of the country's lowest-income students. For FY22, NCAN respectfully requests that Congress fund the SEOG program at a total of $1.061 billion.

Sixty-four percent of today's students work while enrolled in school. The Federal Work-Study (FWS) program allows students to work in a flexible environment, learn important skills, and minimize the amount of time they spend commuting between work and campus. For FY22, NCAN respectfully requests that Congress increase the FWS program budget for a total of $1.48 billion.

Federally Funded College Access Programs—TRIO and GEAR UP

Annually, approximately 1.8 million high school seniors are defined as students from low-income backgrounds. A variety of programs are needed to meet all their needs as they pursue their options for education beyond high school. The NCAN community serves approximately 2 million students annually from middle school through college graduation. To reach all the students needing services nationwide, our members build important partnerships both with TRIO and GEAR UP programs. NCAN respectfully requests that Congress continue its investment in federally funded college access programs at the amounts requested by their communities: $1.316 billion for TRIO and $435 million for GEAR UP.

CORPORATION FOR NATIONAL AND COMMUNITY SERVICE (CNCS)

For every dollar spent on national service, the country sees a return on investment that is almost fourfold. Service also plays an important role in the college access movement. Many of NCAN's largest members can maximize their impact on

underrepresented students by participating in the AmeriCorps public-private partnership. Continuing support for CNCS, and specifically the AmeriCorps program, will enable additional volunteers to work with low-income students, students of color, and students who are first in their family to attend college. NCAN respectfully requests of that the Corporation for National and Community Service and the AmeriCorps program receive $1.21 billion and $501 million, respectively, for FY22.

Thank you for this opportunity to provide our funding priorities for the fiscal year 2022. Through continued supports—both financial and programmatic—our country can work together to close gaps in attainment, where a low-income student is about half as likely to complete a postsecondary degree or credential as a high-income student. Thank you for your support of this important goal.

Sincerely.

[This statement was submitted by Kim Cook, Executive Director, National College Attainment Network.]

PREPARED STATEMENT OF THE NATIONAL COUNCIL FOR DIVERSITY IN THE HEALTH PROFESSIONS

Chairwoman Murray, Ranking Member Blunt, and distinguished members of the subcommittee, thank you for the opportunity to submit this statement for the record on behalf of the National Council for Diversity in the Health Professions (NCDHP). I am Dr. Wanda Lipscomb and I serve as President of the NCDHP and Director of the Center of Excellence for Culture Diversity in Medical Education at Michigan State University. NCDHP was established in 2006 and is composed of institutions that are either currently or formerly distinguished as a "Center of Excellence" through the Health Resources and Services Administration's (HRSA)'s Centers of Excellence (COE) program or are a current or former recipient of the Health Careers Opportunities Program (HCOP) grant, now known as the National HCOP Academies program. Every member institution within the council is committed to advancing pipeline programs and programmatic activity that leads to diversity in the health professions.

The National Council for Diversity in Health Professions (NCDHP) is comprised of institutions with Centers of Excellence (COE) and Health Careers Opportunity Program (HCOP) grants funded by the Health Resources and Services Administration under the Title VII Health Professions Training Programs. COE/HCOP grantees are in health professions education and other institutions which excel in the development of educational pipeline programs for individuals from minority and disadvantaged backgrounds, and in the improvement of the quality of health care delivery to medically underserved communities. I am proud to put forth the following recommendations for the fiscal year (FY) 2022 appropriations process:

Minority health professional development is a cost-effective and long-term mechanism of improving health care and decreasing health disparities in minority and underserved communities. 50–80% of Under-Represented Minority (URM) physicians and other health professionals practice in shortage areas serving minority patients. Minority health professionals possess the cultural, experiential and linguistic skills needed to provide cost-effective health care to minority communities. Minority students identified, recruited, supported, admitted, and trained in the health professions in this decade will provide services into the 2060s and 2070s.

HRSA CENTERS OF EXCELLENCE (COE) RECOMMENDATION

COE award recipients serve as innovative resource and education centers to recruit, train, retain and graduate URM students and faculty at health professions schools. Programs improve information resources, clinical education, curricula, and cultural competence as they relate to minority health issues and social determinants of health. These award recipients also focus on facilitating faculty and student research on health issues particularly affecting URM groups. The goal of the program is to effectively deliver health care to underserved communities.

NCDHP recommends $47.42 million for the COE program in Fiscal Year 2022

HRSA HEALTH CAREER OPPORTUNITIES PROGRAM (HCOP) RECOMMENDATION

HCOP provides opportunities for colleges and community-based health professions training and promotes the recruitment of qualified students and non-traditional students like veterans from disadvantaged backgrounds into health and allied health professions programs. As a major federal pipeline program into the health professions, HCOP improves the acceptance, retention and matriculation rates of partici-

pating students by implementing tailored enrichment programs designed to address their academic and social needs.

The NCDHP recommends $47.95 million for the HCOP program in Fiscal Year 2022.

FUNDING JUSTIFICATION AND APPROPRIATIONS HISTORY FOR HRSA'S HCOP AND COE PROGRAMS

—The Association of American Medical Colleges projects that in the U.S. there will be a shortage of nearly 120,000 primary care physicians by the year 2030. Looming workforce shortages exist not only in medicine, but also in dentistry, public health, physician assistants and other health professions. If not adequately addressed, our nation will continue to fall short in addressing the needs of medically underserved communities as most recently exposed by the COVID–19 pandemic.

—We are seeking to restore COE and HCOP funding to FY 2005 levels. For FY 2006 the COE appropriation was cut by 65% from $33M to only $12M. Similarly HCOP was cut by 89% to only $4M. Adjusting for inflation COEs $33M in 2005 dollars would be $45M in 2021 dollars. HCOPs $35M in 2005 would now be $47M.

—The number of COE grantees dropped from 34 (in 2005) to 19 (in 2020), and the number of HCOP grantees dropped from 74 (in 2005) to 22 (in 2020). These programs have not fully recovered. Presently there is not enough funding in either program to support a new competition-only to maintain existing programs. A significant increase is needed in COE and HCOP to increase the number of Latino, Black, American Indian and disadvantaged students recruited, admitted and graduated as culturally competent physicians and other health professionals who have a high likelihood of practicing in underserved minority communities. For example, with increased funding, COE could launch an initiative to increase the number of post-baccalaureate slots and programs that enroll previously rejected applicants in one-year programs, with 90% being accepted to medical school, of which >95% will graduate as physicians.

As you begin the FY 2022 process, NCDHP asks that you further prioritize Title VII health professions training programs. Chairwoman DeLauro, Ranking Member Cole, please allow me to express my appreciation to you and the members of this subcommittee. With your continued help and support, NCDHP member institutions are keeping course to overcome health workforce and health disparities. Thank you for your time and consideration of these requests. We look forward to working with the Subcommittee to prioritize the health professions programs in FY 2022 and the future.

[This statement was submitted by Wanda Lipscomb, PH.D., President, National Council for Diversity in the Health Professions.]

PREPARED STATEMENT OF THE NATIONAL ECZEMA ASSOCIATION

SUMMARY OF FISCAL YEAR 2022 APPROPRIATIONS RECOMMENDATIONS

—Please provide the National Institutes of Health (NIH) with at least $46.1 billion to expand and advance critical research activities, and provide individual NIH institutes and centers, such as the National Institute of Allergy and Infectious Diseases (NIAID) and the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) with proportional funding increases.

—While NIH has received notable funding over recent years, funding for the eczema portfolio has stayed relatively flat and additional resources are needed.

—Please provide the Centers for Disease Control and Prevention (CDC) with at least $10 billion to facilitate timely public health efforts on a variety of conditions, including skin disease. Additionally, please provide individual CDC centers, such as the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) with proportional funding increases.

—Please provide $5 million for the new Chronic Disease Education and Awareness Program at CDC.

Thank you for the opportunity to submit testimony on behalf of the National Eczema Association and the over 31 million eczema patients of all ages across the country. Chairwoman Murray, Ranking Blunt, and distinguished members of the

subcommittee, thank you for the ongoing investment in medical research that has facilitated breakthroughs and scientific progress for the eczema community. As you and your colleagues work on appropriations for FY 2022, please continue this investment in medical research and similarly provide robust funding for public health programs. Thank you for your time and for your consideration of these requests.

ABOUT THE NATIONAL ECZEMA ASSOCIATION (NEA)

NEA is the driving force for an eczema community fueled by knowledge, strengthened through collective action and propelled by the promise for a better future.

Reflecting back and looking ahead led us to appreciate how central the concept of "community" has become to NEA's identity and its existence, as is now captured in our aforementioned mission statement. We also recognize that what we mean by the term "eczema community" has expanded over the years to reflect a multitude of personal and professional interests committed to making life better for those who live with eczema. Many people seek out NEA to connect with others who understand and share the experience of living with eczema. Each individual's unique perspective, based on their own experience, is a source of strength and vibrancy for the diversity of our community. Through our dedicated advocates, we will share some of those stories and perspectives with you today.

ABOUT ECZEMA

Eczema is the name for a group of conditions that cause the skin to become itchy, inflamed and red in lighter skin tones or brown, purple, gray or ashen in darker skin tones. Eczema is very common in both children and adults and affects all races and ethnicities. In fact, more than 31 million Americans have some form of eczema-with up to 40% of affected individuals experiencing more severe disease symptoms and chronic disease burden.

Eczema is not contagious. You cannot "catch it" from someone else. While the exact cause of eczema is unknown, researchers do know that people who develop eczema do so because of a combination of genes and environmental triggers.

When an irritant or an allergen from outside or inside the body "switches on" the immune system, it produces inflammation. It is this inflammation that causes the symptoms common to most types of eczema.

There are seven different types of eczema:

—Atopic dermatitis
—Contact dermatitis
—Neurodermatitis
—Dyshidrotic eczema
—Nummular eczema
—Seborrheic dermatitis
—Stasis dermatitis

It is possible to have more than one type of eczema on your body at the same time. Each form of eczema has its own set of triggers and treatment requirements, which is why it is so important to consult with a healthcare provider who is knowledgeable in treating eczema. Many healthcare providers can be involved in the diagnosis and treatment of eczema including primary care providers, pediatricians, dermatologists, and allergists. Recent years of scientific progress have led to the emergence of new therapies, but much more work needs to be done in research and public health to improve care for patients and address areas of continued unmet treatment and quality of life needs.

RECENT ADVANCEMENTS AND EMERGING RESEARCH OPPORTUNITIES

NEA's research priorities, including grants that we fund on an annual basis, focus on improving health outcomes for the community and translating breakthroughs in basic science to diagnostic tools, innovative therapies, and improved healthcare information:

—Cutting-Edge Basic & Translational Science- Innovative investigations of targets, pathways or technologies that will advance understanding of the pathophysiology or natural history of eczema, and potentially lead to novel or enhanced therapeutic/preventative areas of exploration or application.
—Eczema Heterogeneity: Novel Insights- Projects aimed at advancing understanding of the underlying factors contributing to the diversity of eczema clinical presentation, treatment response and comorbidities.
—Innovations in Clinical Practice & Care-Studies addressing approaches to facilitate optimal identification and treatment of eczema and associated comorbidities in all health care settings to enhance patient-reported and patient-centric outcomes.

—Understanding & Alleviating Disease Burden-Insightful proposals that identify, quantify or aim to reduce aspects of eczema burden that negatively affect patient or family/caregiver quality of life (including lifestyle, academic/occupational, or economic impacts) based on patient population, treatment approach, etc.
—Eczema Prevention-Novel investigations into the potential risk factors and strategies of primary eczema prevention at all ages.

Our research efforts overlap with NIH-supported research activities, which currently total a modest-but-meaningful $35 million annually.

PATIENT STORIES

People with eczema and their loved ones are the true experts, which is why we call upon our community regularly to share their stories.

Lindsay is one of our Illinois advocates. She was diagnosed at six years old with eczema. Now, in her 40s, she wants to ensure that policymakers understand that eczema is more than just a rash. While getting access to a biologic has been a challenge (to the point where she had to miss doses), the medicine has changed the way eczema presents on her skin. It still gets angry and red, but it no longer weeps. It will just dry up and flake off. Her body is about 75% clear on a good day, but she can still get bad flares primarily on her face and neck.

Andrea is one of our Connecticut advocates. She has had eczema for 15 years and her youngest child was diagnosed with eczema on the back of her knees two years ago. She advocates that all patients should have access to specialty care because to help heal eczema you need the right support and right care to know the underlying cause.

Traciee is one of our Oregon advocates. She advocates on behalf of herself and all the eczema warriors and their families. She feels strongly that patients should have access to quality healthcare and that fellow eczema warriors should not have to suffer in silence with an uncontrollable itch. The solution is that treatment decisions should be made by the provider who has received extensive training in this disease.

[This statement was submitted by Michele Guadalupe, MPH, Associate Director, Advocacy and Access.]

PREPARED STATEMENT OF THE NATIONAL FAMILY PLANNING & REPRODUCTIVE HEALTH ASSOCIATION

Dear Chairwoman Murray and Ranking Member Blunt:

As President & CEO of the National Family Planning & Reproductive Health Association (NFPRHA), I thank you for this opportunity to provide testimony in support of a fiscal year (FY) 2022 appropriation of $737 million for the Title X family planning program (Office of Population Affairs, funded within the Health Resources and Services Administration account). We are grateful for Chairwoman Murray's longtime leadership in advocating for family planning and urge you to take this substantial step forward in this year's bill.

NFPRHA is a non-partisan, non-profit membership association whose mission is to advance and elevate the importance of family planning in the nation's health care system; NFPRHA membership includes close to 1,000 members that operate or fund more than 3,500 health centers that deliver high-quality family planning education and preventive care to millions of people every year in the United States. These members cover the broad spectrum of publicly funded family planning providers, including state and local health departments, hospitals, family planning councils, federally qualified health centers, Planned Parenthood affiliates, and other private nonprofit agencies. NFPRHA represents three-quarters of all current Title X grantees as well as the majority of grantees that withdrew from the program in 2019 rather than comply with the Trump administration's program rule.

Title X is the nation's only federal program dedicated to providing family planning services for people with low incomes across the United States. In 2018, prior to the implementation of the Trump administration's devastating regulations, nearly 4,000 health centers in the network served nearly 4 million patients.[1] Title X-funded health centers are lifelines for their communities, providing high-quality reproductive and sexual health care, including cancer screenings, testing and treatment for

[1] 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.

sexually transmitted infections, HIV/AIDS education and testing, contraceptive services and supplies, pregnancy testing, and other vital health care services. These centers disproportionately serve people from communities that face systemic barriers to accessing quality health care, including people with low incomes, people who are uninsured or underinsured, people of color, people who live and work in rural areas, LGBTQ people, and young people. In fact, 60% of women who received contraceptive services from a Title X-funded health center in 2016 had no other source of medical care in the prior year,[2] and almost two-thirds of patients at these sites have incomes at or below the federal poverty level.[3]

Unfortunately, the current funding level is woefully below what is required to meet the family planning and sexual health needs of people living with low incomes. Title X has been cut or flat-funded every year for the past decade, and the program's FY2021 allocation is just $286.5 million, the same allocation the program has received for seven fiscal years, and significantly below the allocation from a decade ago. Other important public health programs, such as the Title V Maternal-Child Health Block Grant and the Ryan White HIV/AIDS Program, have seen significant increases in the same period, and people who rely on publicly funded family planning care deserve that same investment in their health care needs. The current allocation is also well below the $737 million estimate that researchers from the Centers for Disease Control and Prevention, the Office of Population Affairs (OPA), and the George Washington University determined in 2016 would be needed annually just to provide family planning care to low-income women without insurance.[4] We urge you to take a substantial step forward for family planning access and appropriate that $737 million for the program in FY2022.

This funding increase is particularly vital given the harms the Trump administration inflicted on the program, the providers funded by it, and, most importantly, the people who seek family planning and sexual health care. On July 15, 2019, that administration's regulations for Title X went into effect, and the impact was felt almost immediately: by fall 2019, approximately 1,000 health centers across 33 states had withdrawn from the program. In 2018, those health centers had provided 1.6 million patients with high-quality Title X-supported family planning and sexual health services.[5] In September 2020, OPA released the first federal data showing the impact of the rule, and the results were devastating: relative to 2018, Title X-funded health centers provided family planning services to 844,083 fewer patients in 2019, a staggering 21% decrease, and that was after just five months of having the rule in effect. In addition, fourteen states lost more than one-third of their patient volume. This drastic decrease translated to hundreds of thousands of fewer contraceptive services provided, more than 1 million fewer STD tests administered, and more than 250,000 fewer life-saving breast and cervical cancer screenings performed with Title X funds.[6] The numbers for 2020—no doubt exacerbated by the impact of COVID–19 on health care access—are even worse, with preliminary data showing that only 1.5 million people were able to receive Title X-supported services in 2020, a drop of 60% from just two years earlier.[7] Six states—Hawaii, Maine, Oregon, Utah, Vermont, and the chairwoman's home state of Washington—have had no Title X-funded services for almost two years.

Compounding these harms, a 2020 study shows that COVID–19 has led many women to want to delay or prevent pregnancy while it has simultaneously made it more difficult for people to access family planning and sexual health care, including contraception. Women of color and women with low incomes are more likely to re-

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[2] Meghan Kavanaugh, "Use of Health Insurance Among Clients Seeking Contraceptive Services at Title X-Funded Facilities in 2016," Guttmacher Institute (June 2018). https://www.guttmacher.org/journals/psrh/2018/06/use-health-insuranceamong-clients-seeking-contraceptive-services-title-x.

[3] Christina Fowler et al, "Family Planning Annual Report: 2019 National Summary," RTI International (September 2020). https://opa.hhs.gov/sites/default/files/2020-09/title-x-fpar-2019-national-summary.pdf.

[4] 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.

[5] Mia Zolna Sean Finn, and Jennifer Frost, "Estimating the impact of changes in the Title X network on patient capacity," Guttmacher Institute (February 2020). https://www.guttmacher.org/article/2020/02/estimating-impact-changes-title-x-network-patient-capacity.

[6] Christina Fowler et al, "Family Planning Annual Report: 2019 National Summary," RTI International (September 2020). https://opa.hhs.gov/sites/default/files/2020-09/title-x-fpar-2019-national-summary.pdf.

[7] Ensuring Access to Equitable, Affordable, Client-Centered, Quality Family Planning Services, 86 Federal Register 19812 (proposed April 15, 2021) (to be codified at 42 CFR 59).

port both findings.[8] The confluence of the Trump administration's rule and a global pandemic means that a significant influx of funds is desperately needed to begin to rebuild the network and restore Title X services to communities across the country as quickly as possible.

These funds will be particularly significant given the Biden administration's commitment to restore the Title X program's commitment to high-quality, client-centered, evidence-based care by fall 2021.[9] That process is moving quickly: on April 15, HHS published a notice of proposed rulemaking, and comments were due on May 17.[10] NFPRHA continues to urge HHS to complete the rulemaking process as quickly as possible and to subsequently make funds available to communities that have been without services as soon as the new rule is in effect.

We thank you for your consideration of this request.

Sincerely.

[This statement was submitted by Clare Coleman, President & CEO, National Family Planning & Reproductive Health Association.]

PREPARED STATEMENT OF THE NATIONAL INSTITUTES OF HEALTH

Good morning, Chairwoman Murray, Ranking Member Blunt, and distinguished Members of the Subcommittee. I am Francis S. Collins, M.D., Ph.D., and I have served as the Director of the National Institutes of Health (NIH) since 2009. It is an honor to appear before you today.

First, I want to thank this Subcommittee for your commitment to NIH, which allowed the biomedical research enterprise to respond quickly to the greatest public health crisis in our generation over the past year. We mounted vigorous research efforts to understand the viral biology and pathogenesis of the coronavirus disease 2019 (COVID–19), develop vaccines in record time, support and commercialize diagnostics at the point of care, and test therapeutics for both outpatient and inpatient settings. This work is far from finished.

The President's Discretionary Request proposes budget authority of $51 billion for NIH in fiscal year (FY) 2022. The Biden Administration places great emphasis on research and development in general. At NIH in particular, the Request proposes to build on the successes of pandemic era research and to put the research enterprise to work on some of our Nation's most persistent and perplexing health challenges, including cancer, Alzheimer's disease, opioid use disorder, health disparities, maternal mortality, HIV/AIDS, gun violence, climate change, and other areas with major implications for our Nation's health.

First and foremost, the President's Request proposes $6.5 billion to establish the Advanced Research Projects Agency for Health—ARPA–H to drive transformational innovation in health research and speed application and implementation of health breakthroughs. ARPA–H will tackle bold challenges requiring large scale, cross-sector coordination, employing a non-traditional and nimble approach to high risk research, modeled after DARPA in the Department of Defense. To achieve this, ARPA–H will invest in emergent opportunities by conducting advanced systematic horizon scans of academic and industry efforts, leveraging novel public-private partnerships, recruiting visionary program managers, and using directive approaches that provide quick funding decisions to support projects that are results-driven and time-limited. Potential areas of transformative research driven by ARPA–H include: the use of the mRNA vaccines to teach the immune system to recognize any of the 50 common genetic mutations that drive cancer; development of a universal vaccine that protects against the 10 most common infectious diseases in a single shot; development of wearable sensors to measure blood pressure accurately 24/7; and leveraging of artificial intelligence technology to advance care for individual patients and improve detection of early predictors of disease.

ARPA–H represents the kind of transformative idea for biomedical research that only comes along once in a long while. Our confidence that NIH is ready has been greatly advanced by our experience in addressing the COVID–19 pandemic—devel-

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[8] Lindberg LD et al, "Early Impacts of the COVID–19 Pandemic: Findings from the 2020 Guttmacher Survey of Reproductive Health Experiences," Guttmacher Institute (June 2020). https://www.guttmacher.org/report/early-impacts-covid-19-pandemic-findings-2020-guttmacher-survey-reproductive-health.

[9] Office of Population Affairs, "Title X Statutes, Regulations, and Legislative Mandates," US Department of Health and Human Services (March 2021). https://opa.hhs.gov/grant-programs/title-x-service-grants/title-x-statutes-regulations-and-legislative-mandates.

[10] Ensuring Access to Equitable, Affordable, Client-Centered, Quality Family Planning Services, 86 Federal Register 19812 (proposed April 15, 2021) (to be codified at 42 CFR 59).

oping vaccines in record time, establishing an unprecedented public-private partnership on therapeutics that has made it possible to test more than a dozen possible therapeutics in rigorous trials, and building a venture capital model for assessing SARS–CoV–2 diagnostic technologies that has yielded millions of daily tests in just months.

But while we begin to imagine a life after COVID–19, we must acknowledge that there are COVID-related impacts that we have yet to understand and address, including the full impact of the pandemic on children. Children were largely spared from COVID–19 but for some children, exposure to the COVID–19 virus led to Multisystem Inflammatory Syndrome in Children (MIS–C), a severe and sometimes fatal inflammation of organs and tissues. The Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) is leading a multi-institute initiative known as the Collaboration to Assess Risk and Identify loNG-term outcomes for Children with COVID (CARING for Children with COVID), which will assess both short-term and long-term effects of MIS–C and other severe illness related to COVID–19 in children, including cardiovascular and neurodevelopmental complications.

For many Americans, this pandemic and its related socioeconomic effects have had an overwhelming impact on their mental health. Prior research on disasters and epidemics has shown that in the immediate wake of a traumatic experience, large numbers of affected people report distress, including new or worsening symptoms of depression, anxiety, and insomnia. To aid in mental health recovery from the COVID–19 pandemic, NIH will continue to focus on research in this area. This will be done, in part, by utilizing participants in existing cohort studies, who will be surveyed on the effect of the pandemic and various mitigation measures on their physical and mental health.

The COVID–19 pandemic has brought into sharp focus the dramatic health disparities that exist across the American population. In addition, the Nation has been shaken by the killing of George Floyd and other attacks on people of color, forcing a recognition that our country is still suffering the consequences of centuries of racism. NIH will continue to address these disparities, specifically through research managed by the National Institute on Minority Health and Health Disparities (NIMHD), the National Heart, Lung, and Blood Institute (NHLBI), the National Institute of Nursing Research (NINR) and the Fogarty International Center (Fogarty).

NIMHD looks to better understand the human biological and behavioral mechanisms and pathways that affect disparity populations, better understand the long-term effects of disasters on health care systems caring for populations with health disparities and research focusing on the societal-level mechanisms and pathways that influence disease risk, resilience, morbidity and mortality. NINR and Fogarty both look to better understand and reduce rural health disparities in low-income counties in the southern United States, support nursing science focused on racial, ethnic, and socioeconomic health disparities, with the goal of closing the gap in health inequities and increase health disparity research in low and middle income countries.

In addition to the core health disparities research, the President's Request puts an additional specific focus on maternal morbidity and mortality (MMM), which disproportionately affect specific racial and ethnic minority populations. Black and American Indian/Alaska Native individuals are two to four times more likely to die from pregnancy-related or pregnancy-associated causes compared to white individuals. Furthermore, Black, Hispanic and Latina Americans, Asian, Pacific Islander, and American Indian/Alaska Native individuals all have higher incidence of severe maternal morbidity (SMM) compared to white individuals. The Implementing a Maternal Health and Pregnancy Outcomes Vision for Everyone (IMPROVE) initiative supports research on how to mitigate preventable MMM, decrease SMM, and promote health equity in maternal health in the United States.

As the climate continues to change, the risks to human health will grow, exacerbating existing health threats and creating new public health challenges. Major scientific assessments document a wide range of human health outcomes associated with climate change. While all Americans will be affected by climate change, underserved populations are disproportionately vulnerable. These populations of concern include children, the elderly, outdoor workers, and those living in disadvantaged communities. NIH is poised to lead new research efforts to investigate the impact of climate on human health, with the goal to understand all aspects of health-related climate vulnerability. Therefore, the President's Request includes a $100 million increase for research on the human health impacts of climate change.

The FY 2022 President's Discretionary Request makes a major additional investment to address the opioid crisis. The crisis of opioid misuse, addiction, and overdose in the United States is a rapidly evolving and urgent public health emergency

that has been exacerbated by the coronavirus pandemic. Since the declaration of a public health emergency for COVID, illicit fentanyl use and heroin use have increased, and overdoses in May 2020 were 42 percent higher than in May 2019.

The use of opioids together with stimulants, such as methamphetamine, is increasing; and deaths attributed to using these combinations are likewise increasing. Taking note of these trends, FY 2021 appropriation language expanded allowable use of Helping to End Addiction Long-term (HEAL) funds to include research related to stimulant misuse and addiction. Identifying how opioids and stimulants interact in combination to produce increased toxicity will enhance our ability to develop medications to prevent and treat comorbid opioid and stimulant use disorders and overdoses associated with this combination of drugs.

Finally, I'd like to take a moment to thank this Subcommittee for its recognition over the last two years that America's continuing leadership in biomedical research requires infrastructure and facilities that are conducive to cutting-edge research. With your support, we will break ground in the near future on a new Surgical, Radiological, and Laboratory Medicine division of our Clinical Center, which will replace severely outdated and deteriorating operating suites and lab space with state-of-the-art facilities. NIH continuously works to ensure that the buildings and infrastructure on its campuses are safe and reliable and that these real property assets evolve in support of science—but NIH's backlog of maintenance and repair is now nearly $2.5 billion. The President's FY 2022 Discretionary Request includes $250 million to make progress on reducing this backlog and requests flexibility for Institutes and Centers to fund construction, repair, and improvement projects.

COVID–19 compelled us to perform a stress test on biomedical research enterprise. The enterprise performed nobly. We found what worked, and also identified barriers we hadn't fully appreciated before, and invented new ways around them. The President's FY 2022 Discretionary Request is a roadmap for how to build on the successes of research, address our gaps, and apply our insights to the most important problems we face as a nation. With your support, the future is filled with opportunity. My colleagues and I look forward to answering your questions.

[This statement was submitted by Francis S. Collins, M.D., Ph.D., Director, National Institutes of Health.]

PREPARED STATEMENT OF THE NATIONAL KIDNEY FOUNDATION

The National Kidney Foundation (NKF) is pleased to submit testimony to highlight the significant burden that chronic kidney disease (CKD), including irreversible kidney failure, places on patients, families, and our nation's health care system. We urge the subcommittee to increase funding for programs and activities as a bold step to help transform CKD awareness, prevention, detection, and management. Specifically, NKF requests $15 million for CKD activities at the Centers for Disease Control and Prevention and a substantive increase, commensurate with or exceeding the increase for NIH as a whole, for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) for kidney research activities. We also urge greater collaboration between NIDDK and other Institutes studying related comorbidities and conditions, such as hypertension, cardiovascular disease, immunology, disparities, and genomics.

ABOUT CKD

CKD impacts an estimated 37 million American adults and was the nation's 8th leading cause of death in 2020. Although it can be detected through simple blood and urine tests, an estimated 90% of CKD patients are undiagnosed, often until advanced stages when it is too late for interventions to slow disease progression. Alarmingly, some patients are not diagnosed until they have progressed to irreversible kidney failure (end stage kidney failure, or ESKD) and undergo urgent start dialysis. More than 750,000 Americans have irreversible kidney failure, requiring kidney dialysis at least 3 times per week at a dialysis center; daily home dialysis, or a kidney transplant to survive. Medicare spends $130 billion on the care of people with a CKD diagnosis. Individuals with kidney failure represent 1% of Medicare beneficiaries but comprise 7% of Medicare fee-for-service expenditures. The need for a substantially increased federal commitment to address the societal and economic burdens of CKD is undeniable.

CKD is a disease multiplier, with many patients experiencing cardiovascular disease, bone disease, cognitive challenges, depression, and increased hospitalization. CKD also is an independent risk predictor for heart attack and stroke. Early-stage intervention can improve outcomes and lower costs, yet fewer than half of patients

with high blood pressure or diabetes (which together are responsible for three-fourths of all cases of ESKD) receive CKD testing. To improve awareness, early identification, and early-stage intervention, NKF calls on Congress to invest in kidney health programs throughout HHS.

DISPARITIES

CKD is characterized by racial, ethnic, and socioeconomic disparities. Blacks or African Americans, Hispanics, Asian Americans and Pacific Islanders, and Native Americans or Alaska Natives are at higher risk for CKD and ESKD. A common reason is the disproportionate incidence of chronic comorbidities such as diabetes and hypertension in many of these groups. While Blacks or African Americans make up 13 percent of the U.S. population, they account for 35 percent of Americans with kidney failure, and are almost four times more likely than Whites to progress to kidney failure. Hispanic Americans are 1.3 times more likely than Whites to have kidney failure. Blacks or African Americans and Hispanics experience more rapid decline of kidney function than Whites and are less likely to have had a visit with a nephrologist prior to starting dialysis. Disparities are present in kidney transplant as well. Blacks have less access to the kidney wait list and experience a longer wait once listed. As of May 6, 2021, Black patients were 31.5% of the kidney wait list candidates, but in 2020 they received only 27% of kidney transplants. Hispanics represent 21% of the wait list and received 18.4% of kidney transplants.

COVID–19

COVID–19 has amplified the CKD and ESKD disparities discussed above, as kidney patients (including transplant recipients) are at risk for severe COVID–19 infection and mortality. In October 2020, COVID–19 hospitalizations were 2,194 per 100,000 Medicare ESKD beneficiaries, compared to 320 per 100,000 Medicare aged beneficiaries. In data reported by CDC, from February 1–August 31, 2020, a comparison of observed and predicted monthly deaths among ESKD patients showed an estimated 8.7–12.9 excess deaths per 1,000 ESKD patients, or a total of 6,953–10,316 excess deaths. The increased vulnerability is due to a series of factors, including compromised immune systems, multiple comorbidities, and exposure through the in-center dialysis care environment that necessitates close contact with others. Transplant recipients in particular face higher COVID–19 mortality risk. In addition, patients experiencing severe COVID–19 are at an increased risk of developing acute kidney injury (AKI), often requiring the need for acute dialysis and sometimes resulting in CKD or irreversible kidney failure.

KIDNEY PUBLIC AWARENESS INITIATIVE

A key aspect of the Department of Health and Human Services's 2019 Advancing American Kidney Health (AAKH) Initiative is increased awareness of CKD among the public and health care practitioners to improve early detection, provide early intervention and improve outcomes. Early intervention can slow the CKD progression and, in some instances, prevent kidney failure, reduce the impact of comorbidities, and reduce hospitalizations and readmissions. A sustained Kidney Public Awareness Initiative under the guidance of CDC will educate at-risk individuals to enhance awareness of the causes, consequences, and comorbidities of kidney disease, and educate clinical professionals on early detection and opportunities for intervention.

CDC CHRONIC KIDNEY DISEASE INITIATIVE

The CDC Chronic Kidney Disease Initiative comprehensive public health strategy was created at the urging of Congress and NKF 15 years ago. Annual funding has fluctuated between $1.6 million and $2.6 million. This funding level has supported activities including the development of a web site for patients, surveillance and epidemiology activities, and assistance to the National Center for Health Statistics for CKD data collection. However, a more robust effort is needed to increase awareness and reduce incidence of CKD. The National Kidney Foundation requests additional funds to establish a CKD screening program to detect people at high risk and examine the benefits screening this population; determine changes in provider behavior and care, and monitor patients' health outcomes. Additional funding would also expand capacity for national CKD prevalence surveillance to allow for repeated laboratory measures in the National Health and Nutrition Examination Survey (NHANES). Current national estimates of CKD prevalence using NHANES rely on single measurements of both serum creatinine and urinary albumin, preventing re-

searchers from estimating CKD persistence. NKF requests $15 million to the CDC for these enhanced activities.

NIH NIDDK

Despite the high prevalence of CKD and its impact on patients and Medicare, NIH funding for kidney disease research is only about $700 million annually. NIH invests only $18 per CKD patient, a fraction of what it spends on other major diseases. Fiscal Year 2021 funding for NIDDK increased by less than 1%, the smallest percentage increase of any disease Institute under NIH. From FY 2015–2020, NIH monetary support for kidney research increased at half the rate of NIH funding increases overall. 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.

In December 2020, NKF established Research Roundtables comprised of nephrology leaders from prominent academic institutions, the pharmaceutical industry, and key bodies with expertise in the multiple areas of pre-clinical and clinical research, including pediatric nephrology, genetics, epidemiology, drug development, public health, and health equity. In addition, kidney disease patients as well as family members of children with kidney disease and living kidney donors were recruited to share patient priorities and viewpoints on research needs.

The Roundtables were charged with identifying pre-clinical and clinical areas of research in which additional funding could help bridge existing deficits in kidney disease treatments and reduce kidney disease incidence, reduce health disparities, and lower healthcare costs. Their final recommendations are expected in June 2021, which NKF will share with policy makers.

As the first step towards expanding kidney research opportunities, NKF requests a substantive funding increase for NIDDK in FY 2022 that is at least commensurate with if not exceeding the percentage increase to NIH as a whole. We also request additional support from other Institutes on kidney activities. Opportunities include NHLBI support for cardiorenal syndromes in CKD patients; NIAID initiatives to study CKD effects on the immune system; and NCI activities to study decreased kidney function in cancer patients. Thank you for your consideration of the National Kidney Foundation's requests for Fiscal Year 2022.

[This statement was submitted by Sharon Pearce, Senior Vice President, Government Relations.]

PREPARED STATEMENT OF THE NATIONAL KIDNEY FOUNDATION, THE AMERICAN SOCIETY OF NEPHROLOGY, THE AMERICAN SOCIETY OF PEDIATRIC NEPHROLOGY, AND THE NATIONAL KIDNEY FOUNDATION

On behalf of more than 37 million children, adolescents, and adults living with chronic kidney diseases (CKD) in the United States, the American Society of Nephrology, the American Society of Pediatric Nephrology, and the National Kidney Foundation request $46.11 billion for the National Institutes of Health in FY 2022, an increase of 7.3% that will provide real growth of 5% after accounting for the biomedical research and development price index of 2.3%, and request an increase for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) that is at least proportional to the increase for NIH. Greater investment in kidney research is needed to advance understanding of the under-recognized public health epidemic of kidney diseases and address the disproportionate impact of COVID–19 and racial disparities experienced by Americans living with kidney diseases.

For nearly 800,000 Americans, kidney diseases progress to kidney failure, a life-threatening condition for which there is no cure. Kidney failure is most commonly managed by in-center hemodialysis, a therapy that has changed little in the 50 years since its development with a survival rate worse than most cancers (and comparable with brain cancers), or a kidney transplant, the optimal therapy for most patients but often inaccessible due to a shortage of organs and inequities in our nation's transplant health system. Both therapies involve suppression of the immune system and put patients at increased risk of communicable diseases—especially COVID–19—and significant racial and ethnic disparities exist in terms of therapy access and patient outcomes.

Almost 50 years ago, Congress made a commitment to treat all Americans with irreversible kidney failure through the Medicare End-Stage Renal Disease (ESRD) Program regardless of age. Medicare spends $130 billion on the care of people with

kidney diseases, or 22% percent of all Medicare fee-for-service spending. Of this amount, $49 billion is spent managing the care of people with kidney failure. Individuals with kidney failure represent only 1% of Medicare beneficiaries but comprise 7.2% of Medicare fee-for-service expenditures. Despite this enormous societal cost, kidney disease research supported by NIH is equivalent to one-half of one percent of Medicare fee for service expenditures for beneficiaries with kidney diseases and kidney failure.

People with kidney diseases face stark racial and socioeconomic disparities in disease burden and access to care. Black Americans (17%) and Hispanic Americans (15%) are more likely to have kidney diseases than white Americans (14%) and these disparities increase as kidney diseases progress to kidney failure: Black Americans are 3.5 times more likely than white Americans to have kidney failure and Hispanic Americans are 1.5 times more likely to have kidney failure than white Americans. Disparities in prevalence and outcomes are due to multiple factors including lack of access to care, social determinates of health, and systemic racism. Greater investment in research is needed to increase understanding about the underlying causes of disparities and generate interventions to address them.

Kidney disease patients also are at an increased risk of severe outcomes from COVID–19, such as hospitalization and death, due to their vulnerable physical conditions, multiple chronic conditions, weakened immune systems, and for those on dialysis, the need to leave home three times a week to receive care in a facility with other vulnerable patients. Further, COVID–19 has been shown to cause kidney damage in as many as 50% of hospitalized COVID–19 patients, even those without a previous history of kidney disease, often requiring emergency dialysis. While the long-term effects of COVID–19 on kidney health and function are under investigation, it is likely that COVID–19 will lead to an influx of new patients with kidney diseases, and that some of these patients will require ongoing care. Despite the severe impact of COVID–19 on people with kidney diseases and kidney health, no dedicated COVID–19 funding has been provided to NIDDK to-date, forcing research of the impact of COVID–19 on kidney health to come at the expense of existing research projects.

Many kidney disease patients also experience comorbidities such as cardiovascular disease (including heart attack and stroke), anemia, bone disease, hypertension, and diabetes. Pediatric kidney disease patients often have rare medical conditions with different needs associated with them than typical adult patients, which must be better understood. Greater investment in kidney research should be an urgent priority to slow disease progression, improve treatment, reduce morbidities, and improve patients' quality of life. NIDDK-funded scientists have produced several major breakthroughs in the past several years that require further investment to stimulate therapeutic advancements. For example, NIDDK launched the Kidney Precision Medicine Project that will pinpoint targets for novel therapies-setting the stage for personalized medicine in kidney care. However, additional funding is needed to accelerate these and other novel opportunities to improve the care of patients with kidney disease. Better understanding of the natural history of kidney disease and its progression in adults and children could lead to earlier detection and better treatments to slow disease progression and perhaps prevent irreversible kidney failure.

Thank you again for your leadership, and for your consideration of our request. Should you have any questions or wish to discuss kidney disease research in more detail, please contact Erika Miller with the American Society of Pediatric Nephrology at emiller@dc-crd.com; Rachel Meyer with the American Society of Nephrology at rmeyer@asn-online.org; or Lauren Drew with the National Kidney Foundation (NKF) at lauren.drew@kidney.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 21,000 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.

ABOUT THE NATIONAL KIDNEY FOUNDATION

The National Kidney Foundation is the largest, most comprehensive, and long-standing patient-centric organization dedicated to the awareness, prevention, and treatment of kidney disease in the U.S. In addition, NKF has provided evidence-based clinical practice guidelines for all stages of chronic kidney disease (CKD), including transplantation since 1997 through the National Kidney Foundation Kidney Disease Outcomes Quality Initiative (KDOQI). For more information about NKF, visit www.kidney.org

[This statement was submitted by Sharon Pearce, Senior Vice President, Government Relations, National Kidney Foundation, American Society of Nephrology, American Society of Pediatric Nephrology, and National Kidney Foundation.]

PREPARED STATEMENT OF THE NATIONAL MARROW DONOR PROGRAM/BE THE MATCH

Chairwoman Murray, Ranking Member Blunt, 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, continuing the full funding of the C.W. Bill Young Cell Transplantation Program (Program) within the Health Resources and Services Administration (HRSA), Health Care Systems account. In Fiscal Year 2022, we respectfully request that the subcommittee increase funding for the Program to the amount of $56,000,000 to eliminate financial and socioeconomic barriers that reduce access to cellular therapies for thousands of primarily traditionally underserved patients.

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. In 2019, 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 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 two 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 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 prayer, 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 two 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. It's 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 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 39 million selfless volunteers worldwide, like my sons' donors, who stand ready to be a life-saving bone marrow donor. It also includes more than 806,000 cord blood units through Be The Match and international partnerships, 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.

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 funding you provided in Fiscal Year 2021, and which we are asking for in Fiscal Year 2022, 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 adjust 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 potentially life-saving donor, and for those who will need to look to the Program for help in the future, I urge

you to fund the C.W. Bill Young Cell Transplantation Program at $56 million to immediately provide access to therapy at the point of diagnosis for all patients.

Our bold request this year builds upon the full funding you provided in Fiscal Year 2021 to clear a pathway for more patients, especially those from minority and rural communities, to be able to access transplant services. More than any other Committee in Congress, the programs you support save lives every day. The increase we are asking for this year will immediately increase the number of patients who enter the pipeline to receive a bone marrow transplant for a lifesaving cure.

[This statement was submitted by Kristin Akin on behalf of National Marrow Donor Program/Be The Match.]

PREPARED STATEMENT OF THE NATIONAL MULTIPLE SCLEROSIS SOCIETY

Madam Chairwoman and Members of the Subcommittee, the National Multiple Sclerosis Society (Society) thanks you for this opportunity to provide testimony regarding fiscal year 2022 (FY22) funding for the federal agencies under the jurisdiction of the Labor, Health and Human Services, Education and Related Agencies (LHHS) subcommittee. Nearly one million people who live with multiple sclerosis (MS) rely on these agencies and as the U.S. recovers from the COVID–19 pandemic, the federal agencies and programs under the jurisdiction of this Committee are more important than ever.

The Society is supportive of the President's FY22 proposed budget request. We believe this request would support the ability of people with MS to receive the coverage and services they need and fund critical research toward a cure for MS. We urge the Subcommittee to provide the following funding in Fiscal Year 2022 (FY22):

—$500 million for the Agency for Healthcare Research and Quality (AHRQ)
—$10 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;
—$14.2 million for the Lifespan Respite Care Program;
—Robust support for Medicare and Medicaid and protection of Medicaid's current financing structure; and
—At least $46.1 billion for the National Institute of Health (NIH),
—Fully fund 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. The Society is a fundamental partner to the federal agencies under the LHHS jurisdiction, and is focused on curing MS while ensuring that people affected by the disease have what they need to live their best lives.

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

AHRQ is a small agency that is revolutionizing the healthcare system based on health care costs and quality. It provides evidence-based reports for health care providers to use in making health care safer, higher quality, more accessible, equitable, and affordable. These reports are vital to patients and the health care community, which needs high-quality science and evidence-based

information to aid in consultations on treatment decisions. The Society recommends Congress provide $500 million for AHRQ in FY22.

CENTERS FOR DISEASE CONTROL AND PREVENTION

CDC is tasked with protecting public health and safety through the control and prevention of disease, injury, and disability. COVID–19 demonstrated how years of consistent underfunding impacted the Agency's ability to fulfill its mission. Part of that mission that is often overlooked involves data collection for diseases and conditions. The 21st Century Cures Act authorized the creation of the National Neurological Conditions Surveillance System (NNCSS) at CDC, and Congress has funded it since 2018. Although COVID–19 has delayed its efforts, CDC has set up pilot projects in MS and Parkinson's disease to determine the best method to collected incidence and prevalence data. These methods would then 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 recommends that Congress increase funding for the CDC to $10 billion in FY22, inclusive of the $5 million for the NNCSS.

CENTERS FOR MEDICARE & MEDICAID SERVICES

Approximately 25–30 percent of the MS population relies on Medicare as their primary insurer. Many of these individuals are under the age of 65 and are eligible for Medicare due to disability. The Society urges Congress to ensure appropriate reimbursement levels for Medicare providers. These reimbursement levels allow Medicare beneficiaries to maintain affordable access to prescription drugs, diagnostics, durable medical equipment, medically necessary speech, physical and occupational therapy services, and allows the program to update coverage determinations to keep pace with advances in care.

Up to 15 percent of people with MS are thought to qualify for Medicaid benefits for all or part of their health and/or long-term care needs. The Society urges Congress to ensure robust funding for Medicaid that allows for its enrollees to access benefits that are affordable and adequate to their needs. Additionally, we advise Congress to oppose proposals to cap or block grant the program or that impose unreasonable utilization review practices that can result in disruptions in MS care, putting patients at risk of disease exacerbations and irreversible disability. Ensuing that lower income individuals have access to health coverage and care is vital to the continued health and economic recovery of the country 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 but can also become overwhelming. 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 the relief necessary to maintain their own health and bolster family stability. Many existing respite care programs have age eligibility requirements, but 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 $14.2 million for the Lifespan Respite Care Program in FY22.

NATIONAL INSTITUTES OF HEALTH

The importance of the NIH cannot be overstated. It is the nation's premiere biomedical research institution and drives innovation while supporting jobs in all 50 states. The NIH is a fundamental partner in the Society's mission to cure MS while empowering people affected by the disease to live their best lives. To date, the Society has invested over $1 billion in MS research; but we rely on Congress to provide consistent and sustained investments to the NIH to cultivate an environment that is optimal for scientific discovery and innovation. As evident by the NIH funding that paved the way to the development of the mRNA COVID–19 vaccines, 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. The Society urges Congress to provide at least $46.1 billion for the NIH in FY22. This funding level would allow for meaningful growth of 5% in the NIH base budget, and we urge the Agency to continue its efforts to diversify its workforce and grantees and to support the careers of early-career investigators.

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

PCORI serves a vital role in ensuring that the public and private health care 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 various care settings and can inform conversations about value that truly considers the patient perspective. This information is important to aid in shared decision-making conversations between people with MS and their healthcare providers in consultations on treatment decisions. To complete this important work, we urge Congress to fully fund PCORI in FY22.

SOCIAL SECURITY ADMINISTRATION (SSA)

Due to the unpredictable nature and sometimes disabling impairments 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 in FY22.

The Society thanks the Committee for the opportunity to provide written testimony on our recommendations for the base funding for federal agencies programs under the jurisdiction of the FY22 LHHS appropriations bill. The above agencies are of vital importance to people affected by 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 2022 APPROPRIATIONS RECOMMENDATIONS

—The Foundation joins the broader research community in requesting $46.1 billion in discretionary funding for the National Institutes of Health (NIH), an increase of $3.2 billion over FY 2021. Further, please provide proportional increases for the National Cancer Institute (NCI), the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), and other NIH Institutes and Centers.

—Please support adequate funding to establish the new Advanced Research Projects Agency for Health (ARPA–H) at NIH as proposed in the Administration's Budget Request to Congress to facilitate robust and tangible scientific progress on a variety of conditions, particularly cancers.

—The Foundation joins the broader public health community in requesting $10 billion in overall funding for the Centers for Disease Control and Prevention (CDC) to reinvigorate meaningful professional education, public awareness, and public health activities.

—Please provide the new CDC Chronic Disease Education and Awareness Program with $5 million, an increase of $3.5 million over FY 2021, to further advance and expand timely public health efforts with community stakeholders.

Chairwoman Murray, Ranking Member Blunt, 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 potential treatments for pancreatitis. Moreover, we thank you for establishing the new Chronic Disease Education & Awareness Program at CDC with an initial investment of $1.5 million in FY 2021. The COVID–19 pandemic has highlighted the importance of robust investment in public health and with an infusion of much-needed resources for CDC for FY 2022, please also enhance this important new initiative. 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 health care professionals.

CONDITIONS OF THE PANCREAS

Pancreatitis can be acute or 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. The advancements in the pancreatitis research portfolio have now led to treatment review activities at FDA and a critical Patient-Focused Drug Development Initiative meeting with the community.

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. While the details in the budget request remain sparse our hope is the new ARPA–H initiative will greatly enhance cancer research activities at NIH.

Over recent years, key Committee Recommendations have been included that have moved the pancreas and pancreatitis research portfolios forward, and it is our hope that the Subcommittee will continue to demonstrate an interest in this area during the FY 2022 process.

CDC CHRONIC DISEASE EDUCATION & AWARENESS PROGRAM

Thank you again for establishing the CDC Chronic Disease Education & Awareness Program in FY 2021 and providing an initial investment of $1.5 million. For many years, CDC has lacked public health initiatives in a variety of conditions where simple interventions can save lives and lower healthcare costs. Conditions of the pancreas are no exception and access to simple health information can prevent the progress of many conditions and in some cases lower the rate of pancreatic cancer. Many patient organizations are seeking timely collaborations with CDC that can directly impact patients and improve public health using this new mechanism. It is important that this emerging program receives annual funding increases to ensure it can grow and facilitate new projects. While CDC has the ability to fund meritorious proposals, there will be no shortage of opportunities and the current investment of $1.5 million will only go so far. Please increase funding for this program to $5 million for FY 2022.

Adam Barbosa—Rhode Island

I am a 21 year-old resident of Rhode Island. I had my first pancreatic episode at age 15. It wasn't until after my third attack, and many medical tests later, that the Drs. told me I had two genetic mutations (SPINK1 & CFTR) and a physical anomoly (pancreas divisum) that were causing my attacks. I was officially diagnosed with chronic pancreatitis. Since my first attack, my condition went on a downward spiral. I went from a 3-day hospital stay every 5–6 months to a 7-day stay every 2 months, then eventually every 2 weeks. At that point, my case was so severe that the only option I had was to have the TPIAT surgery at the University of Minnesota. The surgery lasted 14 hours, required the removal of 4 organs [pancreas and spleen included], and left me with post-operative cognitive dysfunction. A condition that has

crippled my college studies and hope for a "normal" future. Also, without a pancreas, I became an instant Type-1 diabetic. I now have to count carbs, dose myself with insulin and slug down a fistful of pills [pancreatic enzymes] before anything I eat/drink . I suffer with significant digestive issues and have lost 40 lbs. since surgery. Every day is an intense physical, mental, and emotional struggle. I suffer from depression, anxiety and panic attacks. Things I have come to find patients with a chronic illness have to deal with on a daily basis. There is no real "Recovery" from this surgery. My life is simply an agonizing waiting game for medical advancements.

Jenny Jones—Illinois

I am 36 and live in Chicago, Illinois. I was 9 or 10 years old when I experienced my first pancreatitis attack; my pediatrician at the time ran blood work and immediately said I would need a liver transplant. She also recommended we get a second opinion and see a GI pediatrician specialist at another local hospital. After a full battery of tests, the physician came to the conclusion that I probably had chronic pancreatitis. I am glad that we went for the second opinion. I battled this disease throughout my life, but it ceased after my ERCP from the ages of 17–24. But, when I was 24 the pancreatitis had returned and by then my sister was also diagnosed with pancreatitis. Life was ever more challenging, the pain intolerable, and I could not imagine living another 5–10 years this way. At this point, I had already become a Type 2 diabetic along with dealing with CP. In 2019, I had my 13-hour Total Pancreatectomy Auto Islet Cell Transplant at the University of Chicago Medicine on the South Side of Chicago where they removed my pancreas and transferred any working islets from the pancreas into my liver, removed half my stomach, small intestine, and duodenum. I am almost one-year post op and although I am now Type 3C diabetic, I am glad I choose to have the surgery. I am totally insulin-dependent and rely on an insulin pump as my islets have not awakened yet. My life post-op has been very challenging and I still deal with a measure of pain, and digestive issues. Despite all the surgeries and debilitating illnesses I have learned to become an advocate for others dealing with any chronic debilitating illness.

Cecilia Petricone—Connecticut

My story with pancreatitis started at the age of 12-years-old. Just a few weeks before I was supposed to start middle school I suddenly woke up with excruciating abdominal pain. After the first hospitalization, I started seeing lots of doctors including pancreatic specialists, my official diagnosis became Idiopathic Recurrent Acute Pancreatitis. During the first couple of years, I had genetic testing done which showed I have a SPINK1 mutation, which made me more prone to pancreatitis.

Doctors spent years trying to manage my symptoms. We tried changes to my diet, getting more rest, staying extra hydrated, taking precautions when I got onto airplanes, going on an anti-anxiety and getting multiple pancreatic stents—nothing worked. In fact, my condition worsened! My freshman year at Boston College was when things really escalated. My yearly hospitalizations had become 2–3 a year and my diagnosis transitioned from acute pancreatitis to chronic. My sophomore year of college I made a visit to the ER, unaware that it was the beginning of back-to-back pancreatitis attacks that left me living in a hospital for the majority of time between October 2017 and February 2018. I left school, finishing the fall semester partially from a hospital bed 3 months later than my classmates. I lost a significant amount of weight, was malnourished, and began losing my hair.

That was until March, when my pancreatic specialist recommended I consider getting a Total Pancreatectomy and Islet Auto Transplant (TPIAT). In April of 2018, I had the surgery. Fast forward three years later, I am in no pain and realize I am one of the lucky ones as having the TPIAT does not guarantee a life of being pain-free. I have Type 3C diabetes which I monitor and manage on a daily basis. While I am pain-free, there are mental and emotional hurdles that come with medical experiences as all-encompassing as this. I am deeply grateful to be healthy and to no longer suffer from pancreatitis and I believe that mental health is an incredibly important component of medical issues that needs to be addressed.

Jane Holt—Rhode Island

My name is Jane Holt and I am a patient with chronic pancreatitis from Rhode Island. My journey began in early January, 1988. I was at home, asleep, with my husband and four young children. I woke up in the middle of the night in excruciating pain. It felt as though my insides were exploding. I knew immediately there was something terribly wrong and I needed to go to the hospital. Ten days later my gall bladder was removed, after the surgery, I told the surgeon that the original pain was still there. I was able to get an appointment with a gastroenterologist at BI Deaconess Hospital in Boston in October, 1988. After doing a medical history and

blood work my doctor said he thought I had pancreatitis. I had an ERCP that confirmed this diagnosis. Finally, a cause for the pain and it only took several months instead of years for some patients. In November I had major surgery on my pancreas to open the ducts to my pancreas and the journey continued.

Since then, I've had a few ERCPs, many MRCPs, CAT scans, Ultrasound, and thousands and thousands of blood tests. I have travelled to Mayo Clinic, Lahey Clinic, George Washington Hospital for second opinions. My doctor has brought my records to many medical meetings for input from other physicians. Over the last 32 years I have done everything I can to try and fix this disease or at least find out more about it. For most patients treatment hasn't changed. The only treatment for patients is hospitalization and I would be hospitalized 3 or 4 times a year, sometimes for as long as a month. It is now even getting harder to get the one thing that can help, pain medication. We can't ignore patients like me. We have to do something to make a difference for all of our patients.

[This statement 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 $14.2 million in the FY 2022 Labor, HHS, and Education Appropriations bill for the Lifespan Respite Care Program administered by the Administration for Community Living, Department of Health and Human Services. The request is consistent with the Administration's request to double funding for the program and will allow all States to receive a Lifespan Respite Grant to help family caregivers, regardless of care recipient's age or disability, access affordable respite. Additional funding will help states improve respite quality; expand the respite workforce; and use person and family-centered approaches that provide family caregivers tailored information on how to find, use and pay for respite services.

The pandemic cast a harsh light on the lack of supports for the nation's family caregivers. When congregate and group settings became too risky for older adults and people with disabilities, the importance of family caregivers to providing care at home was greatly amplified. At the same time, the availability of services, such as respite, became harder to access. The Lifespan Respite network responded with flexible respite and support options for family caregivers. During this challenging time, this may have been the only support they received.

Respite Care Saves Money and Benefits Families. Now, more importantly than ever, 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 records of 28,000 children with autism enrolled in Medicaid and concluded that for every $1,000 states spent on respite, there was an 8% 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 reduce caregiver depression, stress and burden linked to caregiver health (Broady and Aggar, 2017; Lopez-Hartmann, et al., 2012; Zarit, et al., 2014).

With at least two-thirds (66%) 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% 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 53 million unpaid family caregivers of adults provide care worth $470 billion annually (National Alliance for Caregiving and AARP, 2020; 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%) of family caregivers care for someone between the ages of 18 and 75 (NAC and AARP, 2020). In addition,

nearly 14 million children with special health care needs require specialized care from parents and guardians (Child and Adolescent Health Measurement Initiative, 2021). Families caring for children with special health care 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% 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%) identified in the National Study of Caregiving were providing substantial help with health care tasks, yet, fewer than 17% used respite (Wolff, 2016). The percentage is similar for parents of children with disabilities. The Elizabeth Dole Foundation continues to recommend that respite should be more widely available to military and Veteran caregivers.

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 (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 health care 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%) reported that finding time to meet their personal needs was a major problem. Yet, more than half of the caregivers of individuals with ID or Autism Spectrum Disorder 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 or meaningful service options 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 services to reduce duplication and fragmentation, and improve respite access and quality.

Since 2009, 37 states and DC have received Lifespan Respite grants. The program received $4.1 million in FY 18 and FY 19, and $6.1 million in FY 2020. We are grateful for the increase to $7.1 million in FY 2021; however, the program received no emergency Congressional supplemental funding during the pandemic, despite the elevated need. 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 for all states and help current grantees complete their ground-breaking work in serving the unserved, and ensuring sustainability by integrating services into statewide No Wrong Door systems for long-term services and supports.

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 check ins, delivery of care packages, online support groups, virtual training and other educational services via Facebook and other social media outlets.

How is Lifespan Respite Program Making a Difference? Key accomplishments of State Lifespan Respite grantees are highlighted in a new ARCH National Respite

Network report, In Support of Caregivers [archrespite.org/key-accomplishments]. State Lifespan Respite programs are engaged in the following 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 were willing and states allowed it, these programs continued to operate with enhance flexibilities 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, MD, ND 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 NE, NY, SC, SD, 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 NC, 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.

During the pandemic, social isolation and severe mental health issues among family caregivers intensified. The CDC found that "unpaid adult caregivers reported having experienced disproportionately worse mental health outcomes, increased substance use, and elevated suicidal ideation." The Lifespan Respite network responded with flexible and innovative respite options. For countless caregivers, respite became their only lifeline to supports, services, and vital human connection. OK, ND, NV, WA, VA, and WI were some of the states that introduced flexibility to their respite voucher programs to encourage use, such as expanded eligibility and timeframes, increased flexibility in who could provide respite to include other family members in the home, and increased voucher amounts. Other Lifespan Respite grantees met the needs of family caregivers through new and creative approaches:

Alabama: Alabama Lifespan Respite, in order to increase targeted support to caregivers during the pandemic, offered Care Chats (one-on-one support by phone or video conferencing) with their social worker staff, monthly support groups, and caregiver mental health education opportunities to help increase overall caregiver wellness. Alabama Lifespan Respite also introduced a Caregiver Wellness Initiative that increases Emergency Respite reimbursement funds and designates funds specifically for mental health counseling to caregivers currently enrolled with their reimbursement (voucher) program. The intended impacts of the Caregiver Wellness Initiative include decreases in caregiver stress, anxiety, fatigue, and burnout after receiving Emergency Respite and/or mental health counseling.

Tennessee: The TN Respite Coalition awarded mini-grants for caregiver-selected items, such as personal protective equipment, tablets enabling internet access to online support groups, home exercise equipment, and movie or magazine subscriptions. Expanding ideas of traditional respite services, the Tennessee Respite Voucher Program provided respite in innovative ways that allowed for safe social distancing but maintained caregiver-provider contact that kept caregivers socially connected during times of increased stress and isolation.

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 $14.2 million in the FY 2022 Labor, HHS, and Education appropriations bill. Families will be able to keep loved ones at home safely and ensure their own well-being, 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 TECHNICAL INSTITUTE FOR THE DEAF

Mr. Chairman and Members of the Committee:

I respectfully submit the FY 2022 budget request for NTID, one of nine colleges of RIT, 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 FY 2022 I would like to request $89,700,000 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 24% of NTID's Operations budget coming from non-federal funds, up from 9% in 1970. Since FY 2006, NTID raised more than $26 million in support from individuals and organizations.

NTID's FY 2022 request of $89,700,000 includes $3,400,000 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 Rochester Regional Health 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 program, 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. The coronavirus has also demonstrated the national need for timely, accurate and official information in ASL about pandemics and health care concerns—a service the Hub could provide.

NTID's FY 2022 request also includes an additional $2,000,000 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 FY 2020, up to 2,023 educators, 1,685 students, 590 employers, 379 interpreters, 241 parents, and 190 vocational rehabilitation staff enrolled in NRSC programs (some may have enrolled in multiple programs).

NTID's FY 2022 operations request also provides $700,000 to establish a Computer Science and Cybersecurity Training Center for deaf and hard-of-hearing students based at RIT's new Global Cybersecurity Institute (GCI), a 52,000-square-feet facility providing students, researchers and industry professionals with the most advanced technology tools and education offerings to help further digital security across the world. The Cybersecurity Training Center would allow NTID to build on its new partnership with the GCI, which is currently offering a boot camp to deaf and hard-of-hearing students that results in an RIT GCI Cybersecurity Bootcamp Certificate and preparation for industry-standard certifications, including CompTIA Security+ and Cybersecurity First Responder. Finally, the requested increase in operations will also provide $2,100,000 for NTID to manage inflationary costs.

ENROLLMENT

Truly a national program, NTID has enrolled students from all 50 states. In Fall 2020 (FY 2021), NTID's enrollment was 1,101 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 FY 2021, 185 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, 181 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 five years, an average of 95% have found jobs commensurate with their education level. Of our FY 2019 graduates (the most recent class for which numbers are available), 95% were employed one year later, with 77% employed in business and industry, 16% in education and non-profits, and 7% 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 FY 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% of NTID deaf and hard-of-hearing graduates with bachelor degrees and 73% with associate degrees report earnings, compared to 58% of NTID deaf and hard-of-hearing students who withdrew from NTID and 69% 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% of NTID deaf and hard-of-hearing associate and bachelor degree graduates participated in the SSI program compared to 8% of deaf and hard-of-hearing students who withdrew from NTID. Similarly, at age 50, only 18% of NTID deaf and hard-of-hearing bachelor degree graduates and 28% of associate degree graduates participated in the SSDI program, compared to 35% 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 FY 2020, 118,240 hours of interpreting and 21,856 hours of real-time captioning were provided to students.

SUMMARY

NTID's FY 2022 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% over the past five years. Therefore, I ask that you please consider funding our FY 2022 request of $89,700,000 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 for the Deaf and Vice President and Dean, Rochester Institute of Technology.]

PREPARED STATEMENT OF THE NATIONAL VIRAL HEPATITIS ROUNDTABLE

Dear Chairwoman Murray, Ranking Member Blunt, and members of the subcommittee,

I am writing on behalf of the National Viral Hepatitis Roundtable (NVHR), a coalition of patients, health care providers, community-based organizations, and public health partners fighting for an equitable world free of viral hepatitis. We are respectfully requesting an increase in funding to CDC's Division of Viral Hepatitis (DVH), to no less than $134 million in FY 2022 from its current level of $39.5 million for FY 2021.

According to data released by the CDC last month, cases of acute hepatitis A increased by a staggering 1300% between 2015 and 2019, representing outbreaks of person-to-person transmission of this vaccine-preventable infection linked to substance use and homelessness. While reported rates of new hepatitis B infections generally remained stable over this period, the overwhelming majority occurred among unvaccinated adults between the ages of 30 and 59, with a substantial number of cases linked to injection drug use. Over this time period, acute hepatitis C cases surged by 63%, with estimated new infections now exceeding annual rates of new HIV infections in the United States. Specifically, CDC estimates 57,500 new hepatitis C infections for 2019, while noting that the true number could be as high as 196,000.

The tragedy of our viral hepatitis response is that these cases reflect failures in prevention, exacerbations in health disparities, and gaps in our public health system. We have strong tools—including vaccination for hepatitis A and B, alongside syringe services programs and medication-assisted treatment for opioid use disorder for hepatitis C—proven effective and well-established in preventing new infections, when implemented comprehensively and at scale. Chronic hepatitis B is treatable and chronic hepatitis C is curable, and indeed CDC's surveillance data and 2021 National Viral Hepatitis Progress Report show promising momentum in decreasing mortality from hepatitis B and hepatitis C, including among communities burdened with substantial racial/ethnic health disparities (Asian and Pacific Islander communities for hepatitis B, and American Indian/Alaskan Native persons and African Americans for hepatitis C).

The Department of Health and Human Services released a new National Viral Hepatitis Strategic Plan at the beginning of 2021, committing the nation to eliminate viral hepatitis as a public health threat by 2030 and outlining a comprehensive and credible set of strategies and priorities to achieve this goal. However, we cannot meet this challenge without reckoning with the persistent underfunding of viral hepatitis within the CDC budget, a chronic shortfall that cascades down to states and local communities struggling to keep pace with shifting trends and increased new cases as a downstream consequence of the broader opioid and stimulant health crisis. CDC's Division of Viral Hepatitis plays an essential role in leading our public health efforts towards viral hepatitis elimination, but can only fulfill that promise with adequate resources. We strongly urge the subcommittee to strengthen our public health infrastructure by investing at least $134 million in CDC's Division of Viral Hepatitis for FY 2022.

In tandem with this investment, we respectfully request that the subcommittee increases CDC's funding for eliminating opioid-related infectious diseases to $120 million in FY 2022, to accelerate urgent efforts to support building out programmatic infrastructure—particularly syringe services programs (SSPs)—capable of prevention and linkage to care for not only HIV and viral hepatitis but other infectious diseases such as endocarditis which disproportionately affect people who inject drugs. These programs continue to serve on the frontlines of both the COVID–19 pandemic and the overdose epidemic, uniquely effective at engaging a highly vulnerable and marginalized population that other systems—including health care—struggle to engage, serve, and retain in a timely and effective manner. In keeping with the vital importance of resourcing these programs, we similarly urge the subcommittee to remove restrictions on the use of federal funds to purchase sterile syringes in order to maximize the impact and benefits of these programs.

In conclusion, we thank the subcommittee for their commitment to public health and attention to viral hepatitis, and would be eager to respond to questions or provide additional information and context to support your work.

[This statement was submitted by Daniel Raymond, Director of Policy, National Viral Hepatitis Roundtable.]

PREPARED STATEMENT OF THE NEPHCURE KIDNEY INTERNATIONAL

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2022

—Provide $46.1 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.
—Provide $10 billion for the Centers for Disease Control and Prevention (CDC) and $5 million for the Chronic Disease Education and Awareness Program.

Chairwoman Murray and Ranking Member Blunt, thank you for the opportunity to present the views of NephCure Kidney International regarding research on focal segmental glomerulosclerosis (FSGS) and nephrotic syndrome (NS). NephCure is the only non-profit organization exclusively devoted to finding a cure and supporting patients with 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 and others. 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 related' 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 aggressive APOL1 gene variants. 75% of Black Americans with FSGS possess this gene. 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% of its entire budget, on ESRD. In 2005, FSGS accounted for 12% of ESRD cases in the U.S., at an an-

nual cost of $3 billion. It is estimated that there are currently approximately 20,000 Americans living with ESRD due to FSGS.

Research on FSGS and other forms of NS could achieve tremendous savings in federal health care 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 health care 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 (NEPTUNE) and the Cure Glomerulonephropathy Network (CureGN).

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 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 GN, a multicenter five-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 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 FY13. 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.

CHRONIC DISEASE EDUCATION AND AWARENESS

We thank the Subcommittee for the creation of the Chronic Disease Education and Awareness Program in FY2021 and encourage continued support by providing $5 million for this critical program in FY2022.

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 two 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!

Thank you for the opportunity to present the views of the FSGS/NS community.

[This statement was submitted by Irving Smokler, PH.D., Board Chairman, Acting 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 2022 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% 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 FY1990 to an estimated $36 million in FY2021. 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 NORTHWEST PORTLAND AREA INDIAN HEALTH BOARD

Greetings Chair Murray, Ranking Member Blunt, and Members of the Subcommittee, for the opportunity to share the Northwest Portland Area Indian Health Board's funding priorities for the Department of Health and Human Services (HHS) in FY 2022. My name is Nickolaus Lewis, and I serve as Council on the Lummi Indian Business Council, and as Chair of the Northwest Portland Area Indian Health Board (NPAIHB or Board). I thank the Subcommittee for the opportunity to provide testimony on FY 2022 HHS appropriations.

The NPAIHB is a tribal organization, established in 1972, under the Indian Self-Determination and Education Assistance Act (ISDEAA), P.L. 93–638 that advocates on behalf of the 43 federally-recognized Indian Tribes in Idaho, Oregon, and Washington on specific health care issues. The Board's mission is to eliminate health dis-

parities and improve the quality of life of American Indian and Alaska Native (AI/AN) people by supporting Northwest Tribes in the delivery of culturally appropriate, high quality health programs and services. "Wellness for the seventh generation" is the Board's vision. In order to achieve this vision, NPAIHB delegates respectfully ask that this Subcommittee consider tribal sovereignty, traditional knowledge, and culture in all policy initiatives and funding opportunities.

Last year, COVID–19 dramatically impacted Northwest Tribes. We are grateful for the diligent work of our Congressional representatives in ensuring that Tribal Nations were provided with resources, including vaccines, to battle this pandemic. We know that working together improved our ability take care of our people despite the long standing systemic and funding shortfalls to the Indian health care system. As we emerge from the pandemic, I make recommendations that will help rebuild and repair the foundational necessities for the Indian health care system.

HHS AND ITS AGENCIES

This Committee must honor tribal sovereignty and trust and treaty obligations as to HHS funding to Tribal Nations. For FY 2022, we ask this Committee to make the legislative changes needed across all HHS agencies to move away from grants and allocate funding to tribes through Indian Self-Determination and Education Assistance Act (ISDEAA) compacts and contracts. We also request Tribal set-asides and direct funding to tribes—not through state block grants.

We also request that this Committee consider the important role that Tribal Epidemiology Centers play in the Indian health system and support funding to TECs. TECs should be funded across HHS agencies to provide support to tribes in their area for any type of data or evaluation component, surveillance support and/or training and technical assistance. TECs know the tribes in their area and should be given the opportunity to support tribes in their roles as public health authorities.

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

Tribal Opioid Response. Through Tribal Opioid Response (TOR) funding, NPAIHB coordinated a TOR consortium of 28 Northwest Tribes. Our tribes have developed innovative opioid programs with positive outcomes reflecting the resilience in our area. For example, the Lummi Nation brought on success coaches (peers) for those using or in recovery and 18 of the 28 TOR consortium tribes have made medication-assisted treatment (MAT) available. However, a funding increase is needed for a more robust opioid response in tribal communities. In FY 2022, we request an increase in TOR funding to $75 million; and an increase in the Tribal MAT funding to $20 million.

Other Grant Programs. Thank you for the increases to the AI/AN Zero Suicide Initiative funding, and Tribal Behavioral Health Grants in FY 2021. For FY 2022, we request the following amounts for Tribal Specific Programs: fund the Tribal Behavioral Health Grant program at least $50 million—$25 million for mental health and $25 million for substance use disorder; fund the Garrett Lee Smith Suicide Prevention Tribal Set Aside at $3.5 million; fund Zero Suicide Initiative at $3 million; and fund the National Child Traumatic Stress Initiative Tribal Set Aside at $1.5 million.

Designated Resources for Youth Behavioral Health Programs. In order to comprehensively address the need for whole person mental health and substance use disorder services for AI/AN youth, there must be dedicated funding streams for culturally-centered prevention, intervention, treatment, aftercare and transitional living support. Funding for Youth Residential Treatment Centers that provide aftercare and transitional living for both substance use disorder and mental health are a priority for Portland Area Tribes and current facilities in the area do not meet demand. For FY 2022, we request $25 million in funding for youth-specific outpatient and inpatient mental health and substance use programs.

OFFICE OF THE SECRETARY

Minority HIV/AIDS Fund. The Minority HIV/AIDS Fund is a significant funding source for communities of color that have not traditionally been supported by mainstream opportunities, and includes important funding to IHS for HIV and hepatitis C (HCV) prevention, treatment, outreach and education. Tribes in the Portland Area appreciated the $1.5 million MHAF Tribal set-aside in FY 2021. For FY 2022, we request that funding for Minority HIV/AIDS Fund be increased to $80 million with a $15 million Tribal set-aside. This is a step toward addressing the impact that HIV has in Indian Country.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

Public Health Infrastructure & Environmental Impacts. COVID–19 has demonstrated the under-investment made by the federal government in public health and medical care infrastructure in the Indian, Tribal, and Urban (I/T/U) health system. The I/T/U system is underfunded, and lacks capacity to respond effectively to public health emergencies like COVID–19. We can no longer allow population density as the primary consideration in the allocation of emergency preparedness resources. In FY 2022, we request at least $1 billion for a Tribal Public Health Emergency Fund established through the Secretary of HHS that tribes can access directly for tribally-declared public health emergencies.

Include Tribes in HIV/HCV Funding Opportunities. HIV/HCV prevention and education generally flows to states via block grants. This leaves many tribes with limited or no resources and forces tribes to compete with states for funding. For FY 2022, we recommend that the Committee set-aside at least $25 million for HIV and HCV prevention for Tribal communities.

Fund Good Health and Wellness in Indian Country (GHWIC). The GHWIC initiative supports AI/AN communities in the implementation of holistic and culturally adapted approaches to reduce and prevent chronic disease through policy, system and environment changes. 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 to address food access issues, food insecurity, and support traditional food and local food system initiatives beyond COVID–19. NPAIHB recommends that the Committee allocate at least $32 million in FY 2022 to the Good Health and Wellness in Indian Country.

CENTERS FOR MEDICARE AND MEDICAID SERVICES (CMS)

Medicaid Legislative Initiative. HHS must work with Congress to pass legislation that creates the authority for states to extend Medicaid eligibility to all AI/AN people with household incomes up to 138% of the federal poverty level; authorizes Indian Health Care Providers (IHCP) in all states to receive Medicaid reimbursement for health care services delivered to AI/AN people under IHCIA; extends 100% FMAP to states for Medicaid services furnished by urban Indian providers permanently; excludes Indian-specific Medicaid provisions in federal law from state waiver authority; and removes the limitation on billing by IHCP for services provided outside the four walls of a tribal clinic.

Medicare Telehealth Reimbursement. Medicare telehealth expansion is set to expire at the end of the current public health emergency. Telehealth provided a way to care for our people during the pandemic and should be made permanent to increase access. We request that this Committee support legislation to make Medicare telehealth flexibilities permanent at the OMB encounter rate at I/T/U facilities, expand telephone-only telehealth visits, direct physician supervision of non-physician providers be provided remotely via telephone, and expand "originating site" locations from which telehealth services can be received, and support inclusion of multiple platforms including FaceTime, Zoom, and Skype.

Dental Health Aide Therapists Reimbursement. In Washington, tribes have faced barriers to get the state plan amendment in Washington approved to include dental health aide therapists (DHATs) working in tribal health programs in the Medicaid program. The state and the Swinomish Indian Tribal Community have petitioned the Ninth Circuit Court of Appeals to hear an appeal on the rejection of the Washington State Plan Amendment. Medicaid reimbursement for DHATs is critical to supporting and expanding dental services in tribal communities. We trust that this matter is resolved soon so tribal health programs in Washington can be reimbursed at the OMB encounter rate for these critical services.

HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

Provider Relief Fund Uninsured Program. The COVID–19 relief legislation packages exclude Indian Health Care Providers from receiving reimbursement from the Provider Relief Fund Uninsured Programs for uninsured American Indian/Alaska Native people. This exclusion is inconsistent with national Indian policy to elevate the health status of AI/AN people by making all resources available to the Indian health system. We request that the Subcommittee support the following legislative language to address this issue:

SEC. XXX. CLARIFICATION REGARDING INDIANS AND UNINSURED INDIVIDUALS.

Subsection (ss) of section 1902 of the Social Security Act (42 U.S.C. 1396a), as added by section 6004(a)(3)(C) of the Families First Coronavirus Response Act, is amended—(ss) in paragraph (2), by inserting "(except Indians (as defined in section 4 of the Indian Health Care Improvement Act (25 U.S.C. 1603)) who receive health services funded by the Indian Health Service, shall not be treated as enrolled in a Federal health care program for purposes of this paragraph)" before the period at the end.

Provider Shortages and Needs. The Broken Promises Report, National Tribal Behavioral Health Agenda, National Tribal Budget Formulation Workgroup Recommendations for 2021, and the IHS Strategic Plan all detail how culturally responsive care is critical for the health and well-being of AI/AN people. There are significant vacancy rates and challenges in filling vacancies at I/T/U facilities. Some of these challenges include: the rural location of tribal facilities, lower salaries, lack of incentives, and insufficient housing for providers.

For these reasons, we strongly recommend that the Committee support funding for HRSA, as follows:

—*Increase Tribal Set-Aside for Loan Forgiveness Program.* Increase tribal set-asides for loan forgiveness and include mid-level health care professionals such as Community Health Aide Program providers in the program.

—*Support Community Health Aide Program Expansion.* As IHS is expanding the CHAP program in the lower 48, HRSA must create new funding opportunities that support national CHAP expansion. We recommend $60 million to support CHAP education programs and other implementation activities.

NATIONAL INSTITUTES OF HEALTH

The Native American Research Centers for Health (NARCH) national program has catalyzed multiple tribal-academic partnerships that have resulted in many successful research projects and training opportunities for AI/AN people interested in science and health of AI/AN people. The NPAIHB's NARCH programs have supported and developed countless Native researchers through this program. We request that NARCH be a congressionally mandated funding priority as it supports tribal health research with the development of tribal health leaders to design and implement research that is responsive to tribal needs. In FY 2022, we recommend increased funding for the NARCH program to $20 million and request that 30% of the funding be directed to enhance AI/AN workforce development in parity with priorities of NIH institutes and centers.

Thank you for this opportunity to provide recommendations to the Committee on FY 2022 funding for HHS. We invite you to visit Portland Area Tribes to learn more about the communities, utilization of HHS funding, and health care needs in our Area. We look forward to working with the Subcommittee on our requests.[1]

PREPARED STATEMENT OF THE NURSING COMMUNITY COALITION

As the nation continues to address COVID–19, 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, the Nursing Community Coalition (NCC) respectfully requests that Congress continues robust and bold investment in nursing workforce, education, and research in Fiscal Year (FY) 2022 by supporting at least $530 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), a doubling of Title VIII funding, and at least $199.755 million for the National Institute of Nursing Research (NINR), which aligns with the President's FY 2022 budget and is 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 health care issues that impact education, research, practice, and regulation. Collectively, the NCC represents Registered Nurses (RNs), Advanced Practice Registered Nurses (APRNs),[1] nurse leaders, students, faculty, and researchers, as well as other nurses with advanced degrees. With more than four million nurses throughout the country, the NCC is committed to advanc-

[1] For more information, please contact Candice Jimenez, cjimenez@npaihb.org.

[1] APRNs include certified nurse-midwives (CNMs), certified registered nurse anesthetists (CRNAs), clinical nurse specialists (CNSs) and nurse practitioners (NPs).

ing the health of our nation through the nursing lens.[2] The nursing workforce is involved at every point of care, which is exemplified by nurses' heroic work during the COVID–19 pandemic. Together, we reiterate the bold request for increased funding for Title VIII Nursing Workforce Development programs and NINR, especially during these unprecedented times.

Providing Care to All Americans Through the Nursing Lens

As we continue to confront today's health care challenges and plan for tomorrow, increased federal resources for our nation's current and future nurses are even more imperative. Title VIII programs are instrumental in bolstering and sustaining the nation's diverse nursing pipeline by addressing all aspects of nursing workforce demand. In fact, the Bureau of Labor Statistics projected that by 2029 demand for RNs would increase 7%, illustrating an employment change of 221,900 nurses.[3] Further, the demand for most APRNs is expected to grow by 45%.[4] This is just one example on why continued and elevated investments in Title VIII Nursing Workforce Development Programs in FY 2022 is essential and will help nurses and nursing students have the resources to tackle our nation's health care needs, remain on the frontlines of the COVID–19 pandemic, assist with the distribution and administration of the vaccine, and be prepared for the public health challenges of the future.

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 frontlines and in rural and underserved areas throughout the country. In Academic Year 2019–2020, ANE programs supported more than 8,200 students.[5] Of these students directly supported by the Advanced Nursing Education Workforce (ANEW) program, 75 percent had clinical training sites in primary care settings, while 73 percent of Nurse Anesthetist Trainee (NAT) recipients were trained in medically underserved areas.[6]

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 $530 million for the Title VIII Nursing Workforce Development programs in FY 2022.

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.[7] It is imperative that we continue to support this necessary scientific research, which is why the Nursing Community Coalition respectfully requests at least $199.755 million for the NINR in FY 2022.

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 providing bold funding for Title VIII and NINR, Congress can continue to reinforce and

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[2] National Council of State Boards of Nursing. (2021). Active RN Licenses: A profile of nursing licensure in the U.S. as of February 9, 2021. Retrieved from: https://www.ncsbn.org/6161.htm.

[3] U.S. Bureau of Labor Statistics. (20). Occupational Outlook Handbook-Registered Nurses. Retrieved from: https://www.bls.gov/ooh/healthcare/registered-nurses.htm.

[4] U.S. Bureau of Labor Statistics. (2021). 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.

[5] Department of Health and Human Services Fiscal Year 2022 Health Resources and Services Administration Justification of Estimates for Appropriations Committees. Pages 153–158. Retrieved from: https://www.hrsa.gov/sites/default/files/hrsa/about/budget/budget-justification-fy2022.pdf.

[6] Department of Health and Human Services Fiscal Year 2022 Health Resources and Services Administration Justification of Estimates for Appropriations Committees. Pages 153–155. Retrieved from: https://www.hrsa.gov/sites/default/files/hrsa/about/budget/budget-justification-fy2022.pdf.

[7] 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.

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
Academy of Neonatal Nursing
American Academy of Nursing
American Association of Colleges of Nursing
American Association of Critical-Care Nurses
American Association of Heart Failure 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 Nursing Informatics 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
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 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 THE NUTRITION & MEDICAL FOODS COALITION

SUMMARY OF FISCAL YEAR 2022 APPROPRIATIONS RECOMMENDATIONS

—NMFC joins the research and patient advocacy community in requesting $46.1 billion in discretionary funding for the National Institutes of Health (NIH), an increase of $3.2 billion over FY 2021.
  —Further, NMFC requests proportionate increases for all NIH Institutes and Centers, including the Office of the Director (which now houses the Office of Nutrition Research), to reflect the vast array of applications for medical foods and nutrition to address a variety of health conditions through ongoing scientific inquiry and advancement.
—The Coalition joins the broader public health community in requesting $10 billion in overall funding for the Centers for Disease Control and Prevention (CDC) to reinvigorate meaningful professional education, public awareness, and public health activities.
—The community encourages ongoing outreach through the annual appropriations process to address systemic (and often arbitrary) barriers that obstruct proper patient access to medical foods including directing HHS and FDA to administer public health programs and regulations where medical foods are classified as prescription medical products intended for the dietary management of unmet needs.

Chairwoman Murray, Ranking Member Blunt, and distinguished Members of the Subcommittee: thank you for the opportunity to submit testimony on behalf of the Nutrition and Medical Foods Coalition (NMFC). We strongly support emerging efforts to modernize the medical foods category and enhance patient access, such as establishing the Office of Nutrition Research within the Office of the NIH Director, and the 2018 National Academies workshop on distinct nutritional requirements. As you work with your colleagues on appropriations for FY 2022, please continue to invest in medical research and public health programs to improve coverage and access for patients in need of medical foods. Medical foods provide important clinical product alternatives when drugs are not effective or well tolerated. Consistent with the establishment of the medical foods regulatory category in the Orphan Drug Act amendments of 1988, increasing medical research and expanding the reimbursement of medical food products from the hospital-only environment to retail pharmacies through Medicare, Medicaid, TRICARE, and medical insurance for federal employees, would enable the use of medical foods to address unmet medical needs and support scientific innovation providing clinical options to physicians as they work to manage national public health issues such as the Opioid Crisis, genetic disorders, and the increasing incidences of chronic diseases and conditions associated with aging like depression, osteoarthritis, IBS, and Alzheimer's. This could, in-turn, manage disease progression and lower national healthcare costs. Thank you for your time and please consider the Coalition a resource.

ABOUT THE COALITION

NMFC is a collaborative, multi-stakeholder effort to promote and advance proper use of safe and effective medical foods. Medical foods occupy a unique niche in healthcare and are used to manage many rare and chronic conditions for patients with unmet medical needs. NMFC is committed to educating policymakers and the general public about the role of medical foods in the healthcare ecosystem, while advancing an agenda focused on increasing medical research, improving regulation and oversight, and increasing access through appropriate insurance coverage and reimbursement.

The Coalition actively supports legislative efforts to address coverage and access, such as the Patient Access to Medical Foods Act (H.R. 56), Medical Nutrition Equity Act, and similar legislation. In this regard, NMFC calls on legislators to ensure that any updates to medical foods coverage:

—Maintains the integrity of the current (aforementioned) definition for the category.
—Does not arbitrarily carve out specific patient communities for coverage while leaving other communities (including patients without digestive or metabolic disorders) behind.
—Provides comprehensive coverage and adequate access to facilitate reasonable outpatient access to medical foods so there is health insurance pharmacy reimbursement in addition to historical access that exists through hospitals.

Moving forward, federal medical research and public health programs can play a key role in informing coverage and access updates while educating patients and providers about innovative (often cost-effective) healthcare options.

ABOUT MEDICAL FOODS

As defined by the Orphan Drug Act of 1988, a medical food is, "a food which is formulated to be consumed or administered enterally under the supervision of a physician, and which is intended for the specific dietary management of a disease or condition for which distinctive nutritional requirements, based on recognized scientific principles, are established by medical evaluation."

Currently, patients in need of medical foods face significant coverage and access barriers often stemming from a lack of awareness of these products and their unique role in the healthcare system. Reimbursement access is grounded in federal and private insurance pharmacy benefit plans often categorically denying coverage of medical foods through pharmacies as a policy matter while they generally reimburse under medical benefits in hospitals. This often results in patients being denied access to nutritional therapies which are necessary alternatives to drugs that are ineffective or not well tolerated. The Food and Drug Administration (FDA) regularly intervenes to provide guidance on medical foods, including through a recent episode where products were mislabeled as Over-The-Counter on massive level, but these interventions are inconsistent at best and often do not resolve underlying coverage issues.

PERSPECTIVE OF CINDY STEINBERG, US PAIN FOUNDATION

One example of important innovation in medical foods is in the area of chronic pain, a highly prevalent yet challenging condition to treat. The CDC has reported that 19.6 million Americans live with high-impact chronic pain resulting from a multitude of serious diseases, conditions and injuries that affects their ability to function on a daily basis. Indeed, chronic pain is the number one cause of disability in the US and globally.

There are few truly effective treatment options and most of these come with difficult side effects, safety concerns or other risks. Opioids do help some with severe pain but carry significant risks when diverted to those with substance abuse disorder. Non-steroidal anti-inflammatory (NSAIDs) medications are widely prescribed but, due to risks of heart attack, stroke and gastrointestinal bleeding are contraindicated for many, especially those with multiple chronic conditions. Acetaminophen has limitations due to insufficient pain relief and liver damage at doses high enough to alleviate serious pain for some. Moreover, federal agencies and the broader stakeholder community have been actively working over recent years to identify non-opioid options for pain management.

Medical foods have been found to fill a need for pain relief for individuals with certain chronic conditions such as osteoarthritis. Medical foods are generally safe products that can address conditions such as pain without causing other side effects. Distinct from both drugs and supplements, medical foods must be used under the supervision of a medical professional. Lack of awareness about medical foods as an emerging, cost-effective treatment option for certain pain conditions amongst healthcare providers and insurers have limited their use. Improving research and coverage for medical foods would offer patients another option, particularly those with multiple chronic conditions and unmet medical needs.

Recommendation:

Please include timely committee recommendations on medical foods research at NIH, like the example below, to sustain progress in this area. Please also work with your colleagues to engage HHS in a productive dialogue and otherwise seek out opportunities to improve coverage and access for patients in need of reliable access to medical foods. Thank you for your time and for your consideration of our request.

RECOMMENDED REPORT LANGUAGE

NATIONAL INSTITUTES OF HEALTH

OFFICE OF THE DIRECTOR

Office of Nutrition Research [ONR].—The Committee applauds NIH for recent efforts to move the Office of Nutrition Research to the Office of the Director in recognition of the fact that scientific progress in nutrition and medical foods now has applications to a variety of health topics and conditions beyond diet and metabolism. NIH is encouraged to continue to advance cross-cutting research through ONR, in-

cluding timely applications for a variety of conditions, such as innovative strategies and alternative therapeutic products for pain management.

[This statement was submitted by P. Keith Daigle, Acting Director, Nutrition & Medical Foods 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.

2021 is the 50th Anniversary of the National Cancer Act and it provides a unique opportunity to renew the country's commitment and bring new urgency to the fight against cancer. Although we have made much progress against cancer in the past half-century, more funding is needed to meet the overwhelming demand for research grants at the National Cancer Institute (NCI), address cancer health disparities, and mitigate the impacts of COVID–19 on cancer research, clinical trials, and patient screenings and treatment. For fiscal year (FY) 2022, we are asking that Congress fund the National Institutes of Health (NIH) at $46.111 billion, including $7.6 billion for the 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.

There is much to celebrate in the fight against the hundreds of diseases we call "cancer." 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. From 1991 to 2018, the cancer death rate fell 31 percent. However, cancer is still the second most common cause of death in men and women in the U.S. In 2021, almost 1.9 million new cancer cases will be diagnosed, and more than 600,000 people will die from cancer. Approximately $183 billion was spent in the U.S. on cancer related health care in 2015, and this amount is projected to grow to $246 billion by 2030-an increase of 34 percent.

Cancer is a disease that affects everyone, but it doesn't affect everyone equally. A close look at cancer incidence and mortality statistics reveals that certain groups, such as African Americans, Asian Americans, Hispanics/Latinos, Native Americans, Alaska Natives, Native Hawaiians/Pacific Islanders, and rural populations are more likely than the general population to suffer from cancer and its associated effects, including premature death. For instance, the death rate for Black men with prostate cancer is more than double that of men in every other population. Black women have a 40 percent higher breast cancer death rate than white women, even though their diagnosis rates are slightly lower.

There are still some cancers for which survival rates are dismally low with few, if any, effective treatments. In 2021, approximately 44 percent of patients will be diagnosed with a cancer that has a five-year survival rate below 50 percent. Research is critical so we can develop additional treatments and tools to ensure more Americans survive a cancer diagnosis.

Additionally, the NCI reports that we may see a rise in cancer mortality rates for the first time in almost 30 years because of the impacts from COVID–19. The COVID–19 pandemic has led to reduced access to care for cancer patients, including delays in cancer screening, diagnosis, and treatment. These delays will likely lead to a rise in late-stage diagnoses and cancer deaths in the years to come.

For the last 50 years, every major medical breakthrough in cancer can be traced back to the NIH and NCI. We know that investment in research at the NIH and NCI leads to lives saved. 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 FY 2020, the NIH provided over $34.6 billion in extramural research to scientists in all 50 states and the District of Columbia. NIH research funding also supported more than 536,000 jobs and more than $91 billion in economic activity last year.

COVID–19 and Cancer Research and Clinical Trials:

The Committee should be aware of the ongoing impact of COVID–19 on the cancer research ecosystem, including clinical trials. Thousands of researchers working on new discoveries that may one day alter the way we treat cancer had their projects disrupted, leading to increased costs and in some cases, having to restart research projects, losing data and productivity in the process.

COVID–19 has had serious consequences for cancer clinical trials, which play a pivotal role in advancing cancer care and treatment. The results of clinical trials

and the broader drug development process can take years to realize, meaning that without aggressive measures to mitigate the impact, the full effect of these disruptions on therapeutic innovation in cancer care is likely to be felt for years to come. Not only are cancer clinical trials critical in the over-all research and progress against the disease, for individual cancer patients, clinical trials often provide the best, and sometimes only, treatment option available.

We therefore urge Congress to provide the NIH with at least $10 billion to restore the research ecosystem so we can continue to make progress in the fight against cancer and other diseases. We hope that members of the Subcommittee can work with their colleagues to ensure this issue is addressed outside the usual appropriations process.

ARPA–H:

We understand that President Biden has called for the creation of an Advanced Research Projects Agency-Health (ARPA–H) as a key component to "drive transformational innovation in health research" to deliver cures for cancer and other diseases. Based upon available information, the initiative is likely to have twin focus areas: transformation of research and speeding application and implementation of breakthroughs in health care, where the current model has failed to deliver medical advancements. The President has spoken about the initiative and has included a $6.5 billion proposal in the his FY2022 budget, but few other details have emerged.

We in the cancer community are excited by a new initiative that focuses separate and additional resources on the development of new diagnostics, treatments, and even cures for cancer. However, we also know that clinical advances for patients have to be built on a broad foundation of basic scientific understanding.

Therefore, OVAC recommends that funding for ARPA–H remain separate from the established research enterprise and that Congress works to ensure that base funding for cancer research at the NCI is increased at a sustained, appropriate rate that ensures the pace of discovery is maintained.

OVAC Priorities for Fiscal Year 2022:

The NCI is currently experiencing a demand for research funding that is far beyond that of any other Institute or Center (IC). Between FY 2013 and FY 2019, the most recent year for which data are available, the number of Research Project Grant (R01) applications to NCI rose by 50.6 percent. For all other ICs during that time, the number of R01 applications rose by just 5.6 percent.

As a result of this extraordinary demand from the scientific community, the RPG success rate at NCI dropped from 13.7 percent in FY 2013 to 11.6 percent in FY 2019. This is a situation unique to NCI, at a time when cancer researchers are making historic advances in new treatments and therapies. The overall success rate for NIH during that same period rose from 16.8 percent to 21.2 percent.

Thanks to bipartisan, bicameral leadership, Congress has increased funding for NIH by $12.9 billion over the past six years. We are especially grateful that Congress has highlighted the need for dedicated funding to address the precipitous decline in the success rate for R01 applications at NCI. Significant, sustained funding increases for NCI are essential to raising the R01 success rate and ensuring progress in the fight against cancer continues.

Therefore, OVAC recommends at least $46.111 billion for NIH in FY 2022, a $3.177 billion increase over the comparable FY 2021 funding level, which would allow the NIH's base budget to keep pace with the biomedical research and development price index and provide meaningful growth of 5 percent. For NCI, we recommend $7.609 billion, the amount proposed by NCI in its FY 2022 professional judgment budget.

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 CDC's DCPC provides key resources to states and communities to prevent cancer by ensuring that at-risk, low-income communities have access to vital cancer prevention programs.

COVID–19's impact on screening and the early-detection of cancer will exacerbate current barriers to cancer prevention and early detection strategies, potentially increasing disparities in overall cancer outcomes. Additionally, addressing the backlog of cancer screenings for those without adequate health coverage will place a new burden on existing cancer screening programs, which have long been underfunded. CDC's programs help ensure that Americans have options for cancer screening regardless of income or insurance status. 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, OVAC recommends $559 million overall for DCPC, an increase of $173.1 million over the FY 2021 level.

Once again, thank you for your continued leadership on funding issues important in the fight against cancer. Funding for cancer research and prevention, survivorship, and must continue to be top budget priorities in order to increase the pace of progress in the fight against cancer.

Below please find an overview of OVAC's program level requests in the Labor-HHS bill:

National Institutes of Health (NIH)—$46.111 billion, including:
—National Cancer Institute (NCI): $7.609 billion
—National Institute on Minority Health and Health Disparities (NIMHD): $419.8 million
—National Institute on Nursing Research (NINR): $187.9 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: $13 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 million

PREPARED STATEMENT OF THE PANDEMIC ACTION NETWORK

On behalf of the Pandemic Action Network—a network of over 100 organizations that work together to drive collective action to help bring an end to COVID–19 and ensure the world is prepared for the next pandemic—I am pleased to offer testimony for Fiscal Year 2022 Labor, Health, and Human Services Appropriations.

To ensure the United States heeds the lessons learned from COVID–19 and helps ensure the world sustainably prioritizes and invests in pandemic preparedness, we respectfully urge you to increase funding to the U.S. Centers for Disease Control and Prevention (CDC) overall and bolster its critical role in promoting global health security; support permanent, dedicated funding for the Biological Advanced Research and Development Authority's (BARDA) work in emerging infectious diseases; and ensure the U.S. government contributes to global R&D efforts by strengthening the Coalition for Preparedness Innovations (CEPI). Specifically, Pandemic Action Network calls on the Committee to prioritize the following investments for FY22:
—No less than $456.4m for CDC's Center for Global Health Division of Global Public Health Protection and $226m for the Global Immunization Division;
—No less than $10m for CDC's Global Water, Sanitation & Hygiene program;
—No less than $735m for CDC's Center for Emerging Zoonotic and Infectious Diseases;
—No less than $300m in CDC's Infectious Disease Rapid Response Fund
—No less than $300m for BARDA's work on Emerging Infectious Diseases
—No less than $200 million support US investment in and partnership with the Coalition for Epidemic Preparedness Innovation (CEPI), in collaboration with BARDA

The COVID–19 pandemic has laid bare the grave health and socio-economic consequences of repeated failures to prioritize and invest in health security and pandemic preparedness both at home and abroad. The pandemic has already cost over 580,000 lives in the United States and 3.4 million around the world. The International Monetary Fund projects it will cost the global economy at least $22 trillion. While vaccination efforts have begun to dramatically reduce COVID–19 transmission in the U.S., the pandemic continues to spread globally as a majority of the world's population still lacks access to vaccines and other lifesaving tools and new variants of the virus continue to emerge. Until the virus is controlled around the world, Americans will not be safe and our domestic recovery will continue to stall.

The COVID–19 pandemic was an avoidable disaster. Partners in our network and infectious disease experts had been warning for decades of the threat of a fast-moving respiratory virus pandemic. Yet a persistent culture of panic and neglect, has prevented forward-looking and long-term investments in global health security. U.S. leadership and international cooperation is essential both to end this pandemic and to prepare for the next one. CDC, BARDA, and other agencies across the Depart-

ment of Health and Human Services have a critical role to play to keep both Americans and the world safe—but they must be appropriately, and sustainably, resourced. The Pandemic Action Network urges this committee and Congress to break this dangerous cycle once and for all and commit to increased—and sustained—investments in pandemic preparedness in Fiscal Year 2022 and beyond.

CDC:

The CDC comprises an essential piece of the U.S. and global health security architecture—by serving as the steward of U.S. public health and by partnering with countries to build and maintain their capacities to detect, prevent, and respond to emerging disease threats.

The Division of Global Public Health Protection (DGHP) works to protect Americans from dangerous health threats around the world and has been vital in the global fight against COVID–19. Graduates of its Field Epidemiology Training Program, a program to train disease detectives around the world, have been supporting COVID–19 responses in their countries through disease detection and rapid response, as well as data analysis, contact tracing, and community outreach. DGHP's Global Rapid Response Team has deployed more than 500 deployments for a total of nearly 16,000 person-days, to assist with COVID–19 emergency response at home and abroad. In a world where pandemic threats are growing in frequency, this critical work needs to be resourced and upscaled.

Many other divisions and programs within CDC are also critical to fighting deadly outbreaks and strengthening global health security, including the Global Immunization Division of the Center for Global Health, the Global Water, Sanitation & Hygiene program, the Center for Emerging Zoonotic and Infectious Diseases, and the Infectious Disease Rapid Response Fund. All have been routinely underfunded relative to their vital roles in protecting American and global health and deserve funding commensurate with their increasing demand and value.

BARDA:

BARDA has been playing an important and unmatched role in accelerating the development of medical countermeasures for emerging infectious diseases, including for Ebola, Zika, and pandemic influenza. The authority partners with industry on late-stage research and development, bridging the "valley of death" between clinical research and product development to translate basic science into urgently needed medical tools and technologies—where few entities operate.

Yet BARDA's work to combat COVID–19 and advance innovations for other emerging and neglected infectious diseases has largely been financed through emergency supplemental funding. This means that only when a disease crisis strikes does BARDA get the go-ahead and funding to advance countermeasures. Decades of research in health R&D laid the groundwork for the accelerated COVID–19 vaccine development—and humanity was lucky that we could build on progress in SARS and mRNA platforms. Emergency, surge funding is not a viable solution for pandemic prevention or preparedness: in many cases it is not even a solution for pandemic response. Annual, targeted funding for emerging infectious disease R&D will enable BARDA to work proactively to counter infectious disease threats so that we are prepared, and not caught flat footed when the next dangerous outbreak happens.

CEPI:

This Committee should also prioritize BARDA's partnership with CEPI, which has played a critical role in the COVID–19 response. Scientific partnership, collaboration, and resource sharing between BARDA and CEPI is critical to leverage their respective strengths and resources, and to promote the development of infectious diseases tools that can be rapidly deployed in a diverse array of settings. The U.S. should be a leading partner in supporting CEPI's new five-year plan of action with an annual appropriation of at least $200 million.

Just as the U.S. military is routinely resourced and prepared to fight a current war while getting ready for the next one, so too should Congress ensure that our civilian health infrastructure is equipped to fight this pandemic and prepare for the next one. We should commit the funds necessary to deploy a robust global response to the evolving COVID–19 pandemic while simultaneously make strong, sustainable, and ultimately cost-effective investments in future pandemic preparedness and prevention—lest we risk repeating the cycle of panic and neglect that spawned this protracted global emergency. Additional and sustained investments in CDC, BARDA, and CEPI are vital to America's health and security and warrant Congress's strong and unwavering support.

PREPARED STATEMENT OF PATH

This testimony is submitted by Jenny Blair 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 Chairwoman Murray, Ranking Member Blunt, and members of the Subcommittee on Labor, Health and Human Services, Education, and Related Agencies to submit written testimony regarding fiscal year (FY) 2022 funding for global health programs within the US 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 FY21 enacted level of $593 million to the Center for Global Heath (CGH) at the Center for Disease Control and Prevention (CDC) to sustain programming and replenish funds that have been diverted for the COVID–19 response that were intended for global immunization, malaria, global health security, and research and development (R&D). Within CGH, we specifically support increases for CDC's Division of Global Health Protection, which should be increased from $203.2 million to at least $456.4 million to bolster capacity to prevent, detect, and rapidly respond to emerging diseases—including the current COVID–19 pandemic—in low- and middle-income countries. We also support an additional $300 million for the Infectious Disease Rapid Response Fund, $30 million for CGH's Division of Parasitic Diseases and Malaria, and $271.1 million for the Global Immunization Division—of which $211.2 million should allocated to polio eradication and $60 million for measles. This funding allows CDC to save lives, reduce disease, prevent and detect future pandemics, and improve health around the world.

The Vital Role of HHS in Global Health and Security

PATH applauds Congressional appropriators for the global health funding that has been provided in four supplementals—the Coronavirus Preparedness and Response Supplemental, the CARES Act, the Coronavirus Response and Relief Supplemental Appropriations Act of 2021, and the American Rescue Plan Act of 2021—over the last year. COVID–19 has reached every country in the world, crippling economies, overwhelming health care systems, filling hospitals, dwindling supplies, and emptying public spaces. While we are beginning to see the end of the pandemic here in the United States, countries such as India and Brazil are still heavily impacted. With the potential for emergence of vaccine-evading strains, COVID–19 will continue to threaten global health security as long as it is uncontrolled anywhere in the world.

Investments that help contain diseases at the source are some of the most effective and important the US government can make. US investments through the CDC have been used to train epidemiologists, engage affected communities, improve disease detection and tracking systems, build Emergency Operations Centers (EOCs), and upgrade laboratories. Such efforts have allowed partner countries to greatly shorten their response times to outbreaks and epidemics—for example, enabling Cameroon to shorten its response timeline from 8 weeks to 24 hours. Many of the US's partner countries have deployed these systems for their COVID–19 response.

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. We must invest not only to end the current pandemic, but also to ensure that we are better prepared for the next one.

Protecting the US 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 US leads the world in 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 US contributed $1.718 billion through the National Institutes of Health (NIH) and $30 million through CDC toward the development of global health products.

In the current pandemic, support through NIH and the Biomedical Advanced Research and Development Authority (BARDA) helped speed the development and manufacturing of vaccines to prevent COVID–19, including through partnerships Janssen Research & Development, part of Johnson & Johnson, as well as Moderna. Under Operation Warp Speed, BARDA pivoted existing programs for pandemic influenza and other threats to accelerate the development of new vaccines, therapeutics, and diagnostic tests.

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 US is making sustained smart 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.

Today more than ever, the US is at the forefront of global health innovation because of long-term investment in NIH, CDC, and BARDA. To accelerate progress toward lifesaving tools for a range of health threats, we call for: maintaining robust funding for NIH and particularly for the National Institute of Allergy and Infectious Diseases (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 BARDA's work in emerging infectious diseases.

As a complement to continued investment in BARDA and NIH, the US should invest in the Coalition for Epidemic Preparedness Innovations (CEPI) which is working to advance at least twelve COVID–19 vaccine candidates. Investment in CEPI would allow the US to leverage funding from other global donors and ensure the US can influence the impact and outcome of CEPI's efforts. A US contribution to CEPI would leverage the contributions of other donors to increase overall pandemic preparedness and response effectiveness, including the potential to help increase the effectiveness of vaccines already being used in the United States.

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 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 worldwide; these programs also bolster local health systems and enable better disease detection. However, the COVID–19 pandemic has severely disrupted global immunization programs and continues to threaten achievement of critical global goals, such as polio eradication. Of the 129 countries able to report routine immunization data at the outset of the pandemic last year, over half reported moderate to total disruption of immunization services. Of the 26 countries that were forced to suspend measles immunization campaigns due to the pandemic, 18 reported measles outbreaks by July of last year, according to data available in November 2020. Suspended campaigns put 94 million people at risk of missing measles vaccinations in 2020. The Global Measles and Rubella Laboratory Network (M&RI), for example, has been repurposed to provide laboratory space, equipment, staff, and reagents for COVID–19 diagnostic testing, and measles immunization staff supported by M&RI are being called on to support COVID–19 responses in many vulnerable countries. These same systems and infrastructure will be essential to ensuring COVID–19 vaccines are distributed equitably.

Even before the COVID–19 pandemic, vaccines for measles, polio, and other diseases were out of reach, on an annual basis, for 20 million children under the age of one. Worldwide, more than 10 million children below the age of one do 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 leave pathways open to disastrous outbreaks in 2020 and future years and will increase imported cases of measles and other vaccine preventable diseases into the US. As health care continues to be disrupted globally, maintaining strong US support for global vaccination efforts—including key goals such as polio eradication, which we are on the brink of achieving—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 US 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, including serving as an evaluation partner in the large-scale pilot implementation of the RTS,S malaria vaccine in Kenya (one of three African countries involved). Malaria prevention and treatment programs have prevented more than seven million deaths globally since 2000. Sustained US commitment made this progress possible.

The World Health Organization estimates that nearly half the world's population lives in areas at risk of malaria-there were an estimated 229 million cases and 409,000 deaths from the disease in 2019 alone. Disruptions of essential health services due to the COVID–19 pandemic are having a catastrophic impact on the most vulnerable communities worldwide, threatening our progress against malaria. According to the Global Fund, in Africa malaria diagnosis and treatment has fallen roughly 15 percent during the pandemic and more than 20 percent of facilities have reported stockouts of medicines for treating children under five. In Asia, diagnosis and treatment has fallen almost 60 percent due to COVID–19, and 37 percent of facilities have reported COVID–19 infections amongst their health workers.

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 FY 2022, 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 ongoing threat of COVID–19. By fully funding global health and BARDA accounts, the US can prevent the further spread of disease, protect the health of Americans, and minimize the impact of COVID–19 on vulnerable populations worldwide.

[This statement was submitted by Jenny Blair, Manager, US & Global Policy and Advocacy, PATH.]

PREPARED STATEMENT OF PATIENT SERVICES, INC.

SUMMARY OF FISCAL YEAR 2022 APPROPRIATIONS RECOMMENDATIONS

PSI joins the broader patient advocacy community in requesting:

—$46.1 billion in discretionary funding for the National Institutes of Health (NIH), an increase of $3.2 billion over FY 2021.
  —Please provide proportional funding increases for the various NIH Institutes and Centers to expand and advance condition-specific research portfolios.
—$10 billion in overall funding for the Centers for Disease Control and Prevention (CDC) to bolster public health activities.
  —Please provide the new CDC Chronic Disease Education and Awareness Program with $5 million, an increase of $3.5 million over FY 2021, to further advance and expand timely public health efforts with community stakeholders.
—$9.2 billion for the Health Resources and Services Administration (HRSA) and $500 million for the Agency for Healthcare Research and Quality (AHRQ).
—PSI joins the broader patient advocacy community in requesting that the subcommittee continue to use the annual appropriations process, spending bills, and corresponding committee reports, to advance efforts that improve coverage and access for patients in need, including restoring equitable access to third party assistance offered by reputable charities.

Chairwoman Murray, Ranking Member Blunt, and distinguished member of the Subcommittee, thank you for your leadership on health funding and patient care issues. I am Gwen Cooper, and I look forward to working with you as the CEO of PSI. We share a goal of improving the lives of patients and families impacted by

rare, chronic, and life-threatening illness. In this regard, thank you for your ongoing efforts to invest in medical research, public health, and patient care programs. For FY 2022, please maintain this investment while continuing to utilize the appropriations process to highlight systemic issues and resolve contemporary coverage and access issues facing patients.

ABOUT PSI

PSI is a national nonprofit charitable assistance program with over 30 years' experience assisting patients in obtaining healthcare coverage and needed care and therapies. Founded by a patient for patients, we know the challenges of chronic illness. We help pay for medications, health insurance premiums and copays, navigate health insurance plans, provide free legal services, and walk alongside patients and their families through every step of their healthcare journey. Over the last ten years, we have had the privilege of providing over $800 million in financial assistance to help people obtain the healthcare they so desperately need. In 2020 alone, nearly 15,000 patients from every state across the nation benefitted from $56 million in financial assistance from PSI. We are honored to do the important work of breaking down barriers to healthcare access and payment options so that patients with rare and chronic diseases can focus on living their best lives.

ABOUT CHARITABLE ASSISTANCE

Patient assistance charities, like PSI, primarily raise private donations to provide health insurance premium assistance; pharmacy and treatment costs, as well as travel, nursing and ancillary services. Our programs help patients who are uninsured and underinsured in the commercial market, and beneficiaries of public insurance coverage like Medicare, Medicaid and TRICARE. PSI bridges the gaps in health coverage for families by providing premium assistance for:

—Medicare beneficiaries for Medicare Part D plans,Medicare Advantage plans and Medigap Plans.
—Patients during the 24-month waiting period for Medicare when qualified for Social Security Disability.
—Patients who no longer qualify for the Medicaid program because of age or income.
—Those who lose employer sponsored coverage through COBRA plans and plans through the Marketplace. In 2020, over 16M Americans lost their employer sponsored healthcare. PSI helped patients secure new plans for coverage lifesaving treatments.

When a patient turns to PSI, they often already have a doctor, and health plan, and a course of therapy. PSI simply assists them with the costs to maintain coverage and access, based on financial need and other factors. For patients with life-threatening conditions, who wish to continue working while managing their conditions, and those who do not qualify for disability or need-based federal programs, maintaining access to life-sustaining care is absolutely critical and few reliable options exist without compassionate charitable assistance. Most patients with rare and chronic diseases do not automatically quality for disability, nor do they want to. They wish to continue living their most productive lives through continued access to treatments required to manage their illness.

CONTEMPORARY EXAMPLES OF "BACKDOORS" TO PRE-EXISTING CONDITION DISCRIMINATION

Third Party Payer

Center for Medicare and Medicaid Services (CMS) has discouraged insurers from accepting payments from third party payers, including organizations like PSI and other nonprofit patient assistance programs (PAPs). This results in severe economic hardships for patients.

In November of 2013, CMS published a Frequently Asked Questions (FAQ) document which discouraged health insurers from accepting payments from third party payors on behalf of enrolled individuals. This FAQ document was CMS' response to reported concerns, by insurers, that accepting payments from someone other than the insured could skew the insurance risk pool and create an unlevel field in the Exchanges.

A subsequent 2014 CMS FAQ document clarified that CMS had not intended to discourage insurers from accepting third party premium and cost-sharing payments from state and federal government programs, Indian tribes, tribal organizations, and urban Indian organizations.

However, insurers were still discouraged from accepting third party payments from any other organizations, including PAPs and other charitable organizations, such as churches. This creates significant barriers to care for many patients who deal with recurring costs and chronic illnesses.

Copay Accumulators

CMS endorsed another tactic used by insurers to limit care for the most ill (and, thus, most expensive) patients—the copayment accumulator. A copay accumulator—or accumulator adjustment program—is a strategy insurance companies and Pharmacy benefit Managers (PBMs) use that stop manufacturer copay assistance coupons from counting towards a patient's deductible and out-of-pocket maximum spending. This is like saying a manufacturer's coupon would not lower your total grocery bill when you use the coupon at the grocery store. These coupons help lower the cost of medications in these scenarios: they can't afford the high cost of the medication; they have a high deductible plan and cannot t afford the copayment, and/or they qualify for PAP assistance but their insurer will not accept the payment due to the CMS rule.

Because CMS has endorsed the copay accumulator mechanism, patients often never reach their out-of-pocket maximum spending, putting other treatment for their diseases in jeopardy.

Specialty Claim Carve-Out or Alternative Funding Model

This prescription drug procurement model improperly uses for-profit drug manufacturers' free assistance programs to the detriment of patients who are forced to continually switch drugs because manufacturer assistance programs are time limited; diseases are not. Additionally, any costs for filling the prescriptions or are not counted toward the patient's out-of-pocket costs.

CONCLUSION

Over previous years, appropriators have asked HHS and CMS to explain the rationale and justifications for taking various coverage and access actions. It would be meaningful to have the new administration's perspective on these issues. The community would welcome the opportunity to share their experiences and collaboratively discuss challenges and opportunities with policymakers. In addition to including timely committee recommendations, please consider questions for the record and similar options to facilitate a productive discussion with the administration on enhancing coverage and access while Congress works on potential legislative solutions, as well. Thank you again and please consider PSI a resource for future conversations.

[This statement was submitted by Gwen Cooper, Chief Executive Officer, Patient Services, Inc.]

PREPARED STATEMENT OF THE PEDIATRIC POLICY COUNCIL

I write on behalf of the Pediatric Policy Council (PPC), a public policy collaborative of the Academic Pediatric Association, the American Pediatric Society, the Association of Medical School Pediatric Department Chairs, and the Society for Pediatric Research. We urge the subcommittee to provide robust investments in pediatric research and training to support the health and well-being of children, as outlined below. We are grateful for the investments Congress has made in these areas in recent years, as evidenced in particular through enhanced support for the National Institutes of Health (NIH) and other key pediatric research priorities, and hope you will support sustained increases in pediatric research and training priorities to enable the next generation of scientific discoveries to benefit child health.

Fiscal Year (FY) 2022 Funding Priorities:

—National Institutes of Health: $46.1 billion
—Eunice Kennedy Shriver National Institute of Child Health and Human Development: $1.7 billion
—Pediatric Subspecialty Loan Repayment Program: $50 million
—Gun Violence Prevention Research: $50 million split evenly between NIH and CDC
—Agency for Healthcare Research and Quality: $500 million
—Children's Hospital Graduate Medical Education: $485 million

National Institutes of Health (NIH):

Biomedical research is key to improving child health and well-being through new cures for pediatric conditions and a deeper understanding of children's unique biology. Research funded by the NIH has made significant strides toward treating and preventing chronic diseases, many of which have their roots in childhood. This work has led to new therapies, vaccines, and diagnostic tests that have improved the lives of millions of people worldwide. Pediatric research has yielded groundbreaking treatments for deadly chronic diseases, saved the lives of premature babies, and even cured some common childhood cancers. NIH funding also helps fund the development of physician scientists through loan repayment and research training awards. The COVID–19 pandemic has only further underscored the importance of the federal investment in biomedical research, which was crucial in developing the scientific knowledge and infrastructure to rapidly study the novel coronavirus in children and adults and to develop needed medical interventions like immunizations that will be key to ending the pandemic.

We urge a funding level for NIH of no less than $46.1 billion in FY 2022, a $3.2 billion increase over the agency's FY 2021 level. Within the overall FY 2022 funding for the NIH, we request $1.7 billion for the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)—the single largest funder of pediatric research within the NIH and a key leader in coordinating and advancing a pediatric research agenda NIH-wide. This amounts to a proportionate increase for NICHD of $117 million over FY 2021.

Pediatric Subspecialty Loan Repayment Program (PSLRP):

Across the country, there are significant shortages of pediatric subspecialists—pediatricians who pursue additional training to care for the most medically complex children—which lead to long travel distances and long appointment wait times for families. There is also a disparity in the geographic distribution of pediatric subspecialists, resulting in many children in underserved rural and urban areas not receiving timely health care. Shortages of pediatric subspecialists may also slow the development of the next generation of treatments and cures for young people, since many pediatric researchers are trained as subspecialists and dedicate their careers to research on complex health needs like Type 1 diabetes and autism spectrum disorder.

PSLRP is designed to address these shortages by providing qualifying child health professionals with up to $35,000 in loan repayment annually in exchange for practicing in an underserved area for at least two years, which would help address high medical school debt that serves as a barrier to pursuing training in a pediatric subspecialty. Congress reauthorized this program last year in the Coronavirus Aid, Relief, and Economic Security (CARES) Act in recognition of the need to support child access to pediatric medical and mental health care amid the COVID–19 pandemic. We urge you to begin addressing these shortages by providing $50 million in initial funding for PSLRP in FY 2022.

Gun Violence Prevention Research:

Gun violence is a public health crisis for citizens of all ages, genders, races, ethnicities, and socio-economic backgrounds—and this includes for children and youth. Firearms are now the leading cause of death for those 1–24 years old in the United States. Suicide accounts for 40% of these deaths. In the last decade, an increasing number of teenagers and young adults have died by suicide using a gun, which results in death more than 90 percent of the time. Funding to better elucidate risk and protective factors for gun violence in children and youth and their families is critical to decrease gun deaths and injuries. For the first time in 25 years, Congress provided a welcomed investment in this research in FY 2020 and again in FY 2021 at the NIH and the Centers for Disease Control and Prevention (CDC). After the absence of research funding for almost 3 generations of young investigators, additional funding is needed to rebuild the public health research infrastructure needed for gun violence. We therefore urge you to provide $50 million in funding for gun violence prevention research split evenly between the NIH and the CDC, a doubling of current funding in line with President Biden's FY 2022 budget request.

Agency for Healthcare Research and Quality (AHRQ):

The Agency for Healthcare Research and Quality (AHRQ) funds research into health care as it is practiced to improve care in the clinic and support quality improvement. For instance, AHRQ research has helped reduce unnecessary blood cultures in critically ill children and led to important insights about the health and economic benefits of increased physical activity in children. AHRQ has also played an important role in the development and evaluation of the Pediatric Quality Meas-

ures Program (PQMP), which is helping to improve quality of care for the 37.6 million children enrolled in Medicaid and the Children's Health Insurance Program. We urge you to provide $500 million in funding for AHRQ in FY 2022.

Children's Hospital Graduate Medical Education (CHGME):

The ability to produce top quality pediatric research is dependent on the availability of trained pediatrician scientists who choose to pursue a career in research. Many factors influence a physician's choice to pursue research, but a stable pipeline of trained clinicians is a critical prerequisite. Freestanding children's hospitals train half of all pediatricians and pediatric subspecialists despite representing less than one percent of hospitals. CHGME is necessary to maintain the number of pediatric residents and fellows in the United States and has allowed participating children's hospitals to improve their training experience for residents and fellows. A strong investment in pediatric training through freestanding children's hospitals is essential to ensuring that future pediatrician scientists are trained and have the opportunity to pursue pediatric research. We urge you to provide $485 million in funding for CHGME in FY 2022.

PREPARED STATEMENT OF ANN D. PEEL

Madam Chairwoman,

Amyloidosis is a rare and usually fatal disease. There is no known cure for amyloidosis, an abnormal folding protein disease that can destroy various major organs. The causes of the disease remain elusive. I ask that you include language in the Committee's report for fiscal year 2022 directing the National Institutes of Health (NIH), Office of the Director, Multi-Institute Research Issues to expand its research efforts into amyloidosis. I also ask the Committee to direct NIH to inform Congress on the steps taken to increase the understanding of the causes of amyloidosis and the measures taken to improve the diagnosis and treatment of this devastating group of diseases. The vaccines developed to combat COVID–19 illustrate the importance of the research necessary to overcome diseases. Only through more research can deaths from amyloidosis be prevented.

Over the years, your Committee has been instrumental in moving forward to finding the causes and a cure for amyloidosis. Efforts made by NIH and Amyloidosis Centers around the country are resulting in many more people being diagnosed and treated for amyloidosis than a decade ago.

I have endured two stem cell transplants in order to fight the deadly disease amyloidosis and have been one of the lucky ones to survive the disease for 18 years. This was due to the intensive, life-saving treatment that I have received through the Amyloidosis Center at Boston University School of Medicine and Boston Medical Center. I continue to participate in a clinical trial that looks for ways to diagnose and treat amyloidosis.

One of the major concerns is that current methods of treatment are risky and unsuitable for many patients. Even with successful initial treatment, amyloidosis remains a threat, since it can recur years later.

Due to research, there are new forms of treatment that are options for me and patients with recurring amyloidosis. These new treatment options were not available 18 years ago. They provide evidence that funding through Health and Human Services can make a difference.

I ask for your support in helping me turn what has been my life-threatening experience into hope for others.

WHAT IS AMYLOIDOSIS?

I have been treated for primary amyloidosis, which is immunoglobulin light chain (AL) amyloidosis. This type of amyloidosis occurs when cells in the bone marrow produce an abnormal amyloidogenic protein and these form amyloid fibrils that are deposited in major organs, such as the heart, kidney and liver. These misfolded proteins clog the organs until they are no longer able to function-sometimes at a very rapid pace.

In addition to AL amyloidosis, a blood or bone marrow disorder, there are also cases of inherited or familial amyloidosis and secondary or reactive amyloidosis. Familial amyloidosis may be present in a significant number of African Americans.

All three types of amyloidosis, left undiagnosed or untreated, are fatal. There is no explanation for how or why amyloidosis develops and there is no known reliable cure. Thousands of people die because they were diagnosed too late to obtain effective treatment. Thousands of others die never knowing they had amyloidosis. The small numbers of those with amyloidosis who are able to obtain treatment face chal-

lenges that can include high dose chemotherapy and stem cell replacement or organ transplantation.

Amyloidosis can cause heart, kidney, or liver dysfunction and failure and severe neurological problems. Left untreated, the average survival is just months from the time of diagnosis.

Researchers have not been able to determine the root cause of the disease or an effective low-risk treatment. Amyloidosis can literally kill people before they even know that they have the disease.

Older Americans are susceptible to heart disease due to amyloid formed from the non-mutated form of the same protein. Another type of amyloidosis, secondary or reactive amyloidosis, occurs in patients with chronic infections or inflammatory diseases.

All of these types of amyloidosis, left undiagnosed or untreated, are fatal.

HOW IS AMYLOIDOSIS TREATED?

Boston University School of Medicine and other centers for amyloidosis treatment have found that high dose intravenous chemotherapy followed by stem cell replacement, or rescue, is an effective treatment in selected patients with AL amyloidosis. Abnormal bone marrow cells are killed through high dose chemotherapy and the patient's own extracted blood stem cells are replaced in order to improve the recovery process. The high dose chemotherapy and stem cell rescue and other new drugs have increased the remission rate and long-term survival dramatically. However, this treatment can also be life threatening and more research needs to be done to provide less risky forms of treatment.

Timely diagnosis and treatment are of great importance. Early treatment is the key to success.

More needs to be done in this area to alert health professionals to identify this disease.

RESEARCH AND DIAGNOSIS

Researchers are moving forward with limited funding to develop targeted treatments that will specifically attack the amyloid proteins. Additional funding for research and equipment is needed to accomplish this task. Only through more research is there hope of further increasing the survival rate and finding treatments to help more patients.

Amyloidosis is vastly under-diagnosed. Thousands of people die because they were not diagnosed or diagnosed too late. More needs to be done to alert health professionals to identify this disease. Although I was diagnosed at a very early stage of the disease, many people are diagnosed after the point that they are physically able to undertake treatment.

I believe there are many more cases of amyloidosis than are known, as the disease can escape diagnosis and patients die of "heart failure," "liver failure," etc. In reality, some of these people had amyloidosis. Perhaps amyloidosis is not as rare a disease as we think.

Through the leadership of this Committee and the further involvement of the U.S. Government, several positive developments have occurred. Research supported by the National Institute of Neurologic Disorders and Stroke at NIH and the Office of Orphan Products Development at the Food and Drug Administration led to successful repurposing of a generic drug that markedly slows progression of familial amyloidosis.

Basic and clinical research at the Boston University Amyloidosis Center has increased: models of light chain (AL) amyloid disease have been developed; serum chaperone proteins that cause amyloid precursor protein misfolding are being identified; imaging techniques for the diagnosis of amyloid disease are being investigated; and new clinical trials for primary and familial amyloidosis are underway. Federal funding for research, equipment and treatment has been an important element in progress to date. Further funding is essential to speed the pace of discovery for basic and clinical research.

Madam Chairwoman, the United States Congress and the Executive branch working together are key to finding a cure for and alerting people to this terrible disease.

I want to use my experience with this rare disease to help save the lives of others. With your support more can be done to help me achieve my dream.

PREPARED STATEMENT OF THE PERSONALIZED MEDICINE COALITION

Chairwoman Murray, Ranking Member Blunt 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 (FY) 2022 appropriations and the importance of the agency's research to personalized medicine. PMC is a nonprofit education and advocacy organization comprised of more than 220 institutions from across the health care spectrum who support this growing field. The tragically uneven effects of the COVID–19 pandemic have underlined the importance of developing more targeted health care interventions just as groundbreaking technologies are giving us an unprecedented ability to understand the biological and environmental factors that drive disease and influence patients' responses to various treatments. As the subcommittee begins work on the FY 2022 Labor, Health and Human Services, Education and Related Agencies appropriations bill, we strongly support the President's proposed increase in funding for NIH to $51 billion, and we request the agency receive no less than $46.1 billion for NIH's base program level budget, $3.2 billion above the comparable FY 2021 funding level.

Personalized medicine, also called precision or individualized medicine, is an evolving field in which physicians use diagnostic tests to determine which medical treatments will work best for each patient or use medical interventions to alter molecular mechanisms that impact health. By combining data from diagnostic tests with an individual's medical history, circumstances and values, health care providers can develop targeted treatment and prevention plans with their patients. Personalized medicine promises to detect the onset of disease, pre-empt its progression, and improve the quality, accessibility, and affordability of health care.[1] By increasing government spending on science at this pivotal moment, Congress can help advance a new era of personalized medicine that promises a brighter future for patients and health systems.

I. THE ROLE OF NIH IN PERSONALIZED MEDICINE

Continued research on the genetic and biological underpinnings of disease has made it possible to develop new personalized medicine treatments for cancers as well as rare, common, and infectious diseases. This research has informed the development of more than 286 personalized treatments[2] and over 166,703 genetic testing products[3] available for patients in 2020. Foundational advances in genetic and genomic technologies have also paved the way for scientists' rapid response to COVID–19. The rapid progress we have seen, from mRNA vaccine development, diagnostic testing, and variant sequencing, to beginning to understand how human genomic variation influences infectivity, disease severity, vaccine efficacy, and treatment response, relies on years of personalized medicine research,[4,5]—as well as years of diligent funding from Congress to support this research.

The widely variable effects of COVID–19 have only highlighted the need for personalized medicine to move further and faster. A $3.2 billion increase would allow for NIH's base budget to keep pace with biomedical inflation and allow meaningful growth of 5 percent. This request also includes the full $496 million NIH is scheduled to receive in FY 2022 from the Innovation Account established in the 21st Century Cures Act (Cures Act).

II. SUSTAINING BASIC AND TRANSLATIONAL RESEARCH FOR PERSONALIZED MEDICINE

NIH is leading scientific discovery for personalized medicine, which begins with basic research that generates fundamental knowledge about the molecular basis of a disease and with translational research aimed at applying that knowledge to develop a treatment or cure. Many institutes and centers at the NIH are supporting research 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), the National Heart, Lung and Blood Institute (NHLBI), and the National Center for Advancing Translational Sciences (NCATS). An increase for NIH in FY 2022 would protect its foundational role in the identification and development of treatments, technologies, and tools for personalized medicine.

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[1] http://www.personalizedmedicinecoalition.org/Userfiles/PMC-Corporate/file/PMC__The__Personalized__Medicine__Report__Opportunity__Challenges__and__the__Future.pdf.

[2] http://www.personalizedmedicinecoalition.org/Userfiles/PMC-Corporate/file/PMC__The__Personalized__Medicine__Report__Opportunity__Challenges__and__the__Future.pdf.

[3] https://doi.org/10.1002/ajmg.c.31881.

[4] https://doi.org/10.1016/j.cell.2021.01.015.

The future of cancer care, for example, is expected to be profoundly influenced by personalized medicine approaches for detecting and treating early- and late-stage cancers. In 2020, for example, FDA approved the first comprehensive pan-tumor liquid biopsy test for patients with advanced cancer that allows physicians to detect actionable biomarkers in patients' blood through next-generation sequencing.[6] As soon as next year, NCI aims to launch large national trials for similar tests that are being developed to detect multiple early-stage cancers in patients' blood.[7] These tests would provide less invasive testing options that can detect cancers at early stages when treatment may be more effective and less costly.

Basic and translational research also offers opportunities for personalized medicine beyond oncology, especially for rare diseases. Although individually rare, rare diseases collectively affect an estimated 25 to 30 million Americans. 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, and in 2019, the estimated economic cost of only 379 rare diseases reached nearly $1 trillion in the U.S.[8] Over the past decade, NIH has helped shift the scientific approach to researching rare diseases from one disease at a time to many diseases. 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 others living with highly prevalent diseases where personalized medicine can offer patients better treatments or a cure. The Alzheimer's Association estimates that 6.2 million Americans are living with Alzheimer's disease, for example.[9] Despite increasing numbers of Alzheimer's diagnoses and FDA's recent approval of the first new Alzheimer's drug in decades, researchers are still studying the genetic underpinnings of Alzheimer's disease to more fully understand its complexity. To shorten the time between the discovery of potential drug targets and the development of new drugs, the Accelerating Medicines Partnership for Alzheimer's disease led by NIH has identified over 500 drug targets, and in 2020 launched a second iteration of the partnership to enable a personalized medicine approach to researching new treatments.[10]

Still, ensuring that the scientific breakthroughs in personalized medicine are impactful to all patients will require the inclusive and equitable representation of patients with diverse characteristics and health needs in research. Improving research policies and incorporating diverse perspectives into solving complex scientific problems, such as through NIH's UNITE initiative and NHGRI's action agenda for a diverse genomics workforce, will play a key role in addressing these disparities, in addition to research on improving minority health and understanding factors contributing to health disparities.

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 provided for by Congress in the Cures Act.

The first initiative, the All of Us™ Research Program, was launched in 2018 to begin collecting genetic and health information from one million volunteers as part of a decades-long research project. As of May 2021, over 382,000 individuals consented to participate and over 279,000 have fully enrolled.[11] More than 80 percent of those individuals are from groups historically underrepresented in research,[12] such as seniors, women, Hispanics and Latinos, African Americans, Asian Americans and members of the LGBTQ community. Last year, program officials met their targets to start returning individual genetic results to participants and inviting researchers to begin using the data collected.[13] The program also began analyzing data from its diverse participant cohort to look for patterns explaining individuals'

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[5] https://doi.org/10.1038/s41586-020-2817-4.

[6] http://www.personalizedmedicinecoalition.org/Userfiles/PMC-Corporate/file/PM__at__FDA__The__Scope__Significance__of__Progress__in__2020.pdf.

[7] https://www.precisiononcologynews.com/policy-legislation/nci-director-sharpless-outlines-ideas-aggressively-lower-cancer-deaths.

[8] https://everylifefoundation.org/burden-study/.

[9] https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf.

[10] https://www.nih.gov/research-training/accelerating-medicines-partnership-amp/alzheimers-disease.

[11] https://www.joinallofus.org/newsletters/2021/may.

[12] https://doi.org/10.1016/j.cell.2021.01.015.

different responses to COVID–19.[14] In the future, pooling health care data across large datasets will play a key role in advancing research for personalized medicine approaches to care.

The second initiative, the Beau Biden Cancer Moonshot, aims to transform the way cancer research is conducted by fostering collaboration and data sharing. Moonshot currently supports over 240 new research projects,[15] including the Partnership for Accelerating Cancer Therapies (PACT). Through PACT, the NIH is collaborating with 12 pharmaceutical companies, the Foundation for NIH, and FDA to identify, develop, and validate biomarkers to advance the discovery of new immunotherapy treatments. Over the past decade, personalized treatments harnessing the immune system have driven declines in mortality for lung cancer and melanoma.

IV. CONCLUSION

PMC appreciates the opportunity to highlight the NIH's importance to the continued success of personalized medicine. As the subcommittee considers the President's proposal, we encourage the subcommittee to support at least a $3.2 billion increase for existing centers and programs, in addition to funding Congress may provide for targeted initiatives such as establishing the President's proposed Advanced Research Projects Agency for Health (ARPA–H). PMC believes that diligently funding basic and translational research at the NIH is key to bringing us closer to a future in which every patient benefits from an individualized approach to health care.

[This statement was submitted by Cynthia A. Bens, Senior Vice President, Public Policy, Personalized Medicine Coalition.]

PREPARED STATEMENT OF THE PHYSICAL ACTIVITY ALLIANCE

Members of the subcommittee, thank you for the opportunity to testify today. My name is Mark Fenton. I am an adjunct associate professor at Tuft University and a nationally recognized public health, planning, and transportation consultant. I am representing the Physical Activity Alliance, the nation's broadest coalition dedicated to promoting physical activity for health. As such, I'm pleased to testify today on specific opportunities to improve Americans' health in the fiscal year (FY) 2022 Labor, Health and Human Services, Education and Related Agencies appropriations bill that address funding for the Centers for Disease Control and Prevention. I respectfully request you work over the next three years to triple the budget of the Centers for Disease Control and Prevention (CDC) National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) to $3.75 billion, including in this next budget at least $125 million for the Division of Nutrition, Physical Activity and Obesity (DNPAO), and $10 million for Active People Healthy Nation (APHN), an initiative to help 27 million Americans become more physically active by 2027.

The Active People Healthy Nation support would build on the increased capacity of the public health infrastructure from a 50-state DNPAO program funding commitment. The 50-state program, including the District of Columbia, would allow for each state to have resources for staff who are experts in:

—Promoting physical activity through community and state changes to increase safe and convenient access to physical activity, especially for those populations most at risk of physical inactivity, through activities such as master planning, access to parks, safe routes to school, and improvements for physically active (walking and bicycling) routes to everyday destinations.
—Promoting nutrition security especially for the youngest and most vulnerable populations
—Obesity prevention and management with linkages to health care systems
—Communication and policy
—Evaluation, quality improvement and accountability
—Equitable and inclusive community engagement

The specific resources for Active People Heathy Nation would allow states, municipalities and, local communities to leverage the expertise of the 50-state program to specifically address the populations who are the most disproportionately affected by risk of chronic diseases (including obesity, diabetes, cancer and heart disease) due to their lack of safe and convenient access to physical activity. This could include but is certainly not limited to:

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[14] https://www.nih.gov/news-events/news-releases/all-us-research-program-launches-covid-19-research-initiatives.
[15] https://doi.org/10.1016/j.ccell.2021.04.015.

—Implementing social support systems and networks to promote walking for older populations.
—Implementing low-cost "quick builds" to improve street designs to encourage safe walking and biking at the local level in specific neighborhoods where health disparities are the greatest.
—Convening local groups to develop action plans for promoting safe and convenient access to local parks and other key destinations.
—Promoting safe routes to schools with design changes (e.g., high visibility crosswalks, traffic calming near schools) to increase safety and to reduce hesitancy from parents.
—Taking steps to prioritize safety over speed in local and state policies and practices.

As a consultant to communities across the country, I have seen the positive impact of these funds in communities, especially for those that are historically underresourced. The pandemic has demonstrated that chronic diseases and infectious diseases are inextricably linked and inequity can be exacerbated. Addressing chronic diseases, their associated risk factors, as well as mental health and well-being are essential for improving our population health and productivity. And physical activity to improve cardiorespiratory fitness are integral interventions. Being physically active is one of the most important lifestyle behaviors people can engage in to maintain their physical health, improve their mental health, and optimize well-being.[1]

—Studies show that physical activity is associated with strong immune response, better outcomes from community-acquired infectious disease, reduced mortality and increased vaccine potency.[2,3,4,5]
—Physical activity also contributes to social connectedness,[6] quality of life,[7] and environmental sustainability.[8,9]
—Regular physical activity is both health-promoting and important for treatment and prevention of diseases such as cardiovascular disease and cancer that are the leading causes of death in the U.S., with numerous benefits that contribute to a disability-free lifespan.[10]
—There are racial, ethnic and socioeconomic status (SES) disparities that exist with regard to physical activity, access to recreational spaces and physical activity-related programs. These disparities differ with respect to occupation, transportation, community infrastructure, and leisure.[11,12,13]

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[1] US Department of Health and Human Services. Physical Activity Guidelines for Americans, 2nd edition. 2018.

[2] Nieman DC, Wentz LM. The compelling link between physical activity and the body's defense system. J Sport Heal Sci. Published online 2019. doi:10.1016/j.jshs.2018.09.009.

[3] Hamer M, Kivimäki M, Gale CR, David Batty G. Lifestyle risk factors, inflammatory mechanisms, and COVID–19 hospitalization: A community-based cohort study of 387,109 adults in UK. Brain Behav Immun. Pblished online 2020.

[4] Dixit S. Can moderate intensity aerobic exercise be an effective and valuable therapy in preventing and controlling the pandemic of COVID–19? Med Hypotheses. Published online 2020.

[5] Perico, L., Benigni, A., Casiraghi, F., Ng, LFP., Renia, L., Remuzzi, G. Immuity, endothelial injury and complement-induced coagulopathy in COVID–19. Nature Reviews Nephrology. October 2020.

[6] Wray, A., Martin, G., Ostermeier, E., Medeiros, A., Little, M., Reilly, K., Gilliland, J. Physical activity and social connectedness interventions in outdoor spaces among children and youth: a rapid review. Health Promotion and Chronic Disease Prevention in Canada. Research Policy and Practice. April 2020; 40(4): 1–12.

[7] Posadzki, P., Pieper, D., Bajpai, R., Makaruk, H., Kongsen, N., Lena Neuhaus, A., Semwal, M., Exercise/physical activity and health outcomes: an overview of Cochrane systematic reviews. BMC Public Health. November 2020. https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-020-09855-3.

[8] Global Advocacy Council for Physical Activity International Society for Physical Activity and Health. The Toronto Charter for Physical Activity: A Global Call for Action. J Phys Act Health. 2010;7 Suppl 3:S370–85.

[9] Safe routes to school: Steps to a greener future. How walking and bicycling to school reduce carbon emissions and air pollutants. Accessed online November 2020 at https://www.saferoutespartnership.org/sites/default/files/pdf/SRTS__GHG__lo__res.pdf.

[10] Wen CP and Wu X. Stressing harms of physical inactivity to promote exercise. Lancet. 2012;380:192–3.

[11] Thornton, C.M., Conway, T.L., Cain, K.L., Gavand, K.A., Saelens, B.E., Frank, L.D., Geremia, C.M., Glanz, K., King, A.C., and Sallis, J.F. Disparities in pedestrian streetscape environments by income and race/ethnicity. SSM-Population Health, 2016; 2, 206–216.

[12] Engelberg, J.K., Conway, T.L., Geremia, C., Cain, K.L., Saelens, B.E., Glanz, K., Frank, L.D., and Sallis, J.F. Socioeconomic and race/ethnic disparities in observed park quality. BMC Public Health, 2016;16:395.

Continued

—Low physical activity and fitness pose immediate and long-term threats to our nation's safety and security. Currently, 71 percent of Americans ages 17–24 fail to meet core eligibility requirements for entrance into the military, creating a serious recruiting deficit.[14] Among those who do meet basic requirements for service, musculoskeletal injuries associated with low fitness levels cost the Department of Defense hundreds of millions of dollars,[15] and have been identified as the most significant medical impediment to military readiness.[16]

Streets and downtowns that are designed to safely accommodate the physically active modes (walking, biking, and transit) along with motor vehicles are more economically robust,[17] have more resilient real estate values,[18] and are increasingly appealing to businesses because of enhanced employee recruitment and retention.[19]

Physical activity is integral to population health and well-being, educational achievement, effective health care delivery, emergency preparedness, and military readiness, and will be critical to our nation's recovery from the pandemic. If we can help more Americans to be physically active, we will save lives, contribute to lower vehicle emissions and health care costs, reduce racial, ethnic, gender, and socioeconomic health disparities, improve mental well-being, and make American employers and the U.S. overall much more productive and successful.

I thank you for the opportunity to offer my perspective today, and for your continued leadership.

PREPARED STATEMENT OF PLANNED PARENTHOOD

Dear Chairwoman Murray and Ranking Member Blunt,

Planned Parenthood is the nation's leading reproductive health care 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 health care, we reach 2.4 million people in our health centers, 1.1 million people through educational programs, and see 198 million visits to our website every year. People come to Planned Parenthood for the accurate information and critical resources they need to stay healthy and reach their life goals. For many of our patients, Planned Parenthood is their only source of care—making our health centers an irreplaceable part of this country's health care system. Backed by more than 17 million supporters, Planned Parenthood Action Fund works every day to defend access to health care and advance reproductive rights at home and abroad. Through our international arm, Planned Parenthood Global, we provide financial and technical support to nearly 100 innovative partners in nine countries in Africa and Latin America for service delivery and advocacy to expand access to reproductive health care and empower people to lead healthier lives.

Longstanding progress towards addressing sexual and reproductive health both here in the United States and around the world has been undermined and is threatened to erode further—both deliberately and as a result of unprecedented challenges, most notably the COVID–19 pandemic. The Biden-Harris administration has taken welcome early actions to reverse the Trump-Pence administration's ideological and harmful policies—including the global gag rule and Title X domestic gag rule—and prioritize sexual and reproductive health and rights, but more action is needed

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[13] Jones, SA., Moore, LV., Moore, K., Zagorski, M., Brines, SJ., Diez Roux, A., Evenson, KR. Disparities in physical activity resource availability in six US regions. Prev Med. 2015; 78:17–22.

[14] U.S. Department of Defense, Joint Advertising Market Research and Studies. (2016). The target population for military recruitment: youth eligible to enlist without a waiver. https://dacowits.defense.gov/Portals/48/Documents/General%20Documents/RFI%20Docs/Sept2016/JAMRS%20RFI%2014. pdf?ver=2016-09-09-164855-510.

[15] Bulzacchelli M, Sulsky S, Zhu L, Brandt S, Barenberg A. The cost of basic combat training injuries in the U.S. Army: injury-related medical care and risk factors. In: Military Performance Division, U.S. Army Research Institute of Environmental Medicine. Edited by Natick MA, March 2017.

[16] Hauret KG, Jones BH, Bullock SH, Canham-Chervak M, Canada S. Musculoskeletal injuries description of an under-recognized injury problem among military personnel. AmJ Prev Med. Jan 2010; 38(1)(suppl):S61–S70.

[17] Liu JH, Wei S, Understanding Economic and Business Impacts of Street Improvements for Bicycle and Pedestrian Mobility: A Multi-City, Multi-Approach Exploration. Nat'l Inst. for Transportaion & Communities, NITC–RR–1031–1161, April 2020.

[18] Bokhari S, How Much is a Point of Walkscore Worth? https://www.redfin.com/news/how-much-is-a-point-of-walk-score-worth/. Aug 2016, update Oct. 2020.

[19] Andersen M, Hall ML, Protected Bike Lanes Mean Business, Alliance for Biking and Walking, 2016, https://www.peoplepoweredmovement.org/site/images/uploads/Protected__Bike__Lanes__Mean__Business.pdf.

from both the administration and congress to ground policies in science and equity and expand access to health care, including sexual and reproductive health, for millions, particularly for those who most often struggle to overcome the systemic barriers to care. Meanwhile the pandemic has exacerbated existing inequities in health care systems and created a growing need for timely services, including those to help with the growing number of households that have identified a need for affordable family planning and increasing rates of sexually-transmitted infections (STIs).

Through these extraordinary challenges, Planned Parenthood health centers continue to expand services and innovate new and better ways to deliver health care and information—through telehealth and in health centers across the country. We are breaking down structural barriers to accessing reproductive health care by making it more timely, relevant and equitable for all people.

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 health care and other resources are among those most severely impacted. The ongoing COVID–19 pandemic has underscored the inequities in access to health care worldwide, both within and between countries, and is further exacerbating gender-based violence and the financial barriers to seeking care that is needed, including sexual and reproductive health services.

On behalf of Planned Parenthood Federation of America, I respectfully request that while assembling legislation to provide appropriations for fiscal year 2022 (FY22) you provide increased funding for key sexual and reproductive health funding priorities while also ending harmful and discriminatory policies that undermine access to care, including by:

1. Building Back the Title X Family Planning Program
2. Increasing Funding for STI Prevention
3. Increasing Funding for the Teen Pregnancy Prevention Program and the CDC's Division of Adolescent School Health, and Eliminate Harmful and Ineffective Abstinence-Only-Until-Marriage Programs
4. Eliminating Harmful Policy Riders that Limit Access to Abortion

1. Building Back the Title X Family Planning Program

Title X is the nation's only federal program dedicated to providing affordable birth control and other reproductive health care to people with low incomes. Despite mass outcry from the public health community and American people, in August 2019 the Trump administration began enforcing a rule that made significant changes to Title X. The gag rule—a harmful regulation that prohibits Title X providers from giving their patients full and accurate information—dismantles the program and blocks people struggling to get by from getting free or low-cost birth control, STI services, cancer screenings, and other essential health care. The gag rule slashed the Title X network's patient capacity nearly in half, creating unacceptable barriers to affordable care. The gag rule resulted in family planning providers in 33 states leaving the program and at least 1.5 million people, many of whom are low-income, losing access to Title X-funded care at the site they had used in 2018. More than 1,000 sites (roughly 25 percent) have left the Title X network; six states (HI, ME, OR, UT, VT, and WA) currently have no Title X-funded services.

In the meantime the COVID–19 pandemic has further exacerbated the county's sexual and reproductive health care needs. In spring 2020, 33 percent of women faced delays or were unable to get contraception or other care because of the COVID–19 pandemic, while 34 percent wanted to get pregnant later or wanted fewer children because of the pandemic. Women belonging to groups already experiencing systemic health and social inequalities—such as Black and Latina women, queer women, and low income women—reported the greatest change in fertility preference and barriers to access.

In April 2021, the Biden administration issued a notice of proposed rulemaking and we applaud their proposal to rescind the gag rule and make several modifications aimed at "strengthen[ing] the program and ensur[ing] access to equitable, affordable, client-centered, quality family planning services for all clients, especially for low-income clients." [1] However, an increase in annual funding will be necessary to help rebuild the Title X network and provide much-needed care to qualifying participants.

[1] https://www.hhs.gov/about/news/2021/04/14/fact-sheet-notice-of-proposed-rulemaking-ensuring-access-to-equitable-affordable-client-centered.html.

The best analysis (conducted prior to the pandemic and without adjusting for inflation) estimates that the Title X program would need $737 million in annual funding to address the unmet family planning needs for low-income women. We urge Congress to provide the program with $512 million in FY22 funding—an increase halfway towards the unmet need of the program—to help rebuild the Title X network and restore access to critical health care services.

2. Increasing 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. This month the latest annual CDC surveillance report announced that STD rates have reached an all-time high for the sixth consecutive year. In 2019, more than 2.5 million cases of syphilis, chlamydia, and gonorrhea diagnoses were identified in the United States.[2] Of particular concern were cases of congenital syphilis—syphilis passed from a mother to her baby during pregnancy—which have quadrupled between 2015. Congenital syphilis can result in miscarriage, stillbirth, newborn death, and severe lifelong physical and neurological problems. The report also identified that disparities in rates persist among racial and ethnic groups. For example, STD rates for Hispanic or Latino people ranging up to two times those of non-Hispanic White people. Rates for American Indian or Alaska Native and Native Hawaiian or Other Pacific Islander people were 3–5 times as high while rates for African American or Black people were five to eight times those of non-Hispanic White people. All of this has likely been exacerbated by the COVID–19 pandemic which has reduced access to essential screening and treatment services and stretched public health resources thin.

Screening and treatment for STIs-including HIV/AIDS-are an essential part of planning for a healthy pregnancy and healthy communities. 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. Increasing funding for the CDC's STI prevention programs is a cost-effective public health investment that will improve the lives of women and all Americans across the country. We ask that you fund CDC/NCHHSTP at $1.4 billion for FY22, including $252.91 million for the Division of STD Prevention.

3. Increasing Funding for the Teen Pregnancy Prevention Program and the CDC's Division of Adolescent School Health, Eliminate 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, less than 43 percent of all high schools and only 18 percent of middle schools across the country provide education on all of the CDC's identified topics that are critical to ensuring sexual health.[3] Congress should continue to make investments in programs that are proven to promote adolescent health by increasing young people's access to medically accurate and age-appropriate sexual health information that they need to make safe and healthy decisions.

Since fiscal year 2010 (FY10), 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. Beginning in 2015, 84 organizations in 33 states, the District of Columbia, and the Marshall Islands were awarded TPPP funds to replicate evidence-based programs in communities with the greatest needs; conduct rigorous evaluation of new and innovative approaches to prevent unintended teen pregnancy; or build capacity to support implementation of evidence-based programs. 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,

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[2] Centers for Disease Control and Prevention (CDC). 2019 STD Surveillance Report. April 13, 2021. https://www.cdc.gov/nchhstp/newsroom/2021/2019-STD-surveillance-report.html.

[3] Centers for Disease Control and Prevention. School Health Profiles 2018: Characteristics of Health Programs Among Secondary Schools. Atlanta: Centers for Disease Control and Prevention; 2019.

highlighted TPPP as a model example of a federal program that has developed evidence in support of good policy.

Planned Parenthood urges you to increase TPPP funding to $150 million. This $49 million funding increase from FY21 to FY22 is partially offset by eliminating $35 million for discretionary sexual risk avoidance (SRA) grants. Additionally we urge you to support $6.8 million for dedicated evaluation transfer authority, and ask that $900,000 of the $6.8 million in Public Health Service Act funding for "Evaluation of Teen Pregnancy Prevention Approaches" be allocated specifically to reactivate the Teen Pregnancy Prevention Evidence Review. 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 ($66 million over the FY21 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 FY22.

4. Eliminating Harmful and Discriminatory Policy Riders That Undermine Access to Abortion and Reject Any New Anti-Sexual and Reproductive Health Provisions

Opponents of sexual and reproductive health and rights have long used the appropriations process to undermine 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, women who work for the federal government, women in prison, and others, including women living in the District of Columbia, which is even prohibited from spending non-federal funds on these services. Separately, the Weldon Amendment has been used to interfere with policies that expand abortion coverage and access, emboldening health entities to refuse to provide, cover, pay for, or refer for abortion services.When elected officials deny certain categories of women insurance coverage for or access to abortion, they either are forced to carry the pregnancy to term or pay for care out of their own pockets or simply do not get the care they need. The result is unfair and discriminatory policy that further exacerbates poor public health outcomes for those who already face significant barriers to care, such as low-income women, immigrant women, young women, and women of color. We urge the Committee to eliminate all such restrictions on access to abortion.

In addition, the Committee should reject any harmful new policy riders we have seen proposed in years past that would roll back progress, including proposals to "defund" Planned Parenthood.

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PPFA issues these requests in the hopes that we can protect and build upon federal investments to make quality reproductive health care affordable and accessible so that women and their families can lead healthier lives. 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 at (jacqueline.ayers@ppfa.org). For more information about domestic priorities, please contact Jack Rayburn, Director, Legislative Affairs at (jack.rayburn@ppfa.org).

Sincerely.

[This statement was submitted by Jacqueline Ayers, Vice President of Public Policy and Government Affairs, Planned Parenthood Federation of America.]

PREPARED STATEMENT OF THE POPULATION ASSOCIATION OF AMERICA/ ASSOCIATION OF POPULATION CENTERS

Thank you, Chair Murray and Ranking Member Blunt 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 FY 2022, we urge the Sub-

committee to adopt the following funding recommendations: $46.1 billion, NIH; $200 million, NCHS; $700 million, IES; and $800 million, BLS. In addition, we urge the subcommittee to accept report language, previously submitted, regarding population research programs and surveys supported by the National Institutes of Health.

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 Chair Murray and Ranking Member Blunt 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 $46.1 billion for the NIH, a $3 billion increase over the NIH's program level funding in FY 2021. We urge that NIA and NICHD, as components of the NIH, receive commensurate funding increases in FY 2022.

NATIONAL INSTITUTE ON AGING

The NIA Division of Behavioral and Social Research (DBSR) is the primary source of federal support for basic population aging research. The NIA Division of Behavioral and Social Research (DBSR) supports a scientifically innovative population aging research portfolio that reflects some of the Institute's, and nation's, highest scientific priorities including Alzheimer's disease and social inequality in health and the aging process. With additional support in FY 2022, DBSR could expand its existing research portfolio to encourage more research on the short and long-term social, behavioral, and economic health consequences of COVID on older people and their families. The population research community is especially eager to see NIA use existing large-scale, longitudinal and panel surveys, such as the Health and Retirement Study, the National Health and Aging Trends Study, and Understanding America Study, to facilitate scientific research on the complex, multifaceted effects of the pandemic on older, diverse populations. Further, the field believes NIA should sustain its support for developing data infrastructure to promote research on racial, ethnic, gender and socioeconomic disparities in health and well-being in later life and the long-term effects of early life experiences. With additional funding in FY 2022, DBSR could support these activities as well as fully fund the NIA 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 12 universities nationwide.

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 Study of Adolescent to Adult 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. Given the dearth of data being collected regarding the short and long-term social, economic, developmental, and health effects of the COVID pandemic on children and families, the field of population research urges NICHD to consider expanding data collection through existing surveys and the NICHD Population Dynamics Centers Research Infrastructure Program. Further, population scientists encourage NICHD to explore the use of existing and new mechanisms to enhance research regarding the effects of COVID on fertility trends and reproductive health overall. With additional funding in FY 2022, the Institute could sustain its existing population research activities as well as implement our field's recommended COVID related research expansions.

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 for NCHS to continue monitoring 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 and APC, as a member of the Friends of NCHS, recommends the agency receive $200 million in FY 2022. In addition, our organizations urge the Subcommittee to reiterate its support for the agency's participation in the Centers for Disease Control (CDC) Data Modernization Initiative (DMI). The CDC should be encouraged to provide NCHS with a greater share of the agency's DMI funding—especially given NCHS has received less than 4 percent of the $600 million that DMI has received since FY 2020. NCHS should be benefitting from DMI funds, as the Committee intended, and applying them to make long overdue and necessary systematic and technological upgrades as well as facilitating enhanced use of Electronic Health Records.

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 FY 2020 and for maintaining the agency's funding level in FY 2021. We are also pleased that BLS received $10 million in FY 2020, and report language in FY 2021, 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. We urge the Subcommittee to give the agency increased support in FY 2022 by providing BLS with $800 million and to adopt, once again, report language urging the agency to maintain its plans for a new NLSY cohort.

INSTITUTE OF EDUCATION SCIENCES

The Institute of Education Sciences (IES) plays a critical role in supporting research used in developing and examining the effectiveness of education programs and curricula. The National Center for Education Statistics (NCES), the statistical arm of IES, provides objective data, statistics, and reports on the condition of education in the U.S. Population scientists rely on NCES surveys to conduct research on topics, such as linkages between educational access/attainment to health outcomes of specific populations, economic well-being, and incarceration rates. The field is pleased NCES is ramping up a new School Pulse Survey (SPS), to begin in August, that will collect data on how schools are adapting during the recovery phase of the pandemic. PAA continues to be concerned, however, that NCES has inadequate staffing to effectively manage the agency's broad array of surveys and other data collection and evaluation programs, and to maintain data quality and program rigor—particularly as it takes on new initiatives such as SPS. Years of staff attrition combined with bureaucratic hurdles have hindered the agency's ability to replace key personnel and maintain an adequate staffing level. We urge the Committee to continue to exert careful oversight of this situation.

Thank you for considering our support for these agencies as the Subcommittee drafts the FY 2022 Labor, Health and Human Services and Education Appropriations bill.

PREPARED STATEMENT OF THE PORT GAMBLE S'KLALLAM TRIBE

Requests and Recommendations:

1. Increase in funding for the Tribal Opioid Response grant program to a minimum of $75 million;
2. Increase in funding for the Temporary Assistance for Needy Families Program to a minimum of $17.8 billion;
3. Increase in funding for the Child Support Program to a minimum of $4.424 billion;
4. Increase in funding for the Head Start Program to a minimum of $17.8 billion;
5. Increase in funding for the Child Care and Development Block Grant to a minimum of $7.3 billion; and
6. Increase in funding for the Low-Income Home Energy Assistance Program to a minimum of $3.85 billion and a tribal set-aside.[1]

INTRODUCTION

The Port Gamble S'Klallam Tribe is a sovereign Indian nation comprised of over 1,342 citizens located on the northern tip of the Kitsap Peninsula in Northwest Washington State. The 1855 Point No Point Treaty reserved hunting, fishing, and gathering rights for our Tribe, and the United States agreed to respect the sovereignty of our Tribe and to protect and provide for the well-being of our Tribe. The United States, therefore, has both treaty and trust obligations to protect our lands and resources and provide for the health and well-being of our citizens. The current COVID–19 pandemic has necessitated the need for more resources and services to provide for the health, safety, and welfare of our tribal citizens as well as American Indian and Alaska Native (AI/AN) people across the United States.

Overarching Comments. Thank you for your commitment to honor and uphold the United States' trust and treaty obligations, strengthen the government-to-government relationship between the United States and tribes, and empower tribes to govern their own communities and make their own decisions. As you know, federal programs and services are critical components of building strong tribal governments, economies, and communities. We look to the Subcommittee to help address the chronic underfunding of unmet federal obligations and duties owed to Indian Country. This includes providing funding and support for the delivery of reliable and quality health care to AI/AN people, ensuring tribal communities are safe and secure, and expanding economic opportunity and community development in tribal communities. We ask the Subcommittee to support increased funding for critical Indian programs and the inclusion of helpful report language on many significant issues impacting Indian Country.

Funding for Tribal Health Care. Appropriations to support health care services are needed to, among other things, address the significant health disparities that persist among AI/AN people, treat chronic diseases that plague tribal communities, update and improve tribal health clinics, and modernize equipment and health information technology within Indian Country. Our Tribe has administered health services to its members for several years, and was one of the first tribes to join the Tribal Self-Governance Project in 1990. We are the only Indian health care provider of both primary and behavioral health services in Kitsap County. Our health programs aim to provide the highest quality medical care and treatment to individuals within our tribal community, but we still face significant challenges related to funding, facilities, and program administration. Due to the COVID–19 pandemic, our health programs have run short of resources and need additional funding to support the services we provide. To strengthen our health programs, we ask for the following in the FY 2022 appropriations:

Tribal Opioid Response. We appreciate the President's proposed funding of $75 million to the Tribal Opioid Response grant program, but more is needed. This program to critical to address the opioid substance use needs in tribal communities. Indian Country, including our Tribe's Reservation, has been severely affected by the opioid epidemic. Increased funding for the Tribal Opioid Response grant program will address increasing rates of opioid dependence, overdose, and other negative con-

[1] We also support the National Congress of American Indians' FY 2022 budget requests. See NCAI, Indian Country FY 2022 Budget Request: Restoring Promises, https://www.ncai.org/resources/ncaipublications/NCAI__IndianCountry__FY2022__BudgetRequest.pdf.

sequences stemming from opioid use. Funding is essential to combat the opioid crisis that imposes threats to Indian Country.

Temporary Assistance for Needy Families (TANF). We support the President's FY 2022 request of $17.8 billion to support the TANF Program, which would be an increase in $600 million over FY 2021. The TANF Program is a capped entitlement program that has continued to receive the same funding level since it was established. The Tribe strongly encourages reauthorization of the TANF Program with higher funding levels in order to provide temporary assistance and economic self-sufficiency for children and families. The Tribe currently receives $516,680 from the TANF Program to support its members and strongly encourages a continuation of at least this amount. However, there remains an unmet need to operate programs for the benefit of low-income families. These programs are necessary for the United States to fulfill its trust responsibility and contribute to the overall well-being of the Tribe's members.

Child Support Program. We reject the President's request to reduce funding for the Child Support Program by $233 million to a total of $4.16 billion. Instead, funding for the Program should be at $4.424 billion, the FY 2020 level. The Tribe operates a robust Child Support Program. The Tribe's Child Support Program has a need of $781,955 to enhance its services offered to children with need and to improve activities offered to children, including an increase of staff members, support staff training, child counseling, and ensuring that the physical environments of the Tribe's Head Start Program is conducive to providing effective program services, increased hours of operation, improved strategic planning for the program, and safe transportation of children in the program safely, An increase in funding for the Child Support Program would allow the Tribe to increase and enhance services to its members. Any decrease in the level of funding for the Child Support Program would cause hardship to the Tribe's members.

Head Start Program. We support the President's request of $11.9 billion for the Head Start Program-an increase of $1.2 billion over the FY 2021 enacted level. The Head Start Program promotes the school readiness of our tribal youth as well as early learning and development, health, and family well-being of children from low-income families. Funding from the Head Start Program greatly assists the Tribe in offering competitive wages to its employees in its Early Head Start Program. The Tribe needs additional funding over and above its current funding to pay its teachers to ensure equitable wages that support Head Start Performance Standard Regulations. Such funding will also help the Tribe recruit and maintain teachers and teaching assistants, which is critical to our education programs and the children the Tribe serves. The Tribe estimates that it needs at least $235,000 to be able to offer competitive wages to its program employees. In addition, the Tribe would like to invest $18,000 in an outdoor learning environment and $75,000 to support Head Start Program Performance Standards. Indigenous learning is based on outdoor environments that reflect tribal culture. The Tribe is in need of funds to plan and develop an outdoor learning environment to support exploration and discovery in forest/beach/wetland/stream. Lastly, the Tribe requests an increase in quality improvement funds to support our students, staff, and families based on community need.

Child Care and Development Block Grant. Our Tribe supports the President's request for providing $7.3 billion in discretionary funds for the Child Care and Development Block Grant. This program supports low-income, working families within our Tribe by providing access to affordable, high quality child care. Adequate child care is essential for our tribal members. The pot of child care money going to Tribal governments from this program needs to be bigger so that the portions of it that Tribes receive can meet their needs. The overall funding amount for the Child Care Development Fund needs to be increased and Tribes should get a 5% set-aside from it. Indian Country, including our Tribe, have a strong need to access the Fund for facility purposes. An increase in funding for the Child Care and Development Block Grant would allow the Tribe to increase and enhance services intended to serve its youth.

Low-Income Home Energy Assistance Program (LIHEAP). We appreciate the President's request to increase funding for the LIHEAP Program by $100 million for a total of $3.85 billion. The LIHEAP Program assists low-income households to pay a proportion of household income for home energy, primarily in meeting their immediate home energy needs. Currently, the Tribe receives $23,979 from LIHEAP to assist its members, but there continues to be an unmet need. The Tribe requests an increase in LIHEAP funding to assist our tribal members in paying their home energy bills. Any decrease or in the current level of funding in the LIHEAP Program would cause significant hardship to the Tribe's members. We also request that a tribal set-aside for the LIHEAP Program be established.

CONCLUSION

Thank you for the opportunity to share our interests regarding FY 2022 appropriations for programs and services that will greatly benefit us as well as other tribes across the United States. On behalf of the Port Gamble S'Klallam Tribe, we thank you and your dedication and continued hard work in protecting the tribal interests. We know that you will be fighting for Indian Country in the appropriations process.

[This statement was submitted by Jeromy Sullivan, Chairman, Port Gamble S'Klallam Tribe.]

PREPARED STATEMENT OF PUBLIC HEALTH-SEATTLE & KING COUNTY, WA

Chair Murray, Ranking Member Blunt, and members of the Subcommittee, my name is Brad Finegood and I work for King County (WA) as a Strategic Adviser for Public Health-Seattle & King County in Seattle, WA.

I am pleased to submit testimony on behalf of King County, WA to urge Congress to appropriate $120 million for the Infectious Diseases and the Opioid Epidemic program at the Centers for Disease Control and Prevention (CDC) at the Department of Health and Human Services (HHS) to save lives and address the overdose crisis by supporting and expanding access to syringe services programs (SSPs).

King County, WA is seeing an unprecedented surge in overdose deaths. In 2020, there were 510 confirmed overdoses in the county, which is more than the 422 experienced in 2019. There has been a year over year rise over the past decade when there were 245 overdose fatalities in 2011. The majority of the drug overdoses include opioids, although a rising number of overdoses also contain stimulants both alone and in polysubstance use overdoses. Our county is also besieged by fentanyl rising from 3 fentanyl related overdose deaths in 2015, to 172 in 2020 with 135 confirmed fentanyl overdoses already in 2021 (as of date authored). We know that access to sterile use equipment is one of the evidence-based interventions that keeps individuals engaged in health services, decreases the likelihood of transmissible diseases and keeps individuals alive.

The United States is experiencing an urgent and unprecedented drug overdose crisis, with more than 100,000 overdose deaths expected to be counted in 2020 and potentially more in 2021. Overdose deaths are expected to have increased by more than 40% than the previous record year of 2019. According to the Washington Department of Health, overdose deaths accelerated in Washington in 2020, increasing by 38% in the first half of 2020 compared to the first half of 2019. The infectious diseases associated with opioid and other drug use also have dramatically increased. Since 2010, the number of new hepatitis C infections has increased by 380%. Outbreaks of viral hepatitis and HIV among people who inject drugs continue to occur nationwide.

Overdose deaths have increased more dramatically among Black people and communities of color. From 2015 to 2018, overdose deaths among African Americans more than doubled (by 2.2 times) and among Hispanic people increased by 1.7 times while increasing among white, non-Hispanic people by 1.3 times. In Washington, the increase in overdose deaths was highest among groups already dealing with inequitable health outcomes: American Indian/Alaska Natives, Hispanic/Latinx, and Black people.

SSPs are an essential component of preventing overdose deaths. Tacoma Needle Exchange proudly services clients, who can exchange their used injection supplies for sterile syringes, which helps prevent the spread of blood-borne pathogens like HIV. Other services include safe injection supplies, naloxone training and distribution, safer sex supplies, and referrals for medication assisted treatment and other medical services. Our outreach staff attempts to meet people where they are at, and to help them address their needs in the safest and healthiest way possible, free of judgement and stigma.

Congress must respond to the overdose crisis, as well as work to prevent and reduce infectious diseases related to drug use, such as HIV and hepatitis C by supporting and expanding access to syringe services programs (SSPs). The CDC has documented over 30 years of studies that show that SSPs reduce overdose deaths and infectious diseases transmission rates as well as increase the number of individuals entering substance use disorder treatment. These studies also confirm that SSPs do not increase illicit drug use or crime and save money.

SSPs are among the only health care services trusted and used by people who use drugs and so can effectively engage this highly stigmatized population. SSPs help protect the community (including first responders) by ensuring safe disposal of sy-

ringes, reducing rates of infectious diseases, and can help providing a pathway to effective mental health and alcohol and other drug treatment and to other medical care.

SSPs are the most effective way to get naloxone—a drug which reverses an opioid overdose—into the hands of people who use drugs, who are most likely to be at the scene of an overdose. People who use drugs are an essential partner in preventing overdose fatalities and are best reached by SSPs. With additional resources, SSPs can reach more people with naloxone, which would help reduce the dramatically increasing number of overdose deaths.

Unfortunately, the nation has insufficient access to SSPs and the COVID–19 pandemic has decreased access to these life-saving services during a time when the need for services has increased dramatically. In January 2021, Drug Policy Alliance conducted a survey of SSPs that showed that 91% of respondents experienced an increase in clients in 2020, many as a result of the COVID–19 pandemic. During this time of skyrocketing need, 42% of respondents experienced funding cuts in 2020 and expect such shortfalls to continue in 2021. As a response to funding shortfalls, many SSPs have been forced to lay off staff and reduce services. In King County service availability has been limited so individuals experienced limited access to life saving interventions like needle exchange and naloxone. Consequently, because of these decreased and limited resources, SSPs cannot reach the millions of people who may benefit from their life-saving services.

Federal funding would expand access to these critical and effective programs. Tacoma, WA's NASEN's statistics show that there are only approximately 400 SSPs operating nationwide. Experts estimate that to sufficiently expand access to SSP programs, the U.S. would require at least 2,000 programs—5 times the number in existence now.

A recent study that assessed the startup costs of an individual program estimated that it would cost (in 2020 dollars) $490,000 for a small rural program and $2.1 million for a large urban program, resulting in an average start-up cost of $1.3 million per program. Based on these numbers the requested funding would provide an 10% increase to currently operating SSPs to help address funding shortfalls and also expand the number of SSPs nationwide.

Finally, expanding access to SSPs will reduce health care costs, including for infectious diseases treatment. Hepatitis C treatment can cost more than $30,000 per person, while HIV treatment can cost upwards of $560,000 per person. Averting even a small number of cases would save millions of dollars in treatment costs in a single year.

The Infectious Diseases and Opioid Epidemic Program at CDC helps to eliminate infections related to injection drug-use and improve their prevention, surveillance, and treatment. It also strengthens and expands access to syringe services programs. In FY2019, CDC began several projects to expand capacity of SSPs nationwide through technical assistance to ensure high-quality, comprehensive services and best practices. With additional FY22 funding, CDC could significantly expand SSPs at this critical time to help prevent overdose deaths, the spread of HIV and viral hepatitis and connect people to life-saving medical care.

On a personal note—in addition to leading the overdose prevention work for King County, I am the brother of overdose victim. Every single person who counts as a fatal overdose is a family member to someone and an individual that could have been saved. We have the tools; we just need the funding to help implement.

I want to thank the Subcommittee for its past funding of the CDC Infectious Diseases and Opioid Epidemic program and urge Congress to provide $120 million for the program in FY22. Thank you also for your time and consideration of my testimony, and please do not hesitate to contact me at brad.finegood@kingcounty.gov if you have questions or need additional information.

Sincerely.

[This statement was submitted by Brad Finegood, MA, LMHC, Strategic Adviser, Public Health-Seattle & King Co., King County, WA.]

PREPARED STATEMENT OF THE PULMONARY HYPERTENSION ASSOCIATION

PHA'S FISCAL YEAR 2022 L-HHS APPROPRIATIONS RECOMMENDATIONS

—At least $46.1 billion in program level funding for the National Institutes of Health (NIH).
—Proportional funding increases for NIH's National Heart, Lung, and Blood Institute (NHLBI); the National Institute of Child Health and Human Development (NICHD), and the National Center for Advancing Translational Sciences (NCATS).

Chairwoman Murray, Ranking Member Blunt 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 FY2022 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, health care 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 FY2022.

NATIONAL INSTITUTES OF HEALTH

Please provide NIH with meaningful increases—including at least $46.1 billion in program funding in FY2022—to facilitate expansion of the PH research portfolio and continued improvement in 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 nearly 1,200 participants with various types of PH, subjects at risk for PH, and healthy controls, PVDOMICS hopes to find new similarities and differences between the current WHO classifications of PH. 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.

Data from the original cohort is currently being prepared for publication and the rich resources of PVDOMICS have spurred many presentations at national and international meetings. With its novel approach to enrollment and data analysis, PVDOMICS is poised to change our thinking about pulmonary hypertension and its classification in the upcoming years.

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 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

Chandani's three-year-old son was diagnosed with severe PH in July 2020 at the age of two. Chandani is a physician herself and so she understands all too well the seriousness of her son's prognosis. Since his diagnosis last year, her son's medical care team has tried progressively increasing therapies in a stepwise fashion, which is often required by insurance companies but is known to lead to worse outcomes than when patients are allowed to immediately begin the treatment prescribed by their doctor.

Currently, Chandani's toddler is receiving three oral drugs in addition to a subcutaneous infusion, all for PH. As of the end of April, he has not been responsive to these therapies which unfortunately indicates a poor prognosis. Currently, without a transplant, her son has a 60% chance of survival over the next five years, and if he were to receive a double-lung transplant, it would statistically add 2.7 years to his life. Studies show that self-reported quality of life for patients with pulmonary hypertension ranks worse than cancer patients. Research and treatment are vitally needed for this disease that has such a fatal prognosis and a poor quality of life.

Denise has a health insurance plan with a $3,000 deductible. She uses a manufacturer copay card to pay for the first of her life-sustaining pulmonary hypertension (PH) medications. However, Denise's health insurance plan will not apply the copay card to her deductible, so when Denise fills the prescription for her second medication, she is responsible for her entire deductible out-of-pocket. When Denise was renewing her health insurance coverage for the year, this information was hidden from her. She was told about other changes to the plan, but the shift to a copay accumulator was never mentioned, nor could Denise find the relevant information online.

Barbara has lived with PH for 21 years and with the treatment of liquid oxygen, she has managed to develop a comparatively active life filled with volunteer work and visits with her children and grandchildren. However, that changed in April 2021 when Barb's Medicare-contracted oxygen supplier stopped delivering liquid oxygen without notice. Instead, they began providing compressed oxygen gas tanks.

Liquid oxygen tanks are light enough to be carried hands-free strapped to the back and hold a sufficient volume of oxygen to provide a continuous stream for 6–8 hours at a time so that Barb is able to breathe easily while still walking around. By contrast, compressed oxygen tanks are heavier and hold a smaller volume of oxygen, so they sustain her for only a fraction of the time that liquid oxygen tanks do. To carry a compressed oxygen tank with her, she must wheel it behind her or struggle with the weight and bulk of the tank if attempting to carry them on her back and change them out every couple of hours.

These new limitations to her lifestyle due to the loss of appropriate treatment for her PH have caused a steep decline in her mood and quality of life and she has quickly become depressed; at a recent visit with her physician, she was told "I've never seen you this bad." The mobility and ease that using a liquid oxygen tank provides Barb is the difference between struggling to complete one errand in a day, versus running multiple errands, feeling capable of going out to have lunch with friends, or being able to comfortably visit her seven grandchildren.

In the past weeks, Barb has spent precious energy calling 30 suppliers within a 100-mile radius of her home searching unsuccessfully for anyone else to provide her with the correct treatment for her PH condition. In her efforts to find out more about the loss of access to liquid oxygen, Barb has heard from many other PH patients from across the country who are experiencing the same situation. This restriction of access to liquid oxygen represents a collective loss in quality of life for the

community of PH patients that could have long-lasting and far-reaching consequences for an already serious, degenerative disease.

Thank you again for your consideration of the PH community's priorities as you develop the FY2022 L–HHS Appropriations bill.

[This statement was submitted by Matt J. Granato, LL.M., MBA, President and CEO, Pulmonary Hypertension Association.]

PREPARED STATEMENT OF ANDREW REAMER

I write to request that the report of the Senate Committee on Appropriations accompanying appropriations legislation for Labor, Health and Human Services, Education, and Related Agencies include language that directs the Bureau of Labor Statistics (BLS), U.S. Department of Labor, to provide memoranda to the Subcommittee, and to the Senate Committee on Health, Education, Labor, and Pensions, regarding the following topics:

—Approaches to accurately measuring the extent and nature of telework and remote work in the United States, by geography and industry, with the implications for future appropriations.

—Approaches to creating a new principal federal economic indicator on well-being, with implications for future appropriations.

—Possible impacts of the Census Bureau's new Disclosure Avoidance System on BLS data derived from Census Bureau statistics and used to determine the allocation of federal financial assistance to states, local areas, and households.

I provide information below in support of this request. I write as a research professor at the George Washington Institute of Public Policy, George Washington University, with a focus on the role of the federal government in facilitating national economic development and competitiveness.

Measures of Telework and Remote Work. News reports make clear that the pandemic has catalyzed a substantial increase in the number of employees who telework from home in lieu of commuting to an office and those who work from a geographic location different than the office to which they report. For the purposes of public policy and business decision-making, BLS statistics should provide reliable estimates of telework and remote work by geography and industry.

My research (available here) identifies 14 federal data collections that independently measure the extent and nature of remote work. Eight collected such data before the pandemic; six added telework questions in response to the pandemic. Six are household surveys, six are establishment surveys, and two prepare occupational profiles. Six are conducted by BLS, five by the Census Bureau, and one each by the Employment and Training Administration, the Federal Highway Administration, and the Office of Personnel Management.

While BLS and other federal agencies are to be lauded for their proactive efforts, it would be desirable to rationalize the plethora of data collections so that BLS may point to a single data series as the most appropriate measure. The choice made will have implications for future appropriations. Consequently, I recommend that the Senate Appropriations Committee report accompanying Labor Department appropriations legislation include a directive that BLS provide the Subcommittee with its views on the preferred approach to measuring telework and remote work and resource requirements to implement it.

Measures of Well-being. Numerous scholars, such as Carol Graham of the Brookings Institution and Angus Deaton and Anne Case of Princeton University, demonstrate through their research the significant increase in despair and deaths of despair, particularly among the white working class. As with telework, several federal agencies are independently seeking to measure the extent of and reasons for despair inside American households and, at present, there is no single reliable, consensus measure of well-being akin to Principal Federal Economic Indicators such as the unemployment rate and the poverty rate.

For FY2021, Congress appropriated funds for BLS to conduct the Well-Being Module of the American Time Use Survey (ATUS). I recommend that Senate Appropriations Committee report language for FY2022 appropriations direct BLS provide the Subcommittee with its views on approaches to creating a reliable, useful well-being indicator and the resources necessary to produce it.

Impacts of Census Differential Privacy Protocols on BLS-guided Federal Financial Assistance. To ensure adherence to Title 13 requirements for confidentiality, the Census Bureau is implementing a new Disclosure Avoidance System (DAS) based on differential privacy protocols that inserts distortions within certain agency datasets while maintaining system-wide statistical accuracy. BLS labor force and price statistics rely on Census Bureau data collections that may be affected by the

new DAS; several federal departments use BLS state and local statistics, such as unemployment rate, to determine program eligibility and allocate by formula billions of dollars in federal financial assistance. At the moment, the effect of the new DAS on the geographic allocation of federal funding is not understood. Consequently, I encourage the Subcommittee to direct BLS to identify which of its datasets might be affected by the new Census DAS and, by extension, which federal funding programs might be affected as well, and how.

Note: I gathered the information contained above through my sponsored research and as the research organization representative on the Workforce Information Advisory Council (WIAC) of the U.S. Secretary of Labor. I submit the above request as a private citizen and not as a representative of any organization or body.

[This statement was submitted by Andrew Reamer, Research Professor, George Washington Institute of Public Policy, George Washington University.]

PREPARED STATEMENT OF RESEARCH!AMERICA

On behalf of the Research!America alliance, 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 2022 (FY22) appropriations. We are grateful that for FY21, the base budgets of the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) were increased and the base budget of the Agency for Healthcare Research and Quality (AHRQ) was maintained, and that the Subcommittee additionally provided dedicated funding for critical research programs. The need for faster medical and public health progress has never been more apparent. Our nation has an opportunity, and on behalf of every American, the obligation, to fight health threats faster, learn from this pandemic to bolster public health capacity and preparedness, and leverage evidence as never before to optimize health care delivery. In that context, we ask that you provide an increase in the base budget (exclusive of new initiatives) for NIH of at least $4.29 billion, for a total of $47.22 billion; an increase of at least $2.18 billion for CDC, for a total of $10 billion; and an increase of at least $162 million for AHRQ, for a total of $500 million, in FY22.

THE NATIONAL INSTITUTES OF HEALTH

We believe it is in the strategic interests of the U.S. to increase funding for NIH to at least $47.22 billion in FY22, an increase of 10% over FY21 funding. Our nation and the global community have witnessed the broadscale impact of a global pandemic, but the reality is that every American either experiences directly or is the loved one of an individual who dies prematurely of a health threat that we can overcome. NIH-conducted and funded research uncovers new knowledge that is the prerequisite to conquering these threats. No entity, in the U.S. or across the globe, has done more to propel academic and private sector progress that saves lives.

NIH funds almost 50,000 competitive grants that are awarded to researchers at over 500 universities, medical schools, and educational institutions in every state. NIH also plays an integral role in educating and training America's future scientists and medical innovators by sponsoring fellowships and training grants.

We believe our nation should seize the opportunity to change the course of history such that we can out-innovate emerging threats and all live longer, healthier lives. Please allocate at least $47.22 billion in FY22 for the base budget of NIH, an increase of 10% over FY21 funding.

THE CENTERS FOR DISEASE CONTROL AND PREVENTION

We urge you to fund the Centers for Disease Control and Prevention (CDC) at a level of $10 billion in FY22, a 27% increase over FY21 enacted. 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 is tasked with protecting and advancing the nation's health, and over the past 70 years it has worked diligently to thwart deadly outbreaks 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 has been an integral part of the effort to mitigate and defeat COVID–19. Their 24/7 response and the guidance that has emerged from their efforts has empowered our nation to weather this pandemic, but their role as the key first re-

sponder when major threats emerge is just part of their contribution to Americans' health, safety, and wellbeing.

CDC is at the forefront of prevention; is working hard and effectively to forestall antibiotic resistance; is the lead federal agency responsible for tracking and forestalling foodborne illness and other local and regional outbreaks; investigates cancer clusters; and protects, investigates, and advances the health of every one of us in myriad ways. Our nation has underfunded CDC at risk to every American: we need to empower this agency to advance the best interests of every American by protecting and advancing the health of all Americans.

The ongoing COVID–19 pandemic, in addition to past outbreaks of Ebola, Zika, influenza, and measles, 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. We cannot allow a gap between the funding provided to CDC and the demands and challenges placed before the agency. We request that CDC receive at least $10 billion in FY22, $2.18 billion over FY21 funding, to ensure the agency can carry out its crucially important responsibilities.

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

We urge you to fund AHRQ at a level of $500 million, a 47.9% increase over FY21 funding, in FY22. AHRQ has been grossly underfunded for decades relative to its mission and the lives and dollars this agency could save if appropriately equipped. AHRQ is the lead federal agency tasked with making sure our nation is not simply making medical progress, but that this progress translates into more effective, efficient, and affordable health care for Americans across the country. As it stands, our nation overspends by an estimated $1 trillion each year and abides deadly medical errors that cost at least 100,000 lives each year because we don't deploy strategies to address inefficiencies and errors in health care. Now is the time to empower AHRQ to address this massive, counterproductive challenge.

AHRQ-funded research identifies and highlights how to stop waste of limited health care dollars, empowering patients to receive the right care at the right time in the right settings. For example, AHRQ-funded research informed the creation of an Antibiotic Stewardship Program (ASP) in 402 hospitals across the U.S. to address the overprescription of antibiotics, which can ultimately lead to them being ineffective. This research program successfully reduced the length of time patients needed to be on antibiotic therapy by an average of 30 days. The research also identified key improvements for future ASPs.

The value of medical discovery and development hinge on smart health care delivery. If we underinvest in AHRQ, we are inviting unnecessary health care 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, and your respective staff members, for your stewardship over these critically important federal spending priorities.

Sincerely.

[This statement was submitted by Ellie Dehoney, Vice President of Policy and Advocacy, Research!America.]

PREPARED STATEMENT OF THE RESTLESS LEGS SYNDROME FOUNDATION

Chairwoman Murray, Ranking Member Blunt, and distinguished members of the Subcommittee, as you work to develop the fiscal year (FY) 2022 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 nearly $2 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 2022 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 FY 2022 to bring NIH's budget up to $46.1 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.

Please provide $5 million for the National Neurological Conditions Surveillance System (NNCSS) for FY 2022. The NNCSS at the Centers for Chronic Disease Control and Prevention (CDC) collects and synthesizes data to help increase our understanding of neurological disorders and to support further neurologic research. RLS remains a severely misunderstood and underdiagnosed neurological disorder, and increased surveillance is vital to improving patient outcomes.

Please provide at least $5,000,000 for the Chronic Diseases Education and Awareness Program at the Centers for Disease Control and Prevention (CDC). With the cessation of the National Healthy Sleep Awareness Project (NHSAP), CDC presently has no active public health activities dedicated to sleep or sleep disorders, despite the fact that sleep affects nearly every body system and many chronic diseases. Please allow the valuable scientific and public health efforts started during the NHSAP to continue.

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 Stephen Smith from Colorado, a RLS Foundation Discussion Board Moderator. Like all those with RLS, night can

bring a feeling of dread. Is this going to be one of those nights when my RLS acts up and I don't get any sleep or will it just be one of those standard nights when my sleep is just poor?

About a year ago, I had one of those nights when my RLS acted up and I knew that I wasn't going to get any sleep at all. So I called my doctor's night service and was instructed to go to the local hospital's Emergency Room and to tell them to call my doctor.

Contrary to hospital policy, the ER doctor decided not to call and also didn't understand RLS or my insomnia complaints. But he jumped on my depressed feelings from insufficient sleep combined with my RLS pacing, which he assumed was agitation, and the opioid that I take for RLS. He then incorrectly concluded I had a drug problem and was suicidal in spite of being told that I was not. So he placed me under a 72hr psychiatric hold and sent me to a psych hospital 3 hours away. I was shipped 180 miles confined to the back seat of a car with raging RLS. The psych hospital didn't carry one of my RLS meds, tramadol, and forced me to go into withdrawal rather than go to the effort to replace it. The abrupt withdrawal from tramadol led to hours of shakes and sweats followed by even more hours of RLS—like pacing for the second night in a row. Since tramadol also acts as an SNRI antidepressant, the abrupt withdrawal caused me to develop SNRI Withdrawal Syndrome. This caused migraine headaches, severe anxiety and depression, nightmares and dreams centered on the horrible experience of being involuntarily confined to the psych hospital due to a neurological disorder. These symptoms went on for months and required drug treatment for anxiety and psychotherapy for the severe depression.

So, now nightfall brings a feeling of trepidation. Is this going to be another night when my RLS acts up or I cannot fall asleep? If I do manage to sleep, will I once again dream of the nightmare of being confined to the psych hospital all due to failure of a number of doctors to understand RLS or to even listen to their patient who is trying to educate them?

Thank you again for the opportunity to share the views of the RLS community.

[This statement was submitted by Karla M. Dzienkowski, RN, BSN, Executive Director, Restless Legs Syndrome Foundation.]

PREPARED STATEMENT OF ROTARY INTERNATIONAL

Chairwoman Murray, members of the Subcommittee:

Rotary appreciates the opportunity to encourage continuation of funding for FY 2022 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 to ensure recovery of polio eradication progress disrupted by the COVID–19 pandemic, stop polio transmission, protect polio free areas, and leverage the resources developed through this global effort for continued value-added impact. The 300,000 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 $2.2 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 will help achieve a polio free world and ensure the continued global health contribution of polio eradication infrastructure and resources.

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% decrease in cases. Thanks to this committee's support, over 19 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.

In 2020, the WHO AFRO region was certified wild polio virus-free after four years without detecting any cases, making it the fifth of six WHO regions to eliminate the virus. This achievement follows the certification of the eradication of Type 3 (WPV3) in October 2019 and wild poliovirus type 2 (WPV2) in September 2015. The eradication of wild polio virus from regions and eradication of strains of the polio virus is further proof that a polio-free world is achievable.

Only two countries, Afghanistan and Pakistan, have confirmed cases of wild polio since August of 2016. As of 3 June 2021, only 2 cases of wild polio virus have been confirmed—one each in Pakistan and Afghanistan. Significant reductions in detection of virus transmission in environmental samples in 2021 are also cause for cautious optimism. Both countries are working to capitalize on low levels of virus transmission by working to reach missed children, prioritizing communities which have had low coverage or which have been resistant to immunization; and ensuring thorough microplanning of immunization and other eradication activities. In Afghanistan, there are increased efforts to target children living in areas which have been inaccessible. This ongoing work is challenging within the context of the NATO withdrawal of troops and related insecurity.

Outbreaks of circulating vaccine-derived poliovirus are ongoing in several countries across Africa and Asia and require continued focus and attention. These were further exacerbated by COVID–19 pandemic-related disruptions in immunization campaigns. 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 program has developed a specific Strategy for the Response to Type 2 Circulating Vaccine-Derived Poliovirus, including the use of a new, more genetically stable vaccine, the novel oral polio vaccine type 2 (nOPV2), for outbreak response.

The COVID–19 pandemic has posed new challenges for global polio eradication activities. In order to protect communities and staff, the Global Polio Eradication Initiative paused immunization campaigns and other essential activities for several months in 2020. In countries that have successfully resumed activities, the programme has developed strategies for prevention and control of COVID–19 and is providing resources such as masks and hand sanitizer to keep frontline health workers protected while ensuring that campaign elements meet physical distancing requirements.

As a result of the pause on activities, and also due to the potential exposure to COVID, the number of vulnerable children has increased the real threat for wider spread of the virus. UNICEF, WHO and Gavi estimate that at least 80 million children under the age of one are at risk due to the COVID–19 related disruption to vaccination activities. These challenges are further compounded by the extraordinary economic and financial constraints in both at-risk countries and from donors which may divert essential political and financial commitments.

This combination of progress in the midst of ongoing challenges underscores the urgency of continued focus to protect the vulnerable gains made toward polio eradication as the COVID–19 pandemic continues to disrupt polio immunization and eradication activities; and 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 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 to CDC has supported the following essential polio eradication activities:

Leadership on surveillance and disease detection. CDC's Atlanta laboratories serve as a global reference center and training facility, providing expertise in virology, diagnostics, and laboratory procedures, including quality assurance, and genomic sequencing of samples obtained worldwide, and training virologists from around the world in advanced poliovirus research and public health laboratory support. CDC also provides the largest volume of operational (poliovirus isolation) and technologically sophisticated (genetic sequencing of polio viruses) lab support to the 145 laboratories of the Global Polio Laboratory Network (GPLN). CDC also developed methods to directly detect poliovirus from patient stool specimens, allowing faster detection. Specific support was also provided to expand environmental surveillance to detect and respond to vaccine-derived poliovirus outbreaks in Democratic Republic of the Congo, Nigeria, Somalia, and Kenya.

CDC provides critical technical capacity and program management expertise which directly contributes to polio eradication activities and is also used to build in-country capacity.

—CDC supported the international assignment of technical staff on direct 2-year assignments to WHO and UNICEF to assist polio-endemic and polio-reinfected priority countries. Funding was also provided to WHO for surveillance, technical staff and immunization activities' operational costs, primarily in Africa.

—CDC's Stop Transmission of Polio (STOP) members continue to play a key role in providing expertise on polio surveillance, data management, campaign planning, implementation and evaluation, program management, and communications in high-risk countries. In 2020, 210 public health professionals were deployed in 42 countries with two-thirds deployed to the African Region, contributing substantially to the region's achievement of wild polio-free status in 2020. STOP program participants worked to improve broader vaccine-preventable disease (VPD) surveillance. In 2020 STOP participants also supported local governments to promote awareness of COVID–19 and provide contract tracing.
—In Afghanistan, CDC led a comprehensive data review in 2020 that evaluated and streamlined data collection to increase efficiency of the evidence-based decision making in campaigns.
—In Pakistan, CDC worked with the government to transform structural and managerial components of the polio program. CDC and NSTOP assumed a new role to improve evidence-based decision making through data usage and risk assessment in the core reservoir districts/towns. CDC also provided broad support to the COVID–19 response in Pakistan, including trainings, case identification, investigation and tracking, and lab sample collection.
—CDC also provided expertise in technical advisory groups, EPI manager and other key global polio meetings.
—CDC also provided instrumental support internationally and domestically in the areas of disease surveillance, health worker training, contact tracing, risk communications and testing through extensive assignment of Atlanta-based polio staff to the CDC COVID–19 response and through support provided to the COVID–19 pandemic response by polio staff in Afghanistan, Pakistan, and across Africa. CDC's commitment to polio eradication is firm and knowing 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.

CDC also works to build Country-level Capacity.

—In collaboration with the Pakistan Ministry of Health, WHO and USAID's mission in Islamabad, CDC trained 88 national epidemiologists from CDC's Field Epidemiology Training Program (FETP) and deployed them to the highest risk districts for circulation of wild polio virus to help improve the quality of surveillance and immunization activities there and to strengthen routine immunization systems.
—CDC also trained and supported 230 staff at the Local Governing Area level in the highest risk states through CDC's National STOP program for Nigeria, playing a key role in interrupting transmission of wild polio. CDC also contributed to UNICEF's expansion of a Community Based Vaccinator Program in Pakistan that includes over 24,000 workers who reach 4 million children annually with both oral and inactivated polio vaccine (IPV); and $3 million for operational costs for NIDs in all polio-endemic countries and outbreak countries. Most of these NIDs would not take place without the assurance of CDC's support.

CDC provided key leadership in development and rollout of novel oral poliovirus vaccine (nOPV), a new tool for polio eradication through preclinical development, laboratory testing and support for nOPV clinical trials. The new vaccine has low neurovirulence, is genetically stable (low reversion rate), can be scaled to production levels, is highly immunogenic, and was safe and well tolerated in vaccine trials. Initial use of nOPV2 is taking place in countries that have secured national immunization and regulatory group approvals and have met strict criteria.

FISCAL YEAR 2022 BUDGET REQUEST

We respectfully $176 million in FY2022 for the polio eradication activities of CDC, the level appropriated by Congress in FY 2021. CDC's priorities are to stop virus transmission in the remaining polio endemic and outbreak countries. CDC will also work with governments and partners in countries experiencing cVDVP outbreaks to resume high quality vaccination campaigns and to boost routine immunization to close immunity gaps. This includes reaching an estimated 80 million children who are vulnerable due to COVID–19 pandemic related disruptions. CDC will also work to address pandemic-related surveillance gaps to safeguard global disease detection and response capacity. CDC will continue planning for a post-polio transition to advance broader global vaccine-preventable diseases (VPD) control and elimination/eradication targets as outlined in CDC's Global Immunization Strategic Framework 2021–2030.

THE ROLE OF ROTARY INTERNATIONAL

Rotary is a global network of leaders who connect in their communities and take action to solve pressing problems. Since 1985, polio eradication has been Rotary's flagship project, with members donating time and money to help immunize nearly 3 billion children in 122 countries. Rotary's chief roles are fundraising, advocacy (including resource mobilization and political advocacy), raising awareness and mobilizing volunteers. There are nearly 300,000 members throughout the United States who have raised more than US$400 million of the more than US$2.2 billion Rotary has contributed to the Global Polio Eradication Initiative. This represents the largest contribution by an international service organization to a public health initiative ever. These funds have benefited 122 countries to buy vaccine and the equipment needed to keep it at the right temperature, and support the means to ensure it reaches every child. More importantly, tens of thousands of our volunteers have been mobilized to work together with their national ministries of health, UNICEF and WHO, and with health providers at the grassroots level in thousands of communities.

Rotary also plays a key role in encouraging country level accountability. Rotary has National PolioPlus Committees, in the endemic countries and over 20 outbreak/at-risk countries. These national committees work to keep the spotlight on polio eradication amidst competing priority from the community level to the federal level.

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 including COVID–19 and will do so long after polio is eradicated. $27 billion in health cost savings 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. As many as 200,000 children could be paralyzed annually in the next decade if the world fails to capitalize on the more than $18 billion already invested in eradication. Success will ensure that the 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

Chairwoman Murray, Ranking Member Blunt, and members of the Subcommittee, my name is Dr. Rachel Bender Ignacio and I serve as an HIV primary care physician at the Madison Clinic and Director of the AIDS Clinical Trials Unit at Harborview Medical Center in Seattle, Washington. I am pleased to submit testimony on behalf of the Ryan White Medical Providers Coalition (RWMPC) of the HIV Medicine Association (HIVMA). I currently serve on the Board of Directors of HIVMA. RWMPC is a national coalition of medical providers and administrators who work in healthcare agencies supported by the Ryan White HIV/AIDS Program funded by the HIV/AIDS Bureau (HAB) at the Health Resources and Services Administration (HRSA).

First, I would like to thank the Subcommittee for increasing FY21 funding 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, expanding the Ryan White Program even further now would help jurisdictions nationwide address ending the HIV epidemic. To achieve this expansion, I request $225.1 million (a 10% or $24 million increase) in FY22 for Ryan White Part C, which supports approximately 350 HIV medical clinics nationwide.

RWMPC also requests additional resources for the ETE initiative to expand access to HIV prevention, care, and treatment, including $364 million for HRSA's ETE program. This funding would include $212 million for the Ryan White Program to provide additional HIV care and treatment, as well as $152 million for the Bureau of

Primary Health Care to support HIV prevention services, including providing Pre-Exposure Prophylaxis (PrEP), medication to prevent HIV. These funding levels also were requested by the President's FY22 budget request.

It is especially important now that 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 pandemic has placed on public health infrastructure and medical facilities, including Ryan White clinics, is significant and limited resources cannot be further stretched.

In fact, COVID–19 has demonstrated why our nation needs to strengthen the public heath infrastructure and medical clinics serving people living with HIV. Ryan White clinics have been critical to providing an effective COVID–19 response and many Ryan White medical providers have been pulled in as leaders of the pandemic response in their jurisdictions. This has worked well as these providers are infectious diseases experts who have significant experience caring for vulnerable populations.

The flexibility of the Ryan White Program and the knowledge and innovation of its medical providers also has allowed Part C clinics to respond to the changing needs of patients and the health care system throughout the transitions and challenges of the COVID–19 pandemic. Part C clinics have helped people with HIV by sustaining access to health care and medication through telehealth and key services, such as case management and transportation; by enrolling new patients who lost their health insurance as a result of the economic downturn; and by providing PPE, food, and housing security during this emergency.

Madison Clinic at Harborview Medical Center in Washington Has Expanded Access to HIV Prevention, Care, & Treatment

Since 1986, the Madison Clinic has served as the leading source of HIV primary care in the Pacific Northwest when its HIV care program was expanded with the assistance of Ryan White Program funding. Since then, the clinic has grown dramatically and now serves 2,800 individuals living with HIV, most with complex medical and psychosocial needs. Approximately 30% of our population is Black or African American (Seattle overall has 7% Black representation), 15% is Latinx, and 10% is Asian, Pacific Islander, or Native American. 47% of patients live at or below the federal poverty level. Like other HIV clinics across the US, ours serves an increasingly aging population, with 60% of patients over the age of 45. As a result, the burden of co-morbid illnesses, such as cancer, cardiovascular disease, and metabolic complications such as diabetes is extremely high. Alarmingly, 12% of patients lack permanent housing, and many patients were negatively impacted by the intersection of housing instability; the opioid epidemic and HIV epidemics; and the COVID–19 pandemic. Madison Clinic, like most Ryan White Part C clinics, also receives support from other parts of the Ryan White Program that help us provide medications, additional medical care, and support services, such as case management and transportation, all key to the comprehensive Ryan White care model that produces outstanding outcomes.

Madison Clinic also provides Pre-Exposure Prophylaxis (PrEP) services across the clinic. This critical HIV prevention tool is integrated at Madison Clinic as part of prevention and primary care services. However, more support for the PrEP program, including for PrEP navigators and lab tests, is needed to scale up these services to meet patient needs.

Many Harborview patients struggle with HIV, substance use disorder (SUD), and related infectious diseases, such as hepatitis C. In response, in partnership with the Public Health Department for Seattle-King County, the Max Clinic was established to care for people living with HIV who have not yet achieved viral suppression and who experience multiple barriers to care. The Max Clinic serves approximately 200 patients, and receives support from Part B of the Ryan White Program as well as funding from the local Health Department.

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 2019, more than 88% of Ryan White patients were virally suppressed—an almost 27% increase in the program-wide viral suppression rate since 2010. In 2020, 94% of Madison Clinic patients have been virally suppressed in spite of the complex challenges the COVID–19 pandemic has presented. The Ryan White Part C program's comprehensive services engage and keep people in HIV care and treatment. For example, 98% of HIV patients are on antiretroviral therapy at Madison Clinic. Early, reliable access to HIV care and treatment helps patients with HIV live healthy and productive lives and is more cost effective.

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. The majority of Madison Clinic providers have the credentials to prescribe buprenorphine therapy (medication assisted treatment for Substance Use Disorder), and our providers treat viral hepatitis, supported by a multidisciplinary team in our clinic. Part C clinics are able to deliver a range of medical and support services, including overdose prevention and harm reduction services, needed to prevent, intervene, and treat substance use disorder as well as related infectious diseases, including HIV, hepatitis C, and sexually-transmitted infections. The experience and expertise of Ryan White Part C medical providers should be leveraged to effectively respond to the opioid epidemic and overdose crisis and to help rapidly expand access to urgently needed SUD services.

Funding for Prevention and Harm Reduction at CDC and Research at NIH is Critical

While my testimony has focused on HRSA programs, the ability to effectively respond to the syndemics of HIV, substance use disorder, and related infectious diseases such as hepatitis C; 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. The AIDS Clinical Trials Unit, a member of the AIDS Clinical Trials Group funded by the NIH, is co-located within Madison Clinic and provides direct access for our patients to participate in research that pushes the envelope on HIV and viral hepatitis treatment, including a focus on HIV remission/cure strategies.

We request $371 million for CDC to provide surveillance, response, and other HIV prevention services as part of the ETE initiative, as well as $120 million for CDC to address the infectious diseases consequences of the opioid epidemic, including by supporting and expanding access to syringe services programs, harm reduction, and overdose prevention. Finally, we support continued robust funding for NIH, including for HIV research. This funding supports discoveries that will help to end the HIV, hepatitis C, and opioid epidemics and that have informed the treatment and prevention of COVID–19.

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 Rachel Bender Ignacio, MD, MPH, HIV Physician and Clinical Researcher at the Madison HIV Clinic.]

PREPARED STATEMENT OF SAFER FOUNDATION

Thank you, Chairwoman Murray, Ranking Member Blunt, and members of the Subcommittee, for inviting me to submit testimony on behalf of the Safer Foundation. My name is Kevin Brown and I serve as the Director of Policy, Advocacy, and Legislative Affairs for the Safer Foundation. For almost 50 years, Safer has provided comprehensive workforce development and reentry services for individuals with criminal legal histories seeking employment. There is dignity in work, and Safer Foundation believes that individuals who have made mistakes should have the opportunity to be self-sufficient and contribute to their families and communities through gainful, living wage employment. Clients come to Safer Foundation because they want and need to work, and Safer helps clients discover career path employment that is personally fulfilling and that pays a living wage.

A critical federal program that supports these efforts is the Reentry Employment Opportunities (REO) program (also known as the Reintegration of Ex-Offenders (RExO) program) within the Department of Labor's Employment & Training Administration. I thank the Subcommittee for providing REO with $100 million in FY21.

Given the need to train people for the jobs our economy requires in industries such as health care, technology, and logistics; to help employers identify the qualified workers they need now; and to help people with criminal legal histories find living wage employment to support successful, long-term reentry, I urge the Subcommittee to provide $150 million for the REO program in FY22.

EMPLOYMENT REDUCES RECIDIVISM AND IMPROVE REENTRY OUTCOMES

1 in 3 adults in the United States has a criminal record that interferes with their ability to find a job.[1] The COVID–19 pandemic has underscored existing barriers to employment for people with criminal legal histories. 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] The REO program improves reentry success by working with individuals to overcome employment barriers with training for jobs in local high-demand industries through career pathways and industry-recognized credentials and by providing needed reentry supports. Increasing REO funding would expand access to these comprehensive workforce development and reentry services that are especially needed now.

Authorized by section 169 of Workforce Innovation and Opportunity Act (WIOA), the REO program provides workforce preparation and reentry services for both adults and young people. REO includes a set-aside to provide services to prepare youth who are justice-system involved and/or who have not completed school or other educational programs for employment. Research has found that incarceration reduces a formerly incarcerated person's earning potential by more than 52 percent,[3] making workforce development services essential for long-term employment and reentry success. In light of the costs of the criminal legal system at the state, local, and federal levels, the REO program is crucial to incubating community-based models of successful reentry through employment.

COVID–19 has impacted employment opportunities for people with criminal legal histories. During the last economic downturn in 2008, the unemployment rate for people with criminal legal histories was 27%—2 points higher than the unemployment rate during the Great Depression. Increasing support for the REO program is an effective way to ensure that individuals with criminal legal histories, who are disproportionately Black people and people of color, are not left out of the nation's economic recovery.

SAFER'S REO-SUPPORTED SERVICES INCREASE EMPLOYMENT BY WORKING WITH BOTH EMPLOYERS AND EMPLOYEES

Safer Foundation offers comprehensive 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 REO grantees.

In addition to working with reentering individuals and their communities, Safer also works closely with employers to identify what types of trained employees are needed. In November 2020, the National Federation of Independent Business (NFIB) reported that 53% of businesses overall (and 89% of those hiring or trying to hire) reported few or no qualified applicants for available positions. While the demand for qualified workers exists, many newly unemployed individuals may not meet the qualifications for particular industries. Safer can be responsive to employer needs by tailoring its programs to develop skilled, qualified workers for specific employment sectors and has partnered with hundreds of employers to do so.

Safer's Training to Work (T2W) program, that was funded in part with a REO grant, improved long-term employment prospects for clients at Safer's Adult Transition Centers (ATC). Participants received case management, education, and training that led to industry-recognized credentials for in-demand employment, such as forklift operation, welding, computer numerical control (CNC) operation, and licensed

[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.

[2] Visher, C., Debus, S., & Yahner, J. Employment After Prison: A Longitudinal Study of Releasees in Three States. Washington, DC: Urban Institute (2008).

[3] Craigie Terry-Ann; Grawert, Ames; Kimble, Cameron, Stiglitz, Joseph (2020); Conviction, Imprisonment, and Lost Earnings: How Involvement with the Criminal Justice System Deepens Inequality: https://www.brennancenter.org/our-work/research-reports/conviction-imprisonment-and-lost-earnings-how-involvement-criminal.

commercial driving (CDL) occupations, and Microsoft technologies training. Given the program's strong employer and credentialing components, REO 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. Increasing REO funding in FY22 to $150 million, including funding for earn and learn apprenticeship opportunities for in demand skills development, would expand these efforts and help provide employers with more qualified employees who are trained, talented, motivated to work.

SAFER'S REO GRANT PRODUCED OUTSTANDING EMPLOYMENT OUTCOMES AND REDUCED RECIDIVISM

Safer's REO grant for the Training to Work (T2W) program significantly outperformed employment targets and dramatically reduced recidivism. For the first cohort of REO T2W participants, 69% of participants obtained employment—15% higher than the grant's employment target. Given the success of this first cohort of participants, T2W was expanded to include a second cohort who did even better with an employment rate of 78%—30% higher than the grant's target. Safer's REO T2W grant also reduced recidivism rates beyond original targets. T2W's first participant cohort had an 11% recidivism rate, and its second participant cohort had a 9% recidivism rate—75% and 80% lower respectively than the national recidivism rate of 44%.[4]

Program evaluation has shown that such success is 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] By increasing and improving employment outcomes, the REO program invests in formerly incarcerated people and their families, provides for a more equitable recovery, and improves public safety.

INVESTMENTS IN REENTRY PROGRAMS ARE CONSISTENT WITH THE FY22 PRESIDENT'S BUDGET REQUEST

Reentry and workforce development are a priority for the current administration, and the FY22 President's Budget requests includes $150 million for the REO program to provide support for "reentry services, and recidivism-reducing programming..." The budget request also calls for increases in skills-building that "advances the goal of developing pathways for diverse workers to access training and career opportunities by also investing in critical programs that serve disadvantaged groups, including justice-involved individuals, [and] at-risk youth."

The REO funding request also is consistent with the administration's goal of pursuing racial equity. Black people and other people of color are disproportionately impacted by the criminal legal system. Black people are incarcerated at more than 5 times the rate of white people. In 2018, the incarceration rate of Black men was 5.8 times higher than that of white men, and Black young men ages 18–19 years old were 12.7 times as likely to be incarcerated as white young men in the same age group. In 2018, Black women were almost twice as likely to be incarcerated as white women, and Black girls were 3 times more likely to be incarcerated than white girls.

Upon release, these disparities persist as a result of systemic and institutional racism and discrimination; collateral consequences of conviction that ban or limit legal access to employment, licensure, and education supports; and a limited investment in resources for the large number of people returning each year who come back to their communities without the basic support and tools needed for long-term success. Providing federal resources for workforce development and reentry helps to ensure greater success and helps to address unfair barriers that exist as a result

[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.

of systemic racism and inequities that disadvantage individuals directly impacted by the criminal legal system.

Finally, the REO program is critical for economic recovery for people with criminal legal histories, especially Black people and people of color, who also have been disproportionately impacted by COVID–19. There has been very limited COVID–19 relief for incarcerated people and people with criminal legal histories, and REO is the only federally appropriated program that focuses on workforce development and employment for people with records (1 out of 3 adults in the U.S. has an arrest or conviction record). As the economy recovers and workforce needs continue to evolve and change, it is essential to ensure that this significant population has the reentry and workforce supports to facilitate gainful employment and long-term reentry success.

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 extensive employment and reentry needs nationwide, as well as 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 $150 million to the REO program in FY22.

Thank you so much for your time and consideration of this important program. If you have questions or need additional information, please don't hesitate to contact me or Jenny Collier at jcollier@colliercollective.org.

[This statement was submitted by Kevin Brown, Director of Policy, Advocacy, and Legislative Affairs.]

PREPARED STATEMENT OF THE SCLERODERMA FOUNDATION

THE FOUNDATION'S FISCAL YEAR 2022 L-HHS APPROPRIATIONS RECOMMENDATIONS

—$10 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 funding increase for CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP).
  —$5 million for the Chronic Disease Education and Awareness Program which seeks to improve public health and lower healthcare costs through targeted awareness, physician education, and public health campaigns conducted in collaboration with stakeholder organizations and communities.
—At least $46.1 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).

Chairwoman Murray, Ranking Member Blunt 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 FY2022 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 continued support of the 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. David Murad, Director of Advocacy, Scleroderma Foundation.]

PREPARED STATEMENT OF THE SEATTLE INDIAN HEALTH BOARD

Chair Murray, Ranking Member Blunt, and members of the Senate Committee on Appropriations—Subcommittee on Labor, Health, and Human Services, Education, and Related Agencies, my name is Esther Lucero. I am Diné, and of Latina descent and as the third generation in my family to live outside of our reservation, I strongly identify as an urban Indian. I serve as the President & CEO of the Seattle Indian Health Board (SIHB), one of 41 Urban Indian Health Programs (UIHP) nationwide. I have had the privilege of serving SIHB for five years. I am honored to have the opportunity to submit my testimony today, including a request for the following 1) Address Department of Health and Human Services (HHS) grant eligibility and grant restrictions 2) Develop an HHS urban confer policy; 3) Ensure HHS public health data access to Tribal Epidemiology Centers (TEC) 4) Create National Institutes of Health (NIH) research funding opportunities specific to urban Indian populations; 5) Invest in Indian healthcare and public health infrastructure, including culturally attuned integrated workforce development.

INDIGENOUS RESILIENCE IN ACTION

I would like to thank the Subcommittee for COVID–19 supplemental funding which has included at least $18 million for UIHPs from the Centers of Disease Control and Prevention (CDC); $9.5 billion for Federally Qualified Health Centers (FQHC) from the Health Resources and Services Administration (HRSA), and; at least $140 million to Indian Health Care Providers through the Substance Abuse and Mental Health Services Administration (SAMHSA). Supplemental funding has demonstrated how successful and resilient our Indian healthcare system can be when properly resourced. I would also like to acknowledge the President's Budget for FY 22 which includes $131.7 billion for HHS, including $12.6 billion for HRSA, and $9.7 billion for SAMHSA. We hope President Biden's proposed increases will support significant investments to FQHCs, tribal and urban Indian populations, and reducing chronic health disparities in Black, Indigenous, and Communities of Color (BIPOC).

As one of 41 Indian Health Service (IHS) designated UIHPs and a HRSA 330 FQHC, SIHB serves over 5,000 patients annually of which 70% identify as American Indian and Alaska Native. UIHPs are a critical component of the Indian healthcare system and offer culturally attuned health services to the 2.2 million American Indians and Alaska Natives who live in 115 counties across 24 states. We also house the Urban Indian Health Institute (UIHI), an IHS designated TEC and public health authority, which conducts research and evaluation, collects and analyzes data, and provides disease surveillance for 62 urban Indian communities nationwide.

As an Indian Health Care Provider, we are actively limiting the spread of COVID–19 in tribal and urban Indian communities. In December 2020, SIHB was the first organization in Seattle to receive a shipment of the Moderna vaccine and since has vaccinated over 12,500 individuals. Locally, we serve as a COVID–19 testing site at our main clinical facility and operate a community-based walk-up testing site at our satellite clinic serving American Indian and Alaska Native people experiencing homelessness in Seattle, Washington. With the support of federal supplemental funding, we continue to secure pharmacy supplies and equipment to respond to the immediate and forthcoming COVID–19 needs in the greater Puget Sound region, including testing kits, panels, and a diagnostic testing machine to improve testing capacity and response times. We have implemented a telehealth program, expanded outpatient behavioral health services, provided rental assistance, and developed a pediatrics clinic to increase child immunization rates. Throughout the pandemic, UIHI has disseminated culturally attuned COVID–19 information through fact sheets, reports, and a COVID–19 Vaccine Poster series to address vaccine hesitancy in the Native community. Recently, UIHI launched For the Love of Our People, a webpage dedicated to bringing Native health experts and creatives to provide engaging, up-to-date information about COVID–19 vaccines and COVID–19 related topics. UIHI has also led local to national public health surveillance for UIHPs through weekly reporting and analysis of local to state COVID–19 case surveillance data.

CONTINUED GAPS FOR URBAN INDIAN ORGANIZATIONS

Address Department of Health and Human Services (HHS) grant eligibility and grant restrictions: UIOs offer culturally responsive services for the 71% of American Indians and Alaska Natives in urban areas. Given that the average IHS grant to an UIHP is $280,000, most UIHPs must seek additional resources from HHS agencies to ensure robust access to health and social services that allow our communities to thrive. Yet, many HHS agencies exclude UIHPs from grant eligibility or apply restrictive grant terms that hinder our ability to provide culturally specific and low-barrier services. To ensure HHS resources for American Indian and Alaska Native people fulfill trust and treaty obligations, we ask Congress to:

Ensure Urban Indian Organizations are included in grant eligibility: If the intent of Congressional funds is to reach all American Indian and Alaska Native people, then legislative and administrative language must include 'tribes, tribal organizations, and Urban Indian Health Programs as defined in Section 4 of the Indian Health Care Improvement Act (authorized under 25 U.S.C. Ch. 18. Subchapter IV § 1653). This ensures federal resources reach American Indian and Alaska Native people, regardless of where they reside.

Address barriers created by GPRA tools: Current requirements of the Government Performance and Results Act (GRPA) performance data is burdensome to patients and providers. To operate a truly culturally attuned and low-barrier Medication Assisted Treatment (MAT) programs, we must address the long-standing issues with cumbersome and onerous GPRA reporting requirements. For example, SIHB provides an unduplicated service of low-barrier MAT services for urban American Indians and Alaska Natives who are disproportionately affected by substance use in Washington State. Our American Indian and Alaska Native patients come to SIHB for our integrated patient-centered care model that promotes the wellness of our patients and is centered on Traditional Indian Medicine. Lengthy and invasive GPRA survey tools directly affect our service delivery system to provide accessible low-barrier and culturally attuned MAT services. We ask that Congress address barriers created by GRPA tools to better support culturally attuned and low barrier services provided by Indian Health Care Providers.

Develop an HHS urban confer policy: To ensure trust and treaty obligations are upheld to all American Indian and Alaska Native citizens, we request the development of an Urban Confer policy across all agencies and departments within HHS jurisdiction. The federal government has an obligation to consult with Tribal Nations on issues that impact tribal communities. In the Indian healthcare system, UIHPs have an Urban Confer mechanism with the IHS that provides an opportunity for an exchange of information and opinions that lead to mutual understanding and emphasize trust, respect, and shared responsibility between UIHPs and government agencies. Urban Confer policies do not substitute for nor invoke the rights of a Tribe as a sovereign nation. An Urban Confer supports the advocacy for the urban Indian community by Indian Health Care Providers who are part of the Indian healthcare system.

The importance of an Urban Confer was made evident in the COVID–19 supplemental resources from Congress. Without an Urban Confer policy, HHS agencies outside of IHS had no formal mechanism for gathering feedback from UIOs and vice versa. As a result, submitting feedback to HRSA, SAMHSA, and the CDC was a significant barrier to accessing COVID–19 supplemental resources for UIOs. For example, the CDC created a funding opportunity for 11 of the 12 TECs by selecting a grant mechanism that failed to include UIOs as eligible entities. This barrier leaves UIOs without access to federal resources, despite Congressional intent.

Ensure HHS public health data access to Tribal Epidemiology Centers (TEC): Despite Congressional authorization to access HHS data as a public health authority, CDC continues to deny UIHI and other TECs access to data collected through the National Notifiable Disease Surveillance System (NNDSS). Timely analysis of NNDSS data and other CDC collected COVID–19 data is critical to supporting both tribes and UIOs to prevent, prepare, and respond to system health inequities experienced by American Indian and Alaska Native communities. A failure to uphold data access perpetuates systemic health inequities in American Indian and Alaska Native communities. With the limited COVID–19 case surveillance data provided, TECs have been able to monitor, evaluate, and respond to COVID–19 through contact tracing, primary collection and secondary analysis of epidemiological data, and development of culturally attuned public health resources. The COVID–19 resources developed by TECs range from public health guidance to treatment and vaccine information that have been disseminated to tribes, tribal organizations, UIOs, and

government agencies. We ask Congress to ensure compliance with data sharing requirements by all HHS agencies with TECs.

Create NIH research funding opportunities specific to urban Indian populations: Current NIH initiatives often are not inclusive of urban Indian populations, despite 71% of all American Indian and Alaska Native people living in urban settings and a growing body of documentation of health disparities among urban Native populations. In addition, the COVID–19 pandemic has highlighted the lack of diversity in clinical trials which perpetuates bias in research studies. In Indian Country, the lack of an American Indian and Alaska Native population samples in clinical trials contributed to vaccine hesitancy and has been used by anti-vaccination advocates to push misinformation into Native communities. We do not advocate for taking away funding for tribally based research. Instead, we urge Congress to ensure NIH create dedicated funding for research and clinical trials that are inclusive of urban Indian populations.

Invest in Indian healthcare infrastructure:

Public health infrastructure: The COVID–19 pandemic has exacerbated the crumbling infrastructure of our public health systems, specifically data systems. Many of the data quality issues identified by UIHI in the Data Genocide report are linked to outdated public health data infrastructure systems that limit the ability to appropriately collect and report data for national public health surveillance and epidemiology. There is an urgent need to invest significant resources in data modernization, specifically across our Indian healthcare system—including tribal health programs, UIHPs, and TECs. Data modernization increases inter-operability of data systems and advances data standards so information can be stored and shared across systems, and facilitate complete reporting of data critical for achieving equity in public health responses. We recommend an increased investment dedicated to infrastructure improvement and construction specifically for UIHPs that does not divert any resources from tribal communities that are also in desperate needs of public health infrastructure investments.

UIHP healthcare facilities: There is no national level data on the infrastructure needs of UIHPs, yet we know from experience our facilities are inefficient and overcrowded, which compromises the provision of critical health services and contribute to health disparities among urban Indian communities. UIHPs are ineligible for the Health Care Facilities Construction line item in the IHS budget. Recent COVID–19 supplements have allowed for some flexible spending to address the overwhelming infrastructure needs of UIHPs, yet lack we still lack the resources needed to develop integrated care settings that are patient-centric and culturally attuned. We ask that Congress identify resources for UIHPs for the construction, expansion, alteration, and renovation of healthcare facilities.

Culturally attuned integrated workforce development: Our healthcare systems are in need of additional investments to fulfill integration of behavioral health and medical care. A 2018 GAO report on IHS found a 25% vacancy rate for nurses, physicians, and other care providers. It is a critical time to make targeted investments in building up a culturally attuned workforce across the Indian healthcare system that is prepared to provide integrate care that address pervasive health disparities among American Indian and Alaska Native populations. We ask Congress to invest in recruitment and retention of health professionals to address chronic health care provider shortages in Indian Country.

Thank you for your support and consideration of the requests. We look forward to our continued work to improve the health and well-being of American Indian and Alaska Native people.

Sincerely.

[This statement was submitted by Esther Lucero (Diné), MPP, President & CEO, Seattle Indian Health Board.]

PREPARED STATEMENT OF THE SLEEP RESEARCH SOCIETY AND PROJECT SLEEP

FISCAL YEAR 2022 APPROPRIATIONS RECOMMENDATIONS

—The sleep community joins the broader research community in requesting $46.1 billion in discretionary funding for the National Institutes of Health (NIH), an increase of $3.2 billion over FY 2021. Sleep impacts nearly every system of the body and various disease processes, please provide proportional funding in-

creases for all NIH Institutes and Centers to further support sleep, circadian, and sleep disorders research activities.

—Please support adequate funding to establish the new Advanced Research Projects Agency for Health (ARPA–H) at NIH as proposed in the Administration's Budget Request to Congress to facilitate robust and tangible scientific progress on a variety of conditions.

—The sleep community joins the broader public health community in requesting $10 billion in overall funding for the Centers for Disease Control and Prevention (CDC) to reinvigorate meaningful professional education, public awareness, and surveillance activities.

—Please provide the new CDC Chronic Disease Education and Awareness Program with $5 million, an increase of $3.5 million over FY 2021, to facilitate additional cooperative agreements to advance timely public health efforts with community stakeholders.

Chairwoman Murray, Ranking Member Blunt, 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 FY 2022 appropriations for medical research and public health programs. We would like to take this opportunity to thank you for providing ongoing investment in the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) through FY 2021 appropriations, particularly for establishing and funding the new CDC Chronic Disease Education & Awareness Program. Please bolster the commitments to NIH and, in particular, CDC as you and your colleagues work on appropriations for FY 2022.

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 pulmonology, psychology, neurology, pharmacology, cardiology, immunology, metabolism, genomics, learning and memory, 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.

NIH SLEEP RESEARCH ACTIVITIES

Over recent years, NIH has seen a meaningful infusion of critical funding. This investment has improved grant funding pay lines, led to significant scientific advancements, and helped to prepare the next generation of young investigators. For FY 2014, the sleep research portfolio at NIH was $233 million annually. For FY 2020, the sleep research portfolio at NIH had grown to $436 million annually, which has been transformative for the field. However, there are still meaningful opportunities for further scientific progress and improved patient care.

Underserved Sleep Disorders State of the Science Conference

While research in sleep and circadian has moved forward in significant ways (including the 2017 Nobel Prize in Medicine), research into specific sleep disorders at NIH remains relatively modest. Narcolepsy, hypersomnia, Kleine Levin syndrome and many other sleep disorders have only a few active grants at any given time. To ensure scientific progress in sleep is translated to innovative therapies, improved diagnostic tools, and meaningful health information, the time is now for a State-of-the-Science conference on sleep disorders. This collaborative opportunity will help create a long-range research plan across NIH that features specific activities for var-

ious sleep disorders. Committee recommendations and related interest in this regard would be timely.

Sleep Health & Health Disparities

Racial-ethnic minorities are more likely to get insufficient sleep, and are more likely to have sleep disorders. Since sleep plays important roles in cardiovascular function, metabolism, immunity, mental health, and brain function, this sleep disparity creates a situation where racial/ethnic minorities are systematically set up for worse health outcomes. Not only does poor sleep lead to worse outcomes on its own, it interacts with other conditions, worsening the already-important problems associated with heart disease, diabetes, obesity, cancer, depression, and other medical conditions. The causes of these sleep disparities are complex and involve a combination of socioeconomic, environmental, and other factors. Unfortunately, there is almost no research on targeting sleep disorders diagnosis and treatments for racial/ethnic minorities, and securing funding for sleep disparities research is extremely difficult. As NIH works to address health disparities, promote health equity, and enhance workforce diversity, sleep and sleep research should be incorporated into emerging activities.

National Heart, Lung, and Blood Institute/National Center on Sleep Disorders Research

NCSDR has a new Director, Dr. Marishka Brown, who is taking the field of sleep research in new and exciting directions while reinvigorating the enthusiasm for sleep research across the federal government. Under Dr. Brown's leadership, NCSDR is preparing to release a strategic plan for research. We ask Congress to provide Dr. Brown with the support she needs, including adequate resources for NHLBI and NCSDR to coordinate ongoing and emerging initiatives.

CDC Chronic Disease Education & Awareness Program

Thank you for establishing the CDC Chronic Disease Education & Awareness program and providing an initial investment of $1.5 million for FY 2021. CDC currently lacks meaningful public health activities focused on sleep and the community plans to engage this new funding mechanism. For FY 2022, please provide $5 million in annual support.

Stacy's Story

Stacy Edwards, of Langley, Washington, first started seeing doctors for fatigue at the age of 15. As she got older, her health declined significantly and she couldn't figure out why. Stacy could sleep 15–18 hours and still felt tired. Doctors were sympathetic, but usually tested for anemia and mono and sent her on her way with no solutions. At age 31, Stacy was finally referred for a sleep study. The results showed that she woke up 29 times per hour due to breathing obstructions, making her diagnosis of sleep apnea on the high side of moderate (almost severe).

Once diagnosed, Stacy started using a CPAP machine and now raises awareness and reduces stigma via her website and social media campaign called CPAP Babes. More recently, at age 34, Stacy was diagnosed with a second sleep disorder, idiopathic hypersomnia. She continues to look for better treatment options to reduce her daytime sleepiness, brain fog, and other associated symptoms. Stacy is passionate about sleep research and awareness because she believes that she lost many years of her life in bed and doesn't want others to suffer for years without answers the way she did. Educating the public and the medical community is a high priority for Stacy.

[This statement was submitted by H. Craig Heller, PhD, President, Sleep Research Society and Project Sleep.]

PREPARED STATEMENT OF THE SOCIETY FOR MATERNAL-FETAL MEDICINE

On behalf of SMFM, I am pleased to submit testimony in support of the important work related to optimizing the health of birthing people and infants being conducted at HHS for FY 2022. SMFM urges Congress to ensure that the National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC), Health Resources and Services Administration (HRSA), and Agency for Healthcare Research and Quality (AHRQ) are adequately funded in FY 2022. Specifically, SMFM urges the Committee to provide at least the following in base program level funding:

—$46.1 billion for the NIH, with $1.7 billion of that funding to support the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD);

—$10 billion for the CDC, including $89 million for the Safe Motherhood Initiative, $100 million for the Surveillance for Emerging Threats to Moms and Babies initiative, and $200 million for the National Center for Health Statistics (NCHS);
—$9.2 billion for the HRSA, including $822.7 million for the Title V Maternal and Child Health Services Block Grant; and
—$500 million for AHRQ.

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 three years of formal education and who are board certified in MFM 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 toward optimizing the care of people 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.

NIH/NICHD

The NICHD's investment in maternal and child health outcomes is essential to understanding and combatting the rising maternal mortality and severe morbidity rates and to optimizing maternal and child health.

Task Force Specific to Pregnant Women and Lactating Women (PRGLAC): SMFM urges Congress to continue its strong support for NIH's efforts to advance the inclusion of pregnant and lactating people in clinical trials and research, specifically by taking necessary steps to implement the recommendations of the PRGLAC Task Force, which was convened by 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 the Task Force further outlined how to implement those recommendations in a follow-up report submitted to the Secretary of Health and Human Services in 2020. In that implementation report, the PRGLAC Task Force described the need to convene an expert panel to develop a framework for addressing medicolegal and liability issues when planning or conducting research specific to pregnant people and lactating people. SMFM requests $1.5 million for NICHD to contract with the National Academies of Sciences, Engineering, and Medicine to convene a panel tasked with developing that framework (language below).

The COVID–19 pandemic again emphasized the importance of including pregnant and lactating people in clinical research. This population was largely excluded from clinical trials for treatments and vaccines, leaving them and their health care providers without clear evidence on safety and efficacy to guide clinical decision-making. 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 mother and their infants.

NICHD Report Language

Liability Study.—Pregnant and Lactating Individuals. The Committee includes $1,500,000 for NICHD to contract with NASEM to convene a panel with specific legal, ethical, regulatory, and policy expertise to develop a framework for addressing medicolegal and liability issues when planning or conducting research specific to pregnant people and lactating people. Specifically, this panel should include individuals with ethical and legal expertise in clinical trials and research; regulatory expertise; plaintiffs' attorneys; pharmaceutical representatives with tort liability and research expertise; insurance industry representatives; federally funded researchers who work with pregnant and lactating women; representatives of institutional review boards (IRBs) and health policy experts.

Maternal-Fetal Medicine Units Network (MFMU): SMFM urges continued strong support of the MFMU and asks that Congress allocate $30 million to support the Network's ongoing work. Established in 1986, MFMU pursues the development of treatments for medical complications during and after pregnancy, including maternal mortality and morbidity, preterm birth, low birth weight, fetal growth abnormalities, and fetal mortality. MFMU is a critical resource to stemming the nation's growing maternal health crisis and addressing emerging threats to maternal and infant health. For instance, during the COVID–19 pandemic, the MFMU was able to quickly pivot resources to monitor the health impact of COVID–19 on pregnant people and their infants, as well as researching effective treatments for pregnant populations. We hope that the NICHD will ensure the MFMU's continued success by

maintaining 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. 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 recent increase in maternal mortality and severe morbidity in the United States. 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 risk of death in the immediate newborn period as well as in infancy and can cause long-term complications. Although the survival rate is improving, many preterm infants have life-long disabilities including cerebral palsy, intellectual disabilities, respiratory problems, and hearing and vision impairment. Preterm birth costs the United States $25.2 billion annually.[1] 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 to change medical practice across the country.

CDC

The CDC's Division of Reproductive Health (DRH) and National Center for Birth Defects and Developmental Disabilities (NCBDDD) are doing important work related to pregnancy. Data collection efforts related to pregnancy outcomes, maternal mortality, and medications in pregnancy must continue.

For instance, CDC's ongoing support for state-based perinatal quality collaboratives and new funding for state maternal mortality review committees (MMRCs) is essential to address the nation's unacceptable maternal death rate. According to the NCHS, the maternal mortality rate in 2019 was 20.1 deaths per 100,000 live births, and racial disparities persisted with a maternal mortality rate of 44.0 per 100,000 live births among non-Hispanic black women compared to 17.9 among non-Hispanic white women.[2] SMFM fully supports Congress' attention to reducing maternal mortality through CDC's Safe Motherhood Initiative, and we ask that you provide at least $89 million for this work. Of that, we ask Congress to allocate the full $43 million included in the President's FY 2022 budget request to fund additional state MMRCs.

SMFM also urges Congress to allocate $100 million for the CDC's Surveillance for Emerging Threats to Moms and Babies initiative housed at the NCBDDD. The state-level surveillance infrastructure supported by the initiative allows state public health departments to monitor health threats stemming from maternal exposures, including infectious diseases such as COVID–19.

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 Maternal and Child Health (MCH) Block Grant. The funds provided through the MCH Block Grant increase access to comprehensive prenatal and postnatal care—especially for patients who are most at risk for adverse health outcomes. The Title V MCH Block Grant programs save federal and state governments money by expanding the 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 hyper-

[1] Waitzman NJ and Jalali A. Updating National Preterm Birth Costs to 2016 with Separate Estimates for Individual States. Salt Lake City, UT: University of Utah; 2019. Available at: https://www.marchofdimes.org/peristats/documents/Cost__of__Prematurity__2019.pdf.

[2] Hoyert DL. Maternal mortality rates in the United States, 2019. NCHS Health E-Stats. 2021.Available at https://www.cdc.gov/nchs/data/hestat/maternal-mortality-2021/maternal-mortality-2021.htm.

tension. We encourage Congress to provide at least $822.7 million for this important program that will help improve maternal and infant health across the United States.

AHRQ

Projects conducted at AHRQ are critical to translate research 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—those with comorbidities and co-existing conditions, including high-risk pregnant people. The agency's work is instrumental in collecting data; funding health services research; and, most importantly, disseminating findings to clinicians to improve maternal health care. Together, AHRQ's intramural programs, such as the Healthcare Cost and Utilization Project (HCUP), Evidence-Based Practice Center Program and Safety Program in Perinatal Care, and extramural research are essential to reducing maternal deaths and adverse pregnancy outcomes. By providing at least $500 million to AHRQ in FY 2022, Congress will allow AHRQ to expand its maternal health portfolio, improving care for nearly 4 million pregnant patients each year.

CONCLUSION

The COVID–19 pandemic has further exposed existing inequities and gaps within our healthcare system for people across the country, including pregnant people. It is more important than ever to prioritize the needs of pregnant people and their infants in federal programs from research, to public health surveillance, to care. We urge HHS to prioritize and adequately fund maternal health efforts for that aim to reduce maternal mortality and severe morbidity during and after the pandemic.

With your support of vital HHS programs, obstetric researchers, clinicians, and patients can address the complex problems of pregnancy and truly improve the health and wellbeing of mothers and infants. Please direct any inquiries about this testimony to Rebecca Abbott, SMFM's Director of Government Relations (rabbott@smfm.org).

PREPARED STATEMENT OF THE SOCIETY FOR NEUROSCIENCE

Chair DeLauro, Ranking Member Cole, and members of the Subcommittee, on behalf of the Society for Neuroscience (SfN), we are honoured to present this testimony in support of robust appropriations for biomedical research at the National Institutes of Health (NIH). SfN urges you to provide at least $46.1 billion, a $3.2 billion increase over FY21, in funding for existing institutes and centers at NIH for FY22, including $496 million from the NIH Innovation Account for 21st Century Cures programs and $560 million for the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative. Dr. Moses Chao and I, as Chair of the Government and Public Affairs Committee and President of SfN respectively, understand the critical importance of federal funding for neuroscience research in the United States. I currently serve as a researcher and as a Professor in the Department of Psychology at Cambridge University and Dr. Chao is a professor of Cell Biology, Physiology and Neuroscience, and Psychiatry at the New York University School of Medicine. Our research serves as two examples of the wide variety of neuroscience research advancing our collective understanding of the brain.

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 underlying compulsive drug use. Drug abuse and addiction have devastating consequences at the individual, family, and society levels. My research group made significant advances in showing structural and neurochemical changes in the brain associated with behavioral impulsivity confer a major risk on vulnerability to develop cocaine addiction. We have also demonstrated the neural circuit basis of transition from recreational to 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 development of novel pharmacological and psychological treatments for addiction that may promote and maintain abstinence from drug use.

Dr. Chao's research efforts focus on growth factors (also called neurotrophins) in the brain. These proteins are crucial for everything from neuron differentiation, growth, and survival during development to learning and memory in children and adults. Deficits in neurotrophins are involved in neurodegenerative disorders such as Alzheimer's, Parkinson's and Huntington's diseases, and Amyotrophic Lateral Sclerosis (ALS), as well as limiting recovery after stroke or brain injury.

Dr. Chao and I cover different areas of neuroscience research, though we have come together to convey the need for further and ongoing investment in neuroscience research. SfN believes strongly in the research continuum: basic science leads to clinical innovations, which leads to translational uses impacting the public's health. Basic science is the foundation upon which all health advances are built. To cure diseases, we need to understand them through fundamental discovery-based research. However, basic research depends on reliable, sustained funding from the federal government. SfN is grateful to Congress for its investments in biomedical research and increases for NIH over the last six years. Growing the NIH budget over $12 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.

THE IMPORTANCE OF THE RESEARCH CONTINUUM

NIH funding for basic research is critical for facilitating groundbreaking discoveries and for training researchers at the bench. For the United States to remain a leader in biomedical research, Congress must continue to support basic research that fuels discoveries as well as the economy. 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 not used elsewhere in the research pipeline. These opportunities create discoveries—sometimes unexpected discoveries—expanding 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 affecting millions of people in the United States and beyond.

NIH basic research funding is also a key economic driver of science in the United States through funding universities and research organizations across the country. Federal investments in scientific research fuel the nation's pharmaceutical, biotechnology and medical device industries. The private sector utilizes basic scientific discoveries funded through NIH to improve health and foster a sustainable trajectory for American's Research and Development (R&D) enterprise. Basic science generates the knowledge needed to uncover the mysteries behind human diseases, which leads to private sector development of new treatments and therapeutics. This important first step is not ordinarily funded by industry given the long-term path of basic science and the pressures for shorter-term return on investments by industry. Congressional investment in basic science is irreplaceable on the pathway for development of drugs, devices, and other treatments for brain-related diseases and disorders.

For example, in 2019, NIH launched—at Congress's direction—the cross-institute Helping to End Addiction Long-term (HEAL) Initiative to respond to the ongoing opioid public health crisis. Through this program, NIH supports the development of new medications to treat all aspects of the opioid addiction cycle and invests in preclinical and translational research in pain management. This work is vital to the translation of exciting new discoveries in the treatment of addiction. In our lab, we have shown 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 reducing the impact of maladaptive drug memories can promote abstinence from drug use, as well as be effective in 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; 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.

Another example of NIH's success in funding neuroscience is the 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. By including funding in 21st Century Cures, 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. SfN appreciates Congress' ongoing investment in the BRAIN Initiative and urges its full funding in FY22. Some recent exciting advancements in NIH funded neuroscience research include the following:

Personalized Medicine for Treating Depression

Major depressive disorder (often referred to as "depression") is one of the most common mental disorders in the United States, affecting more than 17 million adults each year in the United States alone. While there have been great strides in pharmacological treatments for depression, a patient's response to any given antidepressant will vary widely based on their particular brain chemistry. A group

of researchers funded by NIH recently used a machine learning algorithm to analyze patients' brain waves and predict their response to sertraline, a popular antidepressant. These data were taken from an NIMH funded study that used electroencephalography (EEG) to measure the brain's response to taking either a placebo or sertraline. Using an algorithm specially designed to analyze EEG data, the researchers were able to predict whether patients would respond to sertraline treatment based on brain waves measured before treatment. This work is a critical step towards quickly determining the most effective treatment for patients based on their personal brain chemistry and illness.

Understanding How COVID Affects the Brain

In addition to its well-documented effects on the respiratory system, it has become clear that SARS-CoV–2, the virus responsible for COVID–19, has a profound effect on the brain, with neurological symptoms from dizziness and mental fogginess to encephalitis and stroke appearing in COVID–19 patients. SARS-CoV–2 has been found in the cerebrospinal fluid (CSF) of some of these patients, indicating the virus was able to cross into the brain. To understand how the virus could enter the brain, researchers with NIH COVID–19 research funding used stem cells created from human skin cells to make clusters of brain cells called organoids. These organoids were made of cells found in different areas of the brain, and the researchers found that SARS-CoV–2 had a high infection rate for cells from a specialized region called the choroid plexus. The choroid plexus is the region of the brain that creates the CSF cushioning the brain and spinal cord; it is known as a site of infection for other viruses. This finding provides a lead on the location through which SARS-CoV–2 may be entering the brain and a potential target for developing treatments of the neurological effects of COVID–19.

COVID–19 IS A CHALLENGE AND OPPORTUNITY FOR NEUROSCIENCE RESEARCH

Unfortunately, the COVID–19 pandemic slowed progress in neuroscience research, with social distancing requirements hampering ongoing research related to the brain. Investment in neuroscience research, including on the neurological aspects of the SARS–CoV–2 virus and the COVID–19 pandemic itself is needed but cannot be allowed to eclipse or replace regular funding for neuroscience research. We urge you to identify ways to ensure current necessary funding increases to address the COVID–19 emergency do not slow progress on other important and innovative research, including the groundbreaking research in neuroscience and mental health. SfN is grateful Congress requested NIH seek to understand the psychosocial and behavioral health consequences of COVID–19. SfN encourages the Subcommittee to fund basic research on the biology of COVID–19 impacts on brain function as well as impacts on the nervous system in preclinical models and, by extension, on humans. In doing so, SfN encourages Congress and the NIH to prioritize intentional collaboration and coordination to effectively allocate scarce resources so researchers may investigate all facets of infectious and non-infectious disease.

Ongoing research already demonstrates the need for scientists to examine the neurological impacts of COVID–19. While mortality due to SARS–CoV–2 may be primarily due to its effects on the lungs, it is now apparent the virus damages many other organs, including the central nervous system. We need to understand how these direct and indirect effects on other organ systems are producing chronic diseases and long-term disability, making people more susceptible to other chronic disorders covered by the different NIH Institutes. A recent study (Lancet article, Taquet et al 2020) shows an increased risk of psychiatric conditions after COVID–19 diagnosis. Symptoms, such as anxiety, depression, post-traumatic stress disorder, and insomnia were reported. These data, though incomplete, suggest brain impairment occurs as a result of COVID–19 infection. Furthermore, it was found people with two copies of the risk gene for Alzheimer's disease were more likely to have severe COVID–19 (Kuo et al J. Gerontology 2020). These findings, coupled with incidents of memory loss, brain fog and hallucinations reported in the New York Times (3/23/21) demand increased resources to study the impact of this virus on the peripheral and central nervous systems, as well as the immune and inflammatory systems. The COVID–19 public health emergency provides an important example of the critical need for collaborative research and coordinating data and resources across institutes. A balanced and collaborative research effort across institutes will likely be the path toward solving these multiple issues.

CONGRESS & NIH MUST SUPPORT ACCESS TO MODELS NECESSARY FOR NEUROSCIENCE DISCOVERY

Adequate NIH funding is necessary to advancing our understanding of the brain; however, full realization of this funding's promise requires appropriate access to research models, including non-human primate and other animal models. Animal research is highly regulated to ensure the ethical and responsible care and treatment of the animals. SfN and its members take their legal and ethical obligations related to this research very seriously. While SfN recognizes the goal of the reduction, refinement, and eventual replacement of nonhuman primate models in biomedical research, much more research and time is needed before such a goal is attainable. Premature replacement of non-human primate and other animal models may delay or prevent the discovery of treatments and cures-not only for neurological diseases like Alzheimer's disease, addiction, and traumatic brain injury, but also for communicable diseases and countless other conditions. There are currently no viable alternatives available for studying biomedical systems that advance our understanding of the brain and nervous system; or when seeking treatments for diseases and disorders like depression, addiction, Parkinson's Disease, and emotional responses. This research is critically important and has the opportunity to benefit countless people around the world. SfN urges Congress to work with the NIH to ensure this important research can continue.

FUNDING IN REGULAR ORDER

SfN joins the biomedical research community supporting an increase in NIH funding to at least $46.1 billion for existing NIH institutes and centers, a $3.2 billion increase over FY21. 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, more economic growth and more improvements in the public's health. Equally as important as providing a reliable increase in funding for biomedical research is ensuring 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 will be realized, or operating a lab with 90 percent of the awarded funding until appropriations are final. All of the positive benefits research provides in this country may be negatively impacted by these real time considerations. SfN strongly supports the appropriation of NIH funding in a timely manner which avoids delays in approving new research grants or causes reductions in funding for already approved research funding. Meeting the example Congress set in 2018 would be another substantial benefit to science.

SfN thanks the subcommittee for your strong and continued support of biomedical research and looks forward to working with you to ensure the United States remains the global leader in neuroscience research and discovery. Collaboration among Congress, the NIH, and the scientific research community has created great benefits for not only the United States but also for people around the globe suffering from brain-related diseases and disorders. On behalf of the Society for Neuroscience, we urge you to continue this strong support of biomedical research.

[This statement was submitted by Barry Everitt, Sc.D., F.R.S., President, and Moses Chao, PhD, Chair, Government and Public Affairs Committee, Society for Neuroscience.]

PREPARED STATEMENT OF THE SOCIETY FOR WOMEN'S HEALTH RESEARCH

On behalf of the Society for Women's Health Research (SWHR)—whose mission is dedicated to promoting research on biological sex differences in disease and improving women's health through science, policy, and education—I am pleased to submit testimony describing SWHR's funding requests for fiscal year 2022. While SWHR supports strong funding across all federal public health programming, we specifically urge appropriators to support at least $46.1 billion for the National Institutes of Health (NIH), including at least $1.7 billion for the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), and $55.4 million for the Office of Research on Women's Health (ORWH).

Biological differences between women and men influence disease development, progression, and response to treatment, while social determinants of health, including gender, affect disease risk, health care access, and outcomes.

Over the past 15 months, as the world has collectively faced the myriad consequences of the COVID–19 pandemic, we have also seen an array of health disparities exposed, including significant sex and gender differences. For example, men are more likely to develop severe complications from COVID–19 and have a heightened risk of death, while women are more likely to be diagnosed with post-acute sequelae of COVID–19 and report more adverse events following vaccination. Additionally, women have been disproportionately affected by layoffs and socioeconomic challenges, food insecurity, domestic violence, and mental health concerns related to COVID–19.

Nevertheless, much of the ongoing COVID–19 research fails to thoroughly investigate the impact of sex and gender. We have long known that robust funding for federal institutes and offices that prioritize women's health research is critical to achieve health equity for women. Therefore, SWHR urges Congress to prioritize women's health and women's health research in FY 2022 funding legislation, which includes supporting the NIH, ORWH, and NICHD.

THE NATIONAL INSTITUTES OF HEALTH

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.

Within the NIH, there are several initiatives aimed at improving the health of women. Among these initiatives was the agency's Trans-NIH Strategic Plan for Women's Health Research, released in April 2019. The Strategic Plan laid out broad NIH goals that complement its more targeted women's health programs. These initiatives—along with the NIH's continued emphasis on improving standard research methodologies to address sex and gender and providing funding for women's health research—make continued support of NIH necessary in our mission to support women's health.

SWHR urges Congress to provide at least $46.1 billion for the NIH, a $3.2 billion increase over current funding, in FY 2022. This funding level would sustain and bolster NIH's ability to award competitive research grants, support the work of researchers within NIH, and build upon efforts to mitigate the COVID–19 pandemic's impact on ongoing and future research. We also encourage the Committee to work with NIH to ensure that the agency studies the impact of COVID–19, including the race and gender breakdown of participation in the workforce in the wake of the pandemic and how sex as a biological variable impacts short- and long-term health outcomes due to infection with SARS–CoV–2.

THE OFFICE OF RESEARCH ON WOMEN'S HEALTH

For decades, and as late as the 1990s, women were treated as small men in research. Research on diseases and treatments were conducted almost exclusively on male subjects, as researchers sought to avoid the presumed "complications" introduced by including female subjects in their work. Unfortunately, this approach ignored the impact of sex and gender on human development, disease progression, and ultimately, on approaches to research as a whole.

As the NIH focal point for coordinating women's health research, ORWH ensures women are represented across all NIH research and works to improve representation of women and women's health issues within federally funded research. ORWH provides critical leadership to programs, such as the Specialized Centers of Research Excellence, which advances translational research on the role of sex differences in the health of women, and the Implementing a Maternal health and Pregnancy Outcomes Vision for Everyone (IMPROVE) Initiative, which coordinates interdisciplinary research on factors impacting maternal mortality.

In order to allow the Office to continue to coordinate and drive the conversation on women's health across NIH, SWHR recommends $55.4 million in funding for ORWH, an increase on par with the overall NIH budgetary recommendations, for FY 2022. SWHR also recommends an additional $3 million be allocated to the Building Interdisciplinary Research Careers in Women's Health program, an initiative that trains investigators to research sex and gender influences on health. This program has the potential not only to improve women's health by advancing our understanding of sex and gender differences, but also to support a diverse research workforce.

EUNICE KENNEDY SHRIVER NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT

The NICHD provides a home for women's health research in areas including reproductive sciences and maternal health. While the Institute is conducting several areas of critical research, there are two key areas of need within NICHD that could be further supported through additional funding in FY 2022:

Pregnant and Lactating Individuals: Nearly 94% of women take at least one medicine during pregnancy, and 50% take at least one medication during the postpartum period. Yet, pregnant and lactating individuals are excluded from the majority of biomedical research. Consequently, these women and their health care providers do not have access to the information they need to make confident decisions about their health care.

SWHR supports the appropriate inclusion of these populations in clinical research. The federal Task Force on Research Specific to Pregnant Women and Lactating Women, housed within the NICHD, has been crucial to outlining next steps for improving research in pregnant and lactating populations. Based on the Task Force recommendations from August 2020, SWHR requests that Congress include report language recommending that NICHD contract with the National Academy of Medicine to convene a panel with specific legal, ethical, regulatory, and policy experts to develop a framework for addressing legal and liability issues in research specific to pregnant and lactating people.

Uterine Fibroids: There is also need for improved attention to uterine fibroids, one of the most common gynecological conditions nationwide. Approximately 26 million individuals in the United States from ages 15 to 50 have fibroids, and 15 million experience symptoms like severe menstrual bleeding, anemia, impaired fertility, and pregnancy complications. Fibroids cost the health care system $5.9 to $34.4 billion annually.

Additionally, prominent and troubling health disparities exist in fibroids prevalence, onset, and severity. Black women are two to three times more likely to develop fibroids than white women. Black patients also tend to develop fibroids at earlier ages, develop more and larger tumors, and show increased symptom severity.

Yet, despite the prevalence of fibroids, fibroid research remains drastically underfunded compared to disease burden. In 2019, fibroid research received about $17 million in NIH funding, putting it in the bottom 50 of 292 funded conditions.

SWHR calls on Congress to provide at least $1.7 billion for NICHD in FY 2022 and to urge the NICHD to prioritize funding to expand basic, clinical, and translational research pathophysiology to identify early diagnostic methods and fertility-preserving treatments and to understand and mitigate the impact of health disparities.

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The Society for Women's Health Research appreciates the opportunity to submit this testimony and thanks the Subcommittee for considering our requests of at least $46.1 billion for NIH, $55.4 million for ORWH, and at least $1.7 billion for NICHD. We look forward to working with you to support medical and health services research and, therein, the health of the nation. If you have questions or would like more information, please do not hesitate to contact me at kathryn@swhr.org.

[This statement was submitted by Kathryn G. Schubert, President & CEO, Society for Women's Health Research.]

PREPARED STATEMENT OF THE SOCIETY OF GYNECOLOGIC ONCOLOGY

The Society of Gynecologic Oncology thanks the Subcommittee for the opportunity to submit comments for the record regarding our report language recommendations for prioritizing research activities on gynecologic cancers at the NIH National Cancer Institute in Fiscal Year 2022. The Society of Gynecologic Oncology (SGO) is the premier medical specialty society for health care professionals trained in the comprehensive management of gynecologic cancers. The SGO's 2,000 members in the United States and abroad represent the entire gynecologic oncology team dedicated to the treatment and care of patients with gynecologic cancers. The SGO's strategic goals include advancing the prevention, early diagnosis, and treatment of gynecologic cancers by establishing and promoting standards of excellence. Key priorities for the SGO are to advocate for more equitable care for all patients and support research aimed to improve outcomes for diverse patient populations.

Gynecologic cancers are cancers that start in a patient's reproductive organs. There are five types of gynecologic cancers: cervical cancer, ovarian cancer, uterine

also referred to as endometrial cancer, vaginal cancer, and vulvar cancer. Cervical, ovarian, and uterine cancers have both the highest incidence and mortality rates of all the gynecologic cancers.

The American Cancer Society estimates that this year in the United States over 100,000 people will be diagnosed with gynecologic cancers, including 66,570 new cases of uterine cancer, 21,410 cases of ovarian cancer, and 14,480 new cases of cervical cancer. More than 30,000 people will die from these malignancies, including 12,940 deaths from uterine cancer, 13,770 deaths from ovarian cancer, and 4,290 deaths from cervical cancer.

What is most alarming is the American Cancer Society's Annual Report to the Nation on the Status of Cancer, 1975–2014, which compared overall cancer survival rates from 1975–1977 and from 2006–2012 and reported that survival rates increased significantly for all but two cancer types in women, cancer of the cervix and of the uterus.

Furthermore, there are significant health disparities among patients who are diagnosed with these cancers. Despite overall declines in cervical cancer mortality in the U.S. over the past 6 decades, racial and socioeconomic disparities continue to exist in cervical cancer screening, incidence, and mortality, resulting in a disproportionate impact on low-income patients and patients of color. Hispanic patients are most likely to get cervical cancer, followed by African Americans, American Indians and Alaskan natives, and Whites. Hispanic patients are sixty percent (60%) more likely to be diagnosed with and thirty percent (30%) more likely to die from cervical cancer than white patients. Black patients are approximately twice as likely to die of cervical cancer. Socioeconomic status plays a role in these disparities. Patients living below the poverty level and without a high school education are 4.9 and 6.3 times more likely to die of cervical cancer than patients with the highest income and education levels, respectively. As concerning as these figures remain, they may in fact represent an underestimation of the problem especially in black patients. A patient that is diagnosed with invasive cervical cancer often reflects a patient who did not have access to or failed to receive a Pap smear test.

Uterine or endometrial cancer is the most common gynecological cancer, and the fourth most common malignancy among women in the United States. There are significant racial disparities in endometrial cancer as well. Endometrial cancer has been reported to be thirty-one percent (31%) lower among black patients compared to white patients. However, both black and Hispanic patients are less likely to receive evidenced based care. These racial disparities in treatment likely contribute to racial disparities in outcome. The age-adjusted mortality among black patients is approximately 84% higher.

Disparities in access to genetic testing, preventive services, and other aspects of providing care for patients with gynecologic cancers are creating enormous inequities in outcomes and survivorship in our health care system, particularly for endometrial cancer and cervical cancer. Research is needed to help understand barriers to screening programs, discover new approaches to screening, and promote wider implementation of known strategies to facilitate optimal treatments and improved mortality for minority populations with these diseases.

The SGO urges the Subcommittee to adopt the following report language focused on gynecologic cancers in the report accompanying the Fiscal Year 2022 Labor-HHS-Education appropriations bill.

National Institutes of Health

National Cancer Institute

Gynecologic Cancers.—The Committee continues to be concerned about the growing racial, socioeconomic, and geographic disparities in gynecologic cancers. In contrast to most other common cancers in the United States, relative survival for women with newly diagnosed advanced cervical or endometrial cancer has not significantly improved since the 1970s.[1] Furthermore, historical data demonstrates that Black and Latinx women with gynecologic cancers are not as likely to receive standard therapy and/or die more frequently.[2] The current COVID–19 pandemic has only exacerbated the health care disparities that were already present in minority and underrepresented communities. For example, in early 2021 the Centers for Disease Control (CDC) published findings that cervix cancer screenings in California decreased by as much as 78% during the pandemic—and have not recovered. They specifically noted concern because "cervical cancer incidence and mortality rates are

[1] Jemal A, et al. Annual report to the nation on the status of cancer, 1975–2014, featuring survival. J Natl Cancer Inst 2017; 109(9): djx030.

[2] Rauh-Hain JA, et al. Racial and ethnic disparities over time in the treatment and mortality of women with gynecological malignancies. Gynecol Oncol 2018; 149(1): 4–11.

disproportionately higher in Hispanic women and non-Hispanic Black women."[3] Therefore, the Committee urges the NCI to expand the number of program projects, clinical trials, research grants, and contract opportunities for investigators that focus on discoveries that will positively impact access to prevention, early detection, diagnosis, and treatment for gynecologic cancers and address these now well documented disparities. Accelerated progress in reducing gynecologic cancer mortality has been a need for some time. The Committee requests an update on NCI's research program for gynecologic cancers in the fiscal year 2023 Congressional Budget Justification, including specific grants and strategies where the intent is to overcome these racial disparities in gynecologic cancers outcomes, including the underrepresentation of minority women in gynecologic cancer clinical trials.

Thank you in advance for your favorable consideration of this report language request. The SGO believes that pursuit of these important research objectives will help alleviate disparities in prevention, diagnosis, treatment, and survivorship of gynecologic cancers, benefitting minority patients and all patients who are impacted by these diseases.

PREPARED STATEMENT OF THE SOCIETY OF NUCLEAR MEDICINE AND MOLECULAR IMAGING

Madam Chair and members of the Subcommittee, I am Richard L. Wahl, MD, President of the Society of Nuclear Medicine and Molecular Imaging and the Elizabeth E. Mallinckrodt Professor and head of radiology at Washington University School of Medicine in St. Louis, MO.

The Society of Nuclear Medicine and Molecular Imaging (SNMMI) is a nonprofit scientific and professional organization that promotes the science, technology, and practical application of nuclear medicine and molecular imaging. Research in this field has led to breakthroughs for diagnosing and treating patients with deadly conditions such as cancer, heart disease, and Alzheimer's disease. SNMMI strives to be a leader in unifying, advancing, and optimizing molecular imaging, with the ultimate goal of improving human health through noninvasive procedures and therapeutic approaches utilizing internally-administered radiopharmaceuticals. With over 15,000 members worldwide, SNMMI represents nuclear medicine and molecular imaging professionals, including physicians, physicists, radiochemists, pharmacists, and technologists, all of whom are committed to the advancement of the field. It is my pleasure to submit this testimony on behalf of SNMMI. We strongly support the President's request of $52 billion for the National Institutes of Health and ask that no less than $46.111 billion of that be for the NIH's base program budget for FY2022.

Moreover, SNMMI supports a proportional increase to the National Institute of Biomedical Imaging and Bioengineering (NIBIB), resulting in at least $441.1 million for FY2022—a $30.4 million increase over FY2021. These base increases reflect approximately 5% above the biomedical research and development price index (BRDPI). Through consistent, strong funding for NIH and our national research infrastructure we can continue to make advancements that will improve the lives of patients with a wide spectrum of diseases and disorders. SNMMI is grateful for the Subcommittee's past support of NIH and encourages the Subcommittee to continue advancing discovery and innovation in nuclear medicine and molecular imaging.

Nuclear medicine, in particular, is undergoing a renaissance as a precision medicine specialty, with new radiopharmaceuticals, radiopharmaceutical therapies, and instrumentation to elucidate biology and benefit patients. Federal research funding allows our members, partners, and stakeholders to improve imaging tools and therapies, which, in turn, broadens the resources available to address many challenging conditions. As a physician/clinician-scientist, my work has been greatly impacted by NIH funding, resulting in 18 patents, over 450 peer-reviewed scientific manuscripts, and several FDA-approved theranostic (therapy + diagnostics) drugs and devices. I use state-of-the-art technologies like positron emission tomography (PET) combined with computer tomography (CT) and other advanced imaging modalities to improve the diagnosis and treatment of cancer types, including prostate, breast, neuroendocrine, and pancreatic, while also researching rare and orphan diseases.

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[3] Miller MJ, et al. Impact of COVID–19 on cervical cancer screening rates among women aged 21–65 years in a large integrated health care system. CDC Morbidity and Mortality Weekly Report. January 29, 2021; 70(4): 109–113.

NUCLEAR MEDICINE AND MOLECULAR IMAGING: PRECISE AND PERSONALIZED MEDICINE

Nuclear medicine and molecular imaging procedures are used in a wide array of diseases and disorders, including cancer, Alzheimer's and Parkinson's Diseases, and cardiac disease, among others.[1] Congress's support of NIH has helped to advance the science and the researchers who make these discoveries. NIH support is often the foundation of the newest technologies that go on to help patients. This subcommittee's continued support of the NIH, especially the National Cancer Institute (NCI), NIBIB, National Institute on Aging (NIA), National Institute of Neurological Disorders and Stroke (NINDS), National Institute of Mental Health (NIMH), and National Heart, Lung, and Blood Institute (NHLBI), will help scientists address many unmet medical needs. Some of the advances from the nuclear medicine and molecular imaging community in detecting and treating cancer and selecting the right patient for the right therapy are detailed below.

Radiopharmaceutical Imaging and Therapy for Cancer

In the last month alone, two major advancements in the fight against prostate cancer were in the news. Pylarify®, a radioactive imaging agent, was approved by FDA on May 27. This radiotracer seeks out prostate cancer cells throughout the body so the active foci of cancer can be seen on a PET/CT scan. This class of agents targeting prostate specific membrane antigen or PSMA, can identify cancer months or years ahead of standard imaging such as CT or MRI, allowing patients to receive appropriate treatment sooner when it can be more effective. One week later, the results from the VISION trial were announced. This phase III trial enrolled men with late-stage castrate-resistant prostate cancer that had spread and were treated with either a PSMA targeting molecule with the radioisotope lutetium-177 (^{177}Lu) attached, or with the best standard of care. The PSMA part of the drug acts like GPS to seek out prostate cancer cells. The attached lutetium-177 radioisotope destroys the cancer cells while leaving healthy tissue intact. Combined, the radiopharmaceutical therapy is in effect a "smart bomb" to selectively destroy foci of prostate cancer. The men treated with ^{177}Lu-PSMA had a four-month longer median survival than men receiving best standard of care alone. These results prompted FDA to label the treatment as a breakthrough therapy which will accelerate its approval time and allow it to reach patients in need faster. None of this would have been possible without the early support of 13 NIH grants.[2]

Imaging and therapy molecule pairs, such as those using PSMA molecules as targeting agents, are often referred to as theranostics, a rapidly developing area of personalized medicine. If the diagnostic version of the molecule can find the cancer with a PET scan, then the same molecule with a therapeutic isotope can be used to attack the cancer. Further advancements in the theranostics space are anticipated. This treatment principle is being applied to cancer types for which we have no or few treatment options, such as pancreatic cancer. An exciting new class of theranostic molecules are those targeting fibroblast-activation-protein (FAP).[3] This protein (FAP) is overexpressed in many cancer types including breast, pancreas, lung, kidney, and ovarian. The FAP molecule can be labeled as a diagnostic agent and then as a therapy. This treatment paradigm gives doctors a new tool in the fight against cancer. The NCI is currently supporting a phase 1 clinical trial (NCT04457258) on this promising new agent.

None of these advances would be possible without the support of radiochemistry and isotope production research. The next generation of radioisotopes, alpha emitting therapeutic isotopes, which have much greater cancer killing power per radioactive decay, are in clinicals trials and are expected to provide better patient outcomes. Support of that research is critical.

Quantitative Molecular Imaging

A PET scanner is often thought of as an imaging tool; however, it is inherently a highly specific measuring tool. Recent advances in PET technology such as PET/

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[1] Wahl RL, Chareonthaitawee P, Clarke B, Drzezga A, Lindenberg L, Rahmim A, Thackeray J, Ulaner GA, Weber W, Zukotynski K, Sunderland J. Mars Shot for Nuclear Medicine, Molecular Imaging, and Molecularly Targeted Radiopharmaceutical Therapy. J Nucl Med. 2021 Jan;62(1):6–14. doi: 10.2967/jnumed.120.253450. PMID: 33334911.

[2] Szabo Z, Mena E, Rowe SP, et al. Initial Evaluation of [(18)F]DCFPyL for Prostate-Specific Membrane Antigen (PSMA)-Targeted PET Imaging of Prostate Cancer. Mol Imaging Biol. 2015;17:565–574.

[3] Kratochwil C, Flechsig P, Lindner T, Abderrahim L, Altmann A, Mier W, Adeberg S, Rathke H, Röhrich M, Winter H, Plinkert PK, Marme F, Lang M, Kauczor HU, Jäger D, Debus J, Haberkorn U, Giesel FL. 68Ga-FAPI PET/CT: Tracer Uptake in 28 Different Kinds of Cancer. J Nucl Med. 2019 Jun;60(6):801–805. doi: 10.2967/jnumed.119.227967. Epub 2019 Apr 6. PMID: 30954939; PMCID: PMC6581228.

MRI and total-body PET, where the whole body can be imaged at once, have opened new research possibilities.[4] To realize the full potential of these advances, quantitative analysis will be required to appreciate the sensitivity of the scanner and the tracers it measures. The NCI has supported the harmonization of PET/CT scanners through numerous grants including NIH R01CA169072, and for the last decade, the NCI, through their Cancer Imaging Program has developed and supported a consortium of academic sites called the Quantitative Imaging Network performing and advancing quantitative imaging mostly in support of clinical trials.

Imaging of the brain in Alzheimer Disease

In the past weeks, the FDA approved an innovative antibody therapy for Alzheimer's disease which removes amyloid plaque from the brain. At present, PET scanning using radiotracers that target the amyloid protein or the abnormal tau protein seen in dementias of the Alzheimer type have been key to identifying patients who may be suitable candidates for such clinical trials and these emerging therapies. The support of the NIH was key to developing these brain imaging agents and continued NIH support is essential to allow PET to probe the earliest changes of dementia and to monitor the effects of emerging innovative therapies. There are now several FDA approved PET imaging agents to identify patients with amyloid or tau deposition, helping identify how to best target limited resources to patient groups most likely to benefit from such therapies. The ability to select patients most likely to respond to therapy is expected to save tens of billions in healthcare dollars per year.

Immuno-oncology Imaging

In 1980, the NCI added $13.5M to their budget for new Biological Response Modifiers, this triggered a search for agents able to modify a body's response to tumor cells.[5] That investment spawned the multi-billion-dollar drug class of immune checkpoint inhibitors (ICI), starting with the approval of Yervoy® (ipilumimab) in 2011. In the US in 2020, a year severely impacted by the COVID–19 pandemic, sales of the top three ICI topped $17B. ICIs are generally considered to be safe and effective treatment options for numerous cancer types including lung cancers and melanoma, and some people like former US President Jimmy Carter had a remarkable response to ICI therapy. However, they do not work in all patients; indeed over half of patients treated with these agents die of their disease. New radiotracers are in development to image the immune system in conjunction with a PET or SPECT camera. Clinical trials with these tools have demonstrated the ability to predict response to ICI therapy after just one cycle of therapy. Future studies will aim to preselect, with imaging, patients who are likely to respond to immune checkpoint inhibitors thus enabling effective therapy earlier and eliminating side effects of futile treatments. The ability to select patients likely to respond to therapy will also save billions in healthcare dollars.

Data Science and Workforce

The field of nuclear medicine and molecular imaging is rapidly expanding with new diagnostic imaging tracers, radiopharmaceutical therapies (RPT), and technologies. With new diagnostic tracers comes a need to properly interpret the innovative scans. Artificial intelligence (AI) algorithms can assist with the tedious components of image interpretation and even help with quality report generation. Development of well-credentialed registries of studies to train and validate such AI algorithms, reflecting diverse sets of patients will help advance this field. Radiopharmaceuticals therapies (RPTs), like other oncology therapies, are often studied in and approved for patients with late-stage disease, for example, after all other treatments have failed. To harness the full potential of RPTs, use earlier in the disease course may be advisable. Image and clinical data registries are needed to capture post-approval information on the use of RPTs and the patient outcomes to further guide their use. Recent imaging and therapy FDA approvals in prostate cancer and Alzheimer's disease, two highly prevalent conditions, require that the highly specialized field of nuclear medicine and molecular imaging train a cadre of qualified individuals to diagnose and treat these patients. It is critical for the NIH to fund and expand training grants so that our brightest scientists have the skills to develop a sus-

[4] Meikle SR, Sossi V, Roncali E, Cherry SR, Banati R, Mankoff D, Jones T, James M, Sutcliffe J, Ouyang J, Petibon Y, Ma C, El Fakhri G, Surti S, Karp JS, Badawi RD, Yamaya T, Akamatsu G, Schramm G, Rezaei A, Nuyts J, Fulton R, Kyme A, Lois C, Sari H, Price J, Boellaard R, Jeraj R, Bailey DL, Eslick E, Willowson KP, Dutta J. Quantitative PET in the 2020s: a roadmap. Phys Med Biol. 2021 Mar 12;66(6):06RM01. doi: 10.1088/1361–6560/abd4f7. PMID: 33339012.

[5] https://www.whatisbiotechnology.org/index.php/timeline/science/immunotherapy/80.

tainable career pathway. Funding for AI technologies and registries will improve patient care and outcomes.

SUMMARY AND CONCLUSION

Robust NIH funding is crucial to advancing our efforts to detect and treat serious medical conditions. NIH investments help to sustain both our local and national research institutions across every state in the nation. China is advancing rapidly in the high technology medical space notably in AI. Funding NIH's base program with at least $46.111 billion will help researchers, scientist and physicians retain its competitive edge.

Thank you for your strong, continued support of NIH, NCI, NIMH, NIBIB and all the Institutes and Centers working to advance molecular imaging and radiopharmaceutical therapies to improve the lives of patients worldwide. On behalf of the Society of Nuclear Medicine and Molecular Imaging, I urge you to continue your strong support of our nation's research and innovation enterprise.

[This statement was submitted by Richard L. Wahl, MD, President, Society of Nuclear Medicine and Molecular Imaging.]

PREPARED STATEMENT OF THE STUDENT SUPPORT AND ACADEMIC ENRICHMENT PROGRAM

Dear Chairwoman Murray, Ranking Member Blunt, Chairwoman DeLauro, and Ranking Member Cole:

As you consider Fiscal Year 2022 appropriations for the U.S. Departments of Labor, Health and Human Services, and Education, we encourage you to help close opportunity and resource gaps in our nation's public schools by funding the Student Support and Academic Enrichment (SSAE) grant program authorized by Title IV–A of the Every Student Succeeds Act (ESSA) at $2 billion, which represents a $780 million increase over FY2021.

Title IV–A is a flexible grant that supports state and district efforts to: (1) support safe and healthy students by providing comprehensive mental and behavioral health services, implementing violence prevention programs, trauma informed care, school safety trainings; and other evidenced based initiatives; (2) increase student access to a well-rounded education, such as: STEM; computer science and accelerated learning courses; career and technical education; physical education; music; the arts; foreign languages; college and career counseling; effective school library programs; and social and emotional learning; and (3) provide students with access to technology and digital learning materials and educators with professional development and coaching opportunities necessary to effectively use those resources.

Over the last four fiscal years, on a bipartisan basis, Congress has provided a $4 billion investment for Title IV–A, which has allowed districts to meaningfully invest in programs that provide direct educational services and equitable supports to students. Its flexibility has allowed districts to provide funding for critical programs that support educators, school leaders, and students. As district leaders continue to leverage the flexibility of the SSAE grants, they are eager to plan for the continuance and/or expansion of existing programs and services, and to create new programs.

To address unprecedented interruptions to learning caused by COVID–19, we call on Congress now to go beyond what was authorized in ESSA by providing $2 billion for the SSAE block grant. This will allow additional school districts, especially in rural areas, to make investments in not just one, but all three areas that this grant supports. Right now—more than ever—districts need the continued investments in the Title IV–A program.

The continued funding in these critical areas, especially during these uncertain times, will give districts the opportunity to build on the successes from the past 5 fiscal years as well as the ability to use Title IV–A funds to address issues that the COVID–19 crisis has made apparent and exacerbated. This pandemic has made clear that districts face a wide range of unique challenges, whether it's ensuring all children have access to technology for remote or blended learning or the ability to provide mental health supports from afar. As school systems prepare for the return to the classroom, they will need the flexibility of Title IV–A funds to provide social and emotional learning programs, engaging well-rounded classes like music and physical education, and active learning opportunities enabled through technology.

In order to support a safe and healthy school environment and make sure our students receive a well-rounded education that puts them on a path to success, we must continue to invest in our nation's schools, educators, and most importantly,

our students. For these reasons, we urge Congress to fund the SSAE flexible grant program at $2 billion in FY 2022.

Thank you for the consideration of this request, we are grateful for the continued investments in the Student Support and Academic Enrichment grant program under Title IV–A of the Every Student Success Act (ESSA).

Sincerely.

National Organizations
AASA, The School Superintendents Association
Afterschool Alliance
American Counseling Association
American Federation of School Administrators
American Heart Association (AHA)
American Library Association
American Occupational Therapy Association
American Psychological Association
American School Counselor Association
ASCD
Association of Educational Service Agencies
Association of School Business Officials International (ASBO)
Chiefs for Change
City Year Inc.
Collaborative for Academic, Social, and Emotional Learning (CASEL)
Committee for Children
Common Sense
Communities In Schools
Council of Administrators of Special Education
EDGE Consulting Partners
Educational Theatre Association
EduColor
Futures Without Violence
Girl Scouts of the USA
Girls Inc.
Girlstart
International Society for Technology in Education
Joint National Committee for Languages
League of American Orchestras

MENTOR National
National Afterschool Association
National Association for College Admission Counseling
National Association of School Nurses
National Association of School Psychologists
National Association of Secondary School Principals
National Association of State Directors of Special Education (NASDSE)
National Center for Learning Disabilities
National Council for Languages and International Studies
National Council for the Social Studies
National PTA
National Rural Education Advocacy Consortium
National Science Teaching Association
National Summer Learning Association
National Superintendents Roundtable
School Social Work Association of America
School-Based Health Alliance
SHAPE America - Society of Health and Physical Educators
State Education Agency Directors of Arts Education
State Educational Technology Directors Association (SETDA)
Teach Plus
State Organizations
Alabama Association of School Psychologists
Alaska Science Teachers Association

Arizona Science Teachers Association
Arkansas School Psychology Association
Association of School Psychologists of Pennsylvania
Connecticut School Counselor Association
Connecticut Science Teachers Association
Delaware Association of School Psychologists (DASP)
Florida Association of Science Teachers
Guam Association of School Counselors (GASC)
HASTI (Hoosier Association of Science Teachers, Inc.)
Idaho Science Teachers Association (ISTA)
Illinois School Psychologists Association
Indiana Association of School Psychologists
Kentucky Association for Psychology in the Schools (KAPS)
Maine School Counselor Association
Maine Science Teachers Association
Maine Science Teachers Association
Maryland Association of Science Teachers (MAST)
Maryland School Psychologists' Association
Massachusetts Association of Science Teachers
Michigan Science Teachers Association (MSTA)
Michigan Association of School Psychologists
Minnesota Science Teachers Association
Missouri Association of School Psychologists
Montana Science Teachers Association
Nebraska Association of Teachers of Science
Nebraska School Psychologists Association
Nevada School Counselor Association

Nevada State Science Teachers Association
New Hampshire Association of School Psychologists
New Jersey Association of School Psychologists
New York Association of School Psychologists (NYASP)
New York State School Counselor Association
North Dakota Association of School Psychologists
North Carolina School Counselor Association
Ohio School Counselor Association
Oklahoma School Psychological Association
Pennsylvania Science Teachers Association
Rhode Island School Psychologists Association
Science Teachers Association of New York State
Science Teachers Association of Texas
Science Teachers of Missouri
South Carolina Science Council
South Dakota Association of School Psychologists
South Dakota Science Teaching Association
Tennessee Association of School Psychologists (TASP)
Tennessee Science Teachers Association
Texas Association of School Psychologists
Utah Association of School Psychologists
Utah School Counselor Association
Utah Science Teachers Association
Vermont Association of School Psychologists
Washington Science Teachers Association
Washington State Association of School Psychologists
West Virginia School Psychologists Association
West Virginia Science Teachers Association
Wisconsin School Counselor Association
Wisconsin School Psychologists Association

PREPARED STATEMENT OF SUSAN G. KOMEN BREAST CANCER FOUNDATION

Susan G. Komen (Komen) is the world's leading nonprofit breast cancer organization representing the millions of Americans who have been diagnosed with breast cancer and are currently living in the United States. 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 284,200 women and men in the United States that will be diagnosed with breast cancer and the more than 44,000 that will die from the disease in 2021 alone.

Screening tests are used to find breast cancer before it causes any warning signs or symptoms. Regular screening enables us to detect potential cancers at earlier stages and refer patients to further care, often yielding better outcomes for patients and resulting in decreased financial pressure on our healthcare system. Without access to early detection programs, many individuals are forced to delay or forgo screenings, which can lead to disease progression and later-stage breast cancer diagnoses. To ensure access to early detection programs, Komen is requesting that Congress fully fund the Centers for Disease Control's (CDC) National Breast and Cervical Cancer Early Detection Program (NBCCEDP) at the authorized amount of $275 million in Fiscal Year (FY) 2022.

NBCCEDP was established with the passage of the Breast and Cervical Cancer Mortality Prevention Act in 1990. The program plays a critical role in helping low-income, uninsured, and underinsured women who do not qualify for Medicaid receive timely breast and cervical cancer screening, diagnostic and treatment services that are free or low-cost. The covered services include clinical breast examinations, mammograms, pelvic examinations, Pap tests, human papillomavirus (HPV) tests, diagnostic tests if screening results are abnormal, and referrals to treatment. Additionally, the NBCCEDP provides patient navigation services to help women overcome barriers and get timely access to quality care.

For 30 years, NBCCEDP has provided lifesaving breast cancer screening and diagnostic services to eligible women in all 50 states, the District of Columbia, six territories and 13 American Indian/Alaska Native tribes or tribal organizations. NBCCEDP has served more than 5.8 million women since it launched in 1991, detecting over 72,000 breast cancers, nearly 23,000 premalignant breast lesions, 4,900 cervical cancers and 226,000 premalignant cervical lesions. More statistics on the number of women served by the program in each state is available here.

The program, which is a partnership between the CDC and state health departments, also provides public education, outreach, care coordination and quality assurance to increase breast cancer screening rates and reach underserved, vulnerable populations. Each state program operates within the national framework of legislation, policy, and oversight; however, programs vary in funding, infrastructure, populations served and geographical barriers. 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 state legislative constraints.

The COVID–19 pandemic highlighted the broad systemic trend that exists with almost every public health crisis: consequences are more commonly and more severely experienced in low-income, minority and rural communities. Black women in the United States have a breast cancer mortality rate about 40 percent higher than white women. Similarly, Hispanic/Latina and American Indian/Alaska Native women are 30 percent more likely to be diagnosed with advanced stage breast cancer compared with white women. NBCCEDP funding supports interventions which help address inequities in breast cancer screening and diagnosis since the program places special emphasis on women who are geographically or culturally isolated and who identify as racial or ethnic minorities. The program focuses on factors at the interpersonal, organizational, community and policy levels that influence screening. NBCCEDP invests in evidence-based interventions, for health care systems and communities, which reflect cultural competencies needed to reach communities that often distrust the medical system. Use of multicomponent interventions of this type are found to be more effective at connecting historically marginalized communities to services. However, the CDC and state health departments need more support.

More than 2.6 million women are eligible for NBCCEDP breast cancer screening services. Authorized at $275 million, the program is currently funded at approximately $197 million. Unfortunately, at current funding levels NBCCEDP serves fewer than 15 percent of the estimated number of eligible women for breast cancer screening services and less than seven percent of eligible women for cervical cancer screening.

An increase in funding in FY22 will be especially crucial as the nation recovers from the COVID–19 pandemic. Data show that the pandemic has caused people to delay life-saving breast cancer screenings. Models, based on data from the 3-month period from early March 2020 through early June 2020, suggest there could be as many as 36,000 missed or delayed diagnoses of breast cancer because of COVID–19.[1] This delay can mean women will not seek care until the cancer is more advanced, leading to worse outcomes for the patient and much more costly treatment. Furthermore, with many Americans experiencing job loss and financial difficulties

[1] IQVIA Institute for Human Data Science, Shifts in Healthcare Demand, Delivery and Care During the COVID–19 Era (April 2020).

related to the COVID–19 pandemic, with resulting loss of healthcare benefits, continued access to NBCCEDP is needed now more than ever.

The availability of the NBCCEDP impacts every taxpayer and people in every congressional district, as the uninsured will eventually seek care at our states' hospitals with late-stage disease, putting an even greater strain on the patients, the health system and state budgets. Ensuring adequate NBCCEDP funding is key to ensuring that low-income, uninsured, and underinsured women across the country continue to have access to vital screening services, health education and patient navigation services, as well as enabling proper monitoring of state and local breast cancer patterns and trends.

An increased investment in the NBCCEDP will allow the CDC and its state and local partners to broaden its reach and pursue important goals such as implementing innovative strategies and new methods to find eligible women currently not using the program, including those with no source of care, and lower incomes, education, and health literacy levels, ultimately helping to create a more equitable health care system.

The NBCCEDP has bipartisan support in both the Senate and House of Representatives, with letters being submitted in both chambers in support for full authorized funding for the program this year. Increasing funding for NBCCEDP to the authorized level of $275 million in the FY 22 Labor, HHS, Education Appropriations Bill will result in more women being screened, more cancers being diagnosed at earlier stages and ultimately better outcomes for women and lower costs for our health care system.

[This statement was submitted by Molly Guthrie, Sr., Director, Public Policy and Advocacy.]

PREPARED STATEMENT OF THE TASK FORCE FOR GLOBAL HEALTH

Thank you for this opportunity to provide testimony on polio activities at The Task Force for Global Health. I write to express our support for full funding for CDC's polio initiatives.

The Task Force for Global Health, founded nearly 40 years ago to advance health equity, works with partners in more than 150 countries to eliminate diseases, ensure access to vaccines and essential medicines, and strengthen health systems to protect populations. Our expertise includes polio, influenza, COVID–19, hepatitis, neglected tropical diseases; vaccine safety, distribution and access; and health systems strengthening. Our COVID–19 activities include working with 50 countries to deliver vaccines, address vaccine hesitancy, provide vaccine safety guidelines; advise on digital contact tracing; train epidemiologists in disease surveillance and response; distribute essential protection and treatment to hard-hit communities; work through existing health programs to ensure protection for vulnerable groups, such as those afflicted with other diseases; and leverage our existing supply chains to support ongoing response and assist countries in delivering vaccines.

CDC has been engaged in the fight against polio for over 31 years. Its leadership, in providing technical guidance and expertise in countries, regionally and globally as part of the Global Polio Eradication Initiative, has resulted in a reduction in the number of worldwide polio cases from an estimated 350,000 in 1988 to 176 in 2019—a decline of more than 99% in reported cases. It has also resulted in polio-free certification in five of the six regions of the world—the African Region, the Americas, Europe, South East Asia and the Western Pacific. Only two polio-endemic countries (nations that have never interrupted the transmission of wild poliovirus) remain—fghanistan and Pakistan. Without CDC's polio eradication efforts, more than 18 million people who are currently healthy would have been paralyzed by the virus.

At the Task Force for Global Health, we are providing surge capacity expertise and technical assistance to outbreak countries and those at high risk of future outbreak in the African region. Since April 2018, the Global Polio Surge Capacity Team, consisting of a project manager and four senior epidemiologists, have deployed a total of 17 times to Ghana, Ethiopia, Indonesia, Congo-Brazzaville, and Zambia, with a total of nearly 1,250 person days. In a time of growing scale and scope of circulating type 2 vaccine-derived poliovirus (cVDPV2) outbreaks, the team provides highly respected and valued expertise across the Global Polio Eradication Initiative (GPEI) partnership.

In Ministry of Health forums, the team is considered a crucial component of polio outbreak response efforts, often working closely with Emergency Operations Centers and national public health institute staff. They have provided technical assistance for improving active case search, enhancing surveillance efforts, and preparation

and implementation of vaccination campaigns. Supplementary immunization activities have targeted hundreds of millions of children since the team was created, and the long-term nature of their deployments has provided essential continuity in settings that often see high staff turnover.

Since CDC began the Frontline Polio Surge activities in October 2019, the team has provided supervision and direction to the deployed staff, connecting them with district surveillance staff, WHO colleagues, and Ministry of Health staff. They serve as in-country experts and resources to teams deployed at district levels for campaigns and surveillance strengthening activities. A training program to prepare 100 NSTOP (National Stop Transmission of Polio) staff for field deployments was developed and conducted.

In Ethiopia and Zambia, members of the team have taken the lead on supporting the Ministries of Health in developing comprehensive surveillance proposals for continued active case search of Acute Flaccid Paralysis (AFP) cases, with SOPs and protocols for district surveillance staff. These include the utilization of Field Epidemiology Training Program (FETP) residents as sources of valuable local human resource capacity. The institutionalization of this expertise is crucial for these countries working towards controlling outbreaks and ultimately eradicating polio.

Moving forward, we will continue to provide in-person technical assistance to countries facing circulating vaccine-derived type 2 poliovirus outbreaks, to meet surveillance and response needs. This work will include pre-, intra-, and post-vaccination campaign activities. Additionally, the team will apply its extensive breadth of experience in using data for action to strengthen surveillance networks, country outbreak preparedness and response plans, and training materials.

Lastly, we will provide remote technical assistance as needed on campaign data quality, monitoring and evaluation of campaigns, strengthening of EOCs, and supervision of local consultants. Members of the team will continue to provide guidance on various long-term requests from Ministries of Health and international agencies.

Due to Congress's support in FY 2019 and FY 2020, select CDC polio accomplishments include:

—Provide instrumental support internationally and domestically through extensive details to the CDC COVID–19 response and through polio-supported staff to the COVID–19 pandemic response in Afghanistan, Pakistan, and across Africa in the areas of disease surveillance, health worker training, contact tracing, risk communications and testing.

—Provide $56.13 million in FY 2020 to UNICEF for the expansion of Community Based Vaccinator Program in Pakistan that now includes over 24,000 workers (nearly 90% are women) who reach 4 million children annually, approximately 60 million doses of oral polio vaccine, 2.9 million doses of inactivated polio vaccine, and $3 million for operational costs for NIDs in all polio-endemic countries and outbreak countries. Most of these NIDs would not take place without the assurance of CDC's support.

—Provide expertise in virology, diagnostics, and laboratory procedures, including quality assurance, and genomic sequencing of samples obtained worldwide; provide the largest volume of operational (poliovirus isolation) and technologically sophisticated (genetic sequencing of polio viruses) lab support to the 145 laboratories of the global polio laboratory network. CDC has the leading specialized polio reference lab in the world.

—Deploy 210 Stop Transmission of Polio (STOP) members in 42 countries with two-thirds deployed to the African Region which has significantly benefited from STOP support, contributing substantially to the region's achievement of wild polio-free status in 2020. CDC's Stop Transmission of Polio (STOP) program trained and deployed 2100 public health professionals to improve vaccine-preventable disease surveillance and to help plan, implement, and evaluate vaccination campaigns.

—Use STOP participants to support local governments, health facilities, and communities during the COVID–19 pandemic to promote awareness of COVID–19 and provide contract tracing while still supporting VPD surveillance, essential immunization services, and polio eradication efforts.

Global polio initiatives are leading us to a day when polio will be eradicated from our planet. The Task Force for Global Health is honored to support CDC's leadership in its mission and to serve as part of this strong global partnership to end polio in our lifetime.

With Congress' continued support, we will be able to support CDC's outbreak priorities, which include strengthening surveillance for polioviruses in all areas currently below certification standard and rapidly responding to the detection in a population of the types of polioviruses included in discontinued oral polio vaccines. We will also ensure that populations are not exposed to the types of polioviruses in-

cluded in discontinued oral polio vaccines while laying the logistic and epidemiologic groundwork for the complete cessation of use of all oral polio vaccines.

Thank you for the opportunity to provide this testimony.

[This statement was submitted by Dr. Fabien Diomande, Director, Polio Surge Program: Task Force for Global Health.]

PREPARED STATEMENT OF THE TASK FORCE FOR GLOBAL HEALTH

Thank you for allowing me to provide written remarks on behalf of the Coalition for Global Hepatitis Elimination of the Task Force for Global Health. I want to express the Coalition's strong support for funding of at least $250 million for the Department of Health and Human Services' national strategy for the elimination of viral hepatitis and the global and domestic activities needed to achieve the plan's goals for hepatitis elimination.

As the COVID–19 pandemic has taught us, we must eliminate deadly viral threats when we have the opportunity. Now is the time to eliminate hepatitis B virus (HBV) and hepatitis C virus (HCV).

The Task Force for Global Health, founded in 1984 to advance health equity, works with partners in more than 150 countries to eliminate diseases, ensure access to vaccines and essential medicines, and strengthen health systems to protect populations. Our expertise includes neglected tropical diseases and other infectious diseases; vaccine safety, distribution and access; and health systems strengthening.

The Coalition for Global Hepatitis Elimination, a program of the Task Force for Global Health, with support of CDC and NIH, assists the work of public health authorities, clinicians and community organizations working on the front lines to prevent, detect and treat HBV and HCV.

HBV AND HCV INFECTIONS ARE LARGE GLOBAL HEALTH PROBLEMS

In 2015, a total of 296 million and 58 million persons worldwide were living with HBV and HCV infections, respectively, which cause over 1 million deaths per year. In the United States, as many as 2.3 million persons are living with HBV infection and 3.5 million persons are living with HCV infection. The United States has the third largest burden of HCV in the world, after only China and India. Of HBV and HCV infected persons, if undiagnosed and untreated, 20%–25% will die of liver disease or liver cancer. Three of four liver cancer deaths are caused by HBV or HCV.

Hepatitis is a health disparity for racial/ethnic minority populations and for rural America. The health threat of hepatitis B is greatest for Asian Americans who were not vaccinated as children before arriving in the United States. Hepatitis-infected persons in communities of color have limited access to testing and lifesaving treatment, leading to higher death rates for American-Indians/Alaskan Natives and Black Americans. New infections of HCV are rising at an alarmingly fast pace, fueled by the opioid crisis and increases in injection drug use with unsafe equipment. HCV infections rates are increasing the most among young adults in Appalachian states.

All of the public health and biomedical tools needed to address these gaps in hepatitis prevention, testing, and treatment are available. HBV vaccines have been in use for decades. Indeed, the 2020 Nobel Prize in Medicine was awarded to two American scientists for work leading to the discovery of HCV and making possible the reliable tests and first curative therapies for a chronic viral infection. Rarely in public health do we have this opportunity. Now is the time to act within our borders and globally to eliminate viral hepatitis.

Support for the Viral Hepatitis National Strategic Plan for the United States: A Roadmap to Elimination 2021–2025

In January 2021, the Department of Health and Human Services released the Viral Hepatitis National Strategic Plan for the United States: A Roadmap to Elimination 2021–2025. The Plan is the first to join with the global goals adopted by other nations and to aim for elimination of viral hepatitis as a public health threat in the US. With the support of this Committee and of Congress, the nation can act on this first national elimination plan and strengthen efforts to stop hepatitis in its tracks and ensure all people benefit from disease elimination.

The Coalition activities supported by federal agencies, including CDC and NIH, assist the implementation of the HHS strategic plan and achievement of goals for hepatitis elimination. With federal partners, the Coalition is focused on 4 key objectives for advancing hepatitis elimination. The US must advance these priorities at home to ensure the success of the national strategic plan and also provide global leadership in addressing this public health threat.

Priority 1. Assure all newborns receive Hepatitis B vaccination and are protected from HBV infection and liver cancer. A birth dose of hepatitis B vaccine followed by two doses of infant immunizations decreases risk of mother-to-child HBV transmission by 90%. However, less than 50% of children globally receive hepatitis B vaccine within 24 hours, a critical intervention interrupting mother-to-child transmission. Coverage is lowest (10%) in Africa where the prevalence of HBV is the highest in the world. In collaboration with CDC, the Coalition is training public health officials and assisting countries to develop improved vaccination policies. Over 200 Ministry of Health officials, research partners, and civil society members are participating in training sessions to support more governments in adopting hepatitis B newborn vaccine policies and improving coverage. Through these efforts, the Coalition limits continued introduction of HBV into the US and reduces HBV as a health disparity for Asian and African-born Americans.

Priority 2. Implement simple models of care to detect and treat persons living with HBV and HCV. The therapies for HBV and HCV are low cost and safe. Therapies for HCV cure 95% of persons who receive treatment. Most persons globally remain undiagnosed and untreated. Proven models of care by non-specialists increase access to lifesaving testing and treatment. in the US and globally. The Coalition assists health systems simplify care and eliminate HBV and HCV as major causes of death.

Priority 3. Develop tools for tracking progress in elimination. Over the course of the next year, the Coalition will develop national hepatitis elimination profiles for the United States and other high-burden countries bringing together the latest data regarding hepatitis burden and status of policy development with trends in access to vaccination, testing and treatment. These profiles will help countries identify gaps in hepatitis services and assist US Government agencies to prioritize support.

Priority 4. Create additional opportunities to disseminate lessons on effective hepatitis prevention care and treatment. Despite effective tools and model programs, many countries like the United States are facing a rise in new cases or low screening rates. Programs in the United States and across the world benefit from sharing lessons learned, saving time and avoiding redundant research. Over the past year, the Coalition has reached over 1,000 individuals in 64 countries through over 20 stakeholder meetings and web-based educational and training sessions. These events are opportunities for programs to share experiences and resources. The Coalition is collaborating with NIH to publically share NIH-funded research advancing hepatitis elimination and identify further research priorities.

Thank you again for this opportunity to support full funding of the HHS roadmap for hepatitis elimination. The Coalition looks forward to continued collaborations with HHS on the domestic and global activities needed to eliminate viral hepatitis in the United States and globally.

[This statement was submitted by William P. Nichols, Executive Vice President and Chief Operating Officer, Task Force for Global Health.]

PREPARED STATEMENT OF THE TASK FORCE FOR GLOBAL HEALTH, INC.

Thank you for this opportunity to provide testimony on influenza activities at The Task Force for Global Health. I write to express our support for full funding for CDC's influenza initiatives.

The Task Force for Global Health, founded nearly 40 years ago to advance health equity, works with partners in more than 150 countries to eliminate diseases, ensure access to vaccines and essential medicines, and strengthen health systems to protect populations. Our expertise includes polio, influenza, COVID–19, hepatitis, neglected tropical diseases; vaccine safety, distribution and access; and health systems strengthening. Our COVID–19 activities include work with 53 countries to deliver vaccines, address vaccine hesitancy, provide vaccine safety guidelines; advise on digital contact tracing; train epidemiologists in disease surveillance and response; distribute essential protection and treatment to hard-hit communities; work through existing health programs to ensure protection for vulnerable groups, such as those afflicted with other diseases; and leverage our existing supply chains to support ongoing response and assist countries in delivering vaccines. The Task Force's influenza program has provided the framework for our work in COVID–19.

In 2013 with funding from CDC, the Task Force for Global Health established the Partnership for Influenza Vaccine Introduction (PIVI) to create sustainable, seasonal influenza vaccination programs in low- and middle-income countries. The initiative protects communities from the annual impact of flu, and also builds the adult immunization infrastructure, capacity, and vaccine delivery systems critical for future influenza pandemics and other infectious disease epidemics.

During the 2009 influenza pandemic, countries with seasonal influenza vaccination programs were able to import, and use vaccines much faster than countries without such programs.[1] With financial and technical support from CDC, PIVI supports countries in building legal, programmatic, policy-making, and regulatory capacity to quickly import and deploy influenza vaccines. The public-private collaboration provides influenza vaccines allowing countries to annually exercise and evaluate program effectiveness while moving towards country ownership and sustainability. In support of this objective, PIVI funds and fosters creation of regional collaborations that establish multi-country region-level working groups to share data, programmatic experience and explore opportunities for joint vaccine procurement efforts.

The influenza program infrastructure has supported, and continues to support, the efforts to fight COVID–19. From disease risk education and prevention, surveillance, the collection and analysis of laboratory specimens, and the sharing of information and genetic sequence data—the global and national influenza infrastructure is an indispensable component of the public health response to COVID–19. The same influenza vaccine delivery systems that enabled timely and efficient use of seasonal influenza vaccine are, and will be, utilized to deploy COVID–19 vaccine(s) as they become available. PIVI is at the forefront of this work.

In 2020, building on the expertise, the experience, and the lessons learned from the program, the Task Force quickly developed a new program called CoVIP, a public-private partnership between CDC and the Task Force engaging a global collaboration of public health technical experts, to ensure that low and middle-income countries are ready and able to deploy and evaluate COVID–19 vaccines as they become available.

With funding from the CARES Act, the Task Force's influenza program is currently supporting 53 countries with technical assistance and some funding to develop national deployment plans, evaluate programmatic approaches, and refine their vaccine program approaches.

Applying the influenza program tools to the COVID–19 vaccine rollout provides a unique opportunity to rapidly gather information to improve and sustain the vaccines for global use, and establish long-lasting national capacities for future use.

Thank you for the opportunity to provide this testimony.

[This statement was submitted by Dr. Mark McKinlay, Director, Center for Vaccine Equity: Task Force for Global Health, Inc.]

PREPARED STATEMENT OF THE TOURETTE ASSOCIATION OF AMERICA

Dear Chairwoman Murray, Ranking Member Blunt 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 2022 (FY22). 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 FY22 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 (PL. 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 49 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

[1] Porter, R. M. et al. (2020) 'Does having a seasonal influenza program facilitate pandemic preparedness? An analysis of vaccine deployment during the 2009 pandemic', Vaccine. Elsevier, 38(5), pp. 1152–1159.

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% of parents struggle to cover the high costs of services for their child such as counseling, appointments and tutoring; 34% 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% of parents are not able to afford medications and/or desired medical care for their child. A recent Coronavirus impact survey, conducted by TAA (https://tourette.org/coronavirus-and-tourette-syndrome/), found that 82% of respondents said their tics or other symptoms worsened during the pandemic.

The CDC Tourette Syndrome Website (https://www.cdc.gov/ncbddd/tourette/data.html) on data and statistics states that data suggest roughly 50% 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%) 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. These statistics outline the need for additional research on prevalence. Diagnosis is often complicated. Among children diagnosed with TS, 83% 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% of children felt that dealing co-occurring conditions was one of the biggest challenges in managing TS. In addition, 32% of children and 51% 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% of children felt that TS negatively impacted their school experience and education and 69% 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% 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 health care 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 2022 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 TRAINING PROGRAMS IN EPIDEMIOLOGY AND PUBLIC HEALTH INTERVENTIONS NETWORK

Thank you for this opportunity to provide written testimony on behalf of the Training Programs in Epidemiology and Public Health Interventions Network, known as TEPHINET, based at The Task Force for Global Health.

The Task Force for Global Health, founded in 1984 to advance health equity, works with partners in more than 150 countries to eliminate diseases, ensure access to vaccines and essential medicines, and strengthen health systems to protect populations. Our expertise includes neglected tropical diseases and other infectious diseases; vaccine safety, distribution and access; and health systems strengthening. Our COVID–19 activities include: working with 50 countries to help vaccinate their populations, providing vaccine safety guidelines; advising on digital contact tracing; training epidemiologists on disease surveillance and response; distributing essential protection and treatment to hard-hit communities; using existing health programs to ensure protection for vulnerable groups, such as those afflicted with other diseases; overcoming vaccine hesitancy in the United States and leveraging our existing supply chains for ongoing response and to help countries deliver vaccines.

As the Director of TEPHINET, one of the Task Force's 16 global health programs, I am sharing my support for efforts to build the global field epidemiology workforce needed to advance global health security by detecting and responding to disease outbreaks before they become pandemics with devastating human and economic consequences. I would also like to share with you the incredible impact that U.S. funding is already having on building a public health workforce of field epidemiologists worldwide.

TEPHINET, is the global network of Field Epidemiology Training Programs (FETPs) that is funded primarily through the Centers for Disease Control and Prevention (CDC). You might be wondering what a field epidemiologist does and why it is important to train more field epidemiologists around the world. Think of it this way: when there is a fire, we call upon trained and skilled firefighters to rush to the scene of the fire and put it out as soon as possible. Not only are field epidemiologists the firefighters of public health, but they set up the fire alarm systems by developing disease surveillance systems to catch cases early. When there is a disease outbreak, a natural disaster, or a humanitarian crisis unfolding that threatens people's health, field epidemiologists are deployed to the scene. Their task is to understand how and why the health threat is occurring, who is affected, and how to stop its spread at the source. For this reason, field epidemiologists are known as "Disease Detectives." They conduct outbreak investigations, perform contact tracing, monitor travelers at points of entry and attendees at mass gatherings, engage with communities on disease prevention measures, and much more. They are based at ministries of health, national public health institutes (like our CDC) and are in many ways the lynchpin of the overall public health system in a country.

TEPHINET consists of 75 Field Epidemiology Training Programs training field epidemiologists in more than 100 countries. To date, trainees and graduates of our member programs have investigated more than 12,000 outbreaks or acute health events and developed more than 5,000 disease surveillance systems to improve case detection. Worldwide, more than 19,000 FETP alumni have trained as the "boots on the ground" to detect and respond to public health threats.

The need for greater public health capacity to prevent, detect, and respond to public health threats and emerging infectious diseases is a matter of life or death for people around the world. Such capacity makes countries better able to sustain their own national systems, leading to economic growth and reducing the likelihood of political or economic instability.

Never has the need for increased field epidemiology capacity around the globe been more apparent than now, as the world has grappled socially and economically with COVID–19. The field epidemiologists in our network have been working around the clock to trace contacts, investigate and manage cases, analyze COVID–19 data, educate their communities, and much more. Without them, the governments of most countries, like my former home of South Africa, would not have access to reliable data on the spread of COVID–19 in their populations. In many countries, especially the poorest, there is simply no other workforce in place to conduct contact tracing or case investigations. Field Epidemiology Training Programs supported by TEPHINET fill that gap and have been steadily expanding since their founding by the CDC and other partners nearly 40 years ago.

FETPs have trained an estimated 19,000 "Disease Detectives" so far, but the world needs more. COVID–19 and other emerging diseases are not the only threats—FETPs fight every health threat known to us, from well-known issues like Ebola, measles, and polio to lesser known but deadly and debilitating diseases like Lassa fever and monkeypox. While COVID–19 is clearly an emergent threat, there will always be a "disease X" that poses a grave threat to the health of Americans.

In Guinea, a resource-challenged country in West Africa, the FETP housed within the Ministry of Health is providing critical support to help control a recent Ebola outbreak. As of April 13, 2021, Guinea had 23 reported cases of Ebola. FETP trainees and graduates made vital contributions to slowing the outbreak, particularly in the areas of coordination and epidemiology surveillance. They led the development of a surveillance system to detect Ebola cases, as well as the country's Ebola response plan, contact tracing guides, and case definitions for Ebola patients. FETP trainees and graduates consisted the leading Ministry of Health workforce deployed in the field to conduct Ebola-related surveillance. Thanks to the involvement of the FETP, the vast majority (83%) of reports of suspected cases are being investigated. Because of the Guinea FETP, established after the 2014–2016 Ebola outbreak in West Africa had claimed thousands of lives, today Guinea is seeing a dramatically different response compared to the 2014–2016 outbreak—including a significant increase in the known number of contacts traced: 95% of contacts have been traced in the current response.

Before coming to The Task Force, I was the director of the South African Field Epidemiology Training Program (SAFETP), which was started with CDC funding in partnership with the Ministry of Health and the University of Pretoria, which conferred the Master of Public Health degree to graduates. Over time, the program became owned by the National Institute of Communicable Disease, but CDC Pretoria continued to provide support in the form of a Resident Advisor, Scientific Writer, and Statistician. There was an outbreak of diarrheal disease in a small town in Free State province, and the FETP trainees or residents identified the root cause to be poor maintenance at the water treatment plant. Diarrheal disease from drinking unsafe water causes dehydration, which is a killer of children under five. As a result of the investigation done by the FETP residents, the town installed a new water reticulation plant that ultimately benefited residents of the town and improved their quality of life with fewer days of productivity lost due to gastrointestinal illness.

Without enough "Disease Detectives" or boots on the ground to detect and respond to public health emergencies, it will not be long before another outbreak becomes a pandemic with severe human and economic costs. There will be other outbreaks, and no single institution has all the capacity required to be adequately prepared to face future threats. We need to harness the resources and capacities of a wide range of partners and stakeholders and we need political leadership, whole-of-government and whole-of-society commitment. We need to continue the United States' tradition of helping to build sustainable public health systems across the world that ultimately protect all people, including the American people.

In addition to supporting the development of Field Epidemiology Training Programs, TEPHINET and The Task Force for Global Health have been instrumental in developing the Global Field Epidemiology Roadmap, a plan to advance field epidemiology training and capacity building worldwide. As we speak, we at TEPHINET are coordinating a Strategic Leadership Group of more than a dozen public health experts from around the world to lead the implementation of this Roadmap, so that all countries can develop the field epidemiology capacity needed to protect and promote the health of their own populations and collaborate with others to promote global health.

Thank you for your ongoing support of FETPs through the vital funding you provide. Because of this support, more than 100 countries now have a field epidemiology workforce that did not exist prior to the establishment of their FETPs. However, we are still working to achieve the International Health Regulations' target of having one trained field epidemiologist per 200,000 population in every country.

The good news is that this goal is achievable with continued investment. A global commitment to improving global health security by investing in field epidemiology capacity building strengthens health systems by training our world's "Disease Detectives" to respond to public health emergencies, humanitarian crises and natural disasters, and in so doing, saving money, saving resources, and saving lives.

[This statement was submitted by Dr. Carl Reddy, Director, Training Programs in Epidemiology and Public Health Interventions Network.]

PREPARED STATEMENT OF THE TRAUMA CENTER ASSOCIATION OF AMERICA

As you consider Labor Health and Human Services appropriations for Fiscal Year FY (2022), the Trauma Center Association of America (TCAA) asks 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.

According to the Centers for Disease Control and Prevention trauma is the leading cause of death for children and adults under age 44, killing more Americans than AIDS and stroke combined.

Fully funding of MISSION ZERO will allow us to continue to save lives, enhance trauma training for our military healthcare personnel and help trauma centers manage and recover from mandatory furloughs of surgeons, nurses and other staff that were a direct result of the COVID 19 pandemic.

We are grateful for your consideration of this important request. Please do not hesitate to contact us directly if you have any questions or need additional information regarding the MISSION ZERO Act.

PREPARED STATEMENT OF THE TREATMENT ACTION GROUP

Treatment Action Group (TAG) thanks the esteemed members of the subcommittee for the opportunity to submit testimony regarding funding for the U.S. Centers for Disease Control and Prevention (CDC) Division of Tuberculosis Elimination (DTBE) for fiscal year 2022 (FY22) appropriations. TAG is an independent, activist and community-based research and policy think tank fighting for better treatment, prevention, a vaccine, and a cure for HIV, tuberculosis (TB), and hepatitis C virus (HCV). TAG works to ensure that all people with HIV, TB, or HCV receive lifesaving treatment, care, and information. We are science-based treatment activists working to expand and accelerate vital research and effective community engagement with research and policy institutions. Together with a broad coalition of stakeholders in the TB advocacy community, TAG requests that the Subcommittee appropriate $225 million to CDC DTBE for FY22, in particular to expand critical TB research activities at the TB Trials Consortium (TBTC) and mitigate the impact of the COVID–19 pandemic on struggling TB programs across our country.

TAG works in close partnership with TB program practitioners and researchers across the country to advance the collective goal of eliminating TB through comprehensive, safe, and effective TB prevention and treatment. TB cases continue to be reported in every state in the United States (US) every year, with 8,916 cases reported in 2019.[1] It is estimated that approximately 13 million people in the US are currently living with latent TB infection, which can progress to active and contagious disease if left untreated.[2] TB trends in the US are also influenced by many of the same social determinants of health that determine other health disparities—including poverty, lack of access to healthcare, overcrowded housing and homelessness, and other structural factors.[3] This leaves many of the most vulnerable and marginalized members of our society at greater risk of being exposed to TB and developing active disease.

The state and local TB programs that are on the frontlines of preventing and treating TB are engaged in critical work, and they rely on the support of the CDC DTBE for guidance and funding. One important way DTBE supports state and local TB programs is through its research initiatives, including the TBTC. Housed within DTBE, the TBTC is a unique partnership between CDC, health departments, academic research institutions, and trial sites throughout the US and across the globe.[4] TBTC's research is mandated to be programmatically relevant to health departments, meaning that investments in this research network are some of the most cost-effective of any federal research program. Tax payers' investments in the work of the TBTC have supported dozens of studies of critical import to advancing the field and improving TB treatment and prevention for people and communities affected by TB at home and abroad.

This research is sorely needed to advance more tolerable and effective options for TB prevention and treatment. Current treatment guidelines for drug-sensitive TB have been the same for almost four decades, leaving programs and patients reliant on a regimen made up of four drugs taken for 6–9 months requiring long periods of isolation and management of difficult side effects necessitating intensive treatment monitoring. However, promising results from a pivotal phase III trial, TBTC's Study 31 demonstrated that a different combination of medicines enables treatment for drug-sensitive TB to be shortened to just four months without compromising any efficacy.[5] This groundbreaking finding has the potential to dramatically improve rates of treatment completion, drive down TB transmission, and allow TB patients to return to their loved ones and support themselves more quickly than ever before.[6] Study 31 and prior TBTC research at DTBE has had profound global health security implications, where TB was the world's leading cause of death to an infectious disease prior to COVID–19. Research at CDC's TBTC has been the basis for public health treatment and prevention guidelines developed by the World Health Organization (WHO) that are critical for country TB programs where TB is particularly endemic and claims 1.6 million lives a year.

While these results are certainly cause for celebration, much work remains to be done to translate these findings into real public health impact and ensure the availability of shorter treatment regimens to all TB patients and programs. Many other areas of research are also still on the horizon, including better TB prevention options and tools for children and pregnant people. Some of this research is already underway through other TBTC studies.[7] The recent process by TBTC to solicit research proposals (i.e. TBTC re-competition) sets up this heralded research network for the next 10 years of programmatically-relevant research that could include many

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[1] U.S. Centers for Disease Control and Prevention. U.S. TB Statistics. Division of TB Elimination. https://www.cdc.gov/tb/statistics/default.htm.

[2] Ibid.

[3] Ibid.

[4] U.S. Centers for Disease Control and Prevention. Tuberculosis Trials Consortium. Division of TB Elimination. https://www.cdc.gov/tb/topic/research/tbtc/default.htm.

[5] Dorman SE, Nahid P, Kurbatova EV, Goldberg SV, Bozeman L, Burman WJ, Chang KC, Chen M, Cotton M, Dooley KE, Engle M, Feng PJ, Fletcher CV, Ha P, Heilig CM, Johnson JL, Lessem E, Metchock B, Miro JM, Nhung NV, Pettit AC, Phillips PPJ, Podany AT, Purfield AE, Robergeau K, Samaneka W, Scott NA, Sizemore E, Vernon A, Weiner M, Swindells S, Chaisson RE; AIDS Clinical Trials Group and the Tuberculosis Trials Consortium. High-dose rifapentine with or without moxifloxacin for shortening treatment of pulmonary tuberculosis: Study protocol for TBTC study 31/ACTG A5349 phase 3 clinical trial. Contemp Clin Trials. 2020 Mar;90:105938. doi: 10.1016/j.cct.2020.105938. Epub 2020 Jan 22. PMID: 31981713; PMCID: PMC7307310. https://pubmed.ncbi.nlm.nih.gov/31981713/.

[6] Treatment Action Group. TAG Statement: Finally a New Four Month Treatment for Drug Susceptible TB. 2020 October. https://www.treatmentactiongroup.org/statement/finally-a-new-four-month-treatment-for-drug-susceptible-tb/.

[7] U.S. Centers for Disease Control and Prevention. Tuberculosis Trials Consortium—Research Projects. Division of TB Elimination. https://www.cdc.gov/tb/topic/research/tbtc/projects.htm.

of these pressing priorities for TB R&D. But this progress is marred by decades of insufficient federal funding for DTBE, which limits the ambition and scientific integrity of how TBTC can approach its research agenda. In turn, the historical lack of funding to DTBE limits the possibilities of implementation of such research through state and local TB programs.

Decades of stagnant appropriations for DTBE have led to the Division currently being funded at nearly the same level as it was in fiscal year 1994 (see right figure on impact of inflation). Factoring in the rate of inflation over that period, that stagnant funding level has drastically reduced the purchasing power of DTBE.[8] In addition, the costs of TB diagnosis and treatment have steadily risen, especially for drug-resistant forms of TB which can now cost up to several hundred thousand dollars to treat per person.[9] As a direct result, DTBE has been forced to do more with less, necessitating difficult decisions about resource allocation to its lifesaving programmatic and research initiatives. Without sufficient funding to bolster our nation's TB programs, implementation of U.S.-led TB treatment strategies and interventions made possible through publicly funded research at TBTC, remains severely limited.

The COVID–19 pandemic has worsened these capacity constraints. According to a survey of TB program staff in the US, 87% of respondents reported that they or their colleagues had been either partially or completely reassigned to work on COVID–19.[10] In many cases, these reassignments were indefinite, and state and local TB programs continue to operate under reduced capacity and temporary leadership. Many TB clinics, hospitals, and other resources were also designated exclusively for use in the COVID–19 pandemic response, as they were uniquely outfitted for airborne isolation. The expertise of TB public health clinicians, researchers and practitioners in particular, are drawn upon in the COVID–19 response for their critical experience in addressing an airborne infection.

Some of the impacts of the pandemic are not yet visible. TB case reporting dropped by 20% in 2020 compared to 2019. Unprecedented barriers to accessing testing and care stemming from COVID–19 health service disruptions and the reallocation of TB staff and resources from conducting contact tracing, community outreach, and TB treatment monitoring, to COVID–19 response efforts are likely the major causes of this steep drop in TB notifications.[11] The impacts of this reduced capacity to prevent and respond to TB cannot be overstated, and the costs of recovering from such impacts will be much higher than current funding levels allow.

Stagnant funding, and the additional damage wrought by the COVID–19 pandemic, also threaten TB research and development efforts at DTBE. In the aforementioned recent TBTC "re-competition" process for the next 10-year funding cycle, four of the prominent academic institutions that housed some of the crucial leadership for TBTC's most promising studies were excluded in the subsequent cycle due to shrinking research dollars to expand this highly successful clinical trials network.[12] The collective TB expertise held within these institutions is irreplaceable. Higher funding levels for DTBE and its research initiatives, such as TBTC, are vital to retain the invaluable experience necessary to complete study enrollment, data collection, analysis, publication, and translation into policy. Furthermore, expanded resources would position TBTC to embark on a new era of clinical research led by these partners, building on its success shortening treatment and prevention of TB and looking to future opportunities, such as the possibility of TBTC trialing novel TB vaccines. However, without an increase in funding, this experience will be lost, taking with it the promise of TB research breakthroughs like those shown in TBTC Study 31, which demonstrated the first effective short course TB treatment in over 40 years.[13]

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[8] Treatment Action Group. The TB Research Engine That Could: Sustaining the Success of the Tuberculosis Trials Consortium in Turbulent Times. 2021 April. https://www.treatmentactiongroup.org/publication/the-tb-research-engine-that-could/.

[9] U.S. Centers for Disease Control and Prevention. CDC Fact Sheet: The Costly Burden of Drug Resistant TB Disease in the U.S.. National Center for HIV, Hepatitis, STD, and Tuberculosis Prevention—Newsroom. https://www.cdc.gov/nchhstp/newsroom/docs/factsheets/costly-burden-dr-tb-508.pdf.

[10] Stop TB Partnership. The Impact of COVID–19 on the TB Epidemic: A Community Perspective. Geneva: March 2021 https://spark.adobe.com/page/xJ7pygvhrIAqW/.

[11] Deutsch-Feldman M, Pratt RH, Price SF, Tsang CA, Self JL. Tuberculosis—United States, 2020. MMWR Morb Mortal Wkly Rep 2021;70:409–414. DOI: https://www.cdc.gov/mmwr/volumes/70/wr/mm7012a1.htm?s__cid=mm7012a1__w.

[12] Treatment Action Group. The TB Research Engine That Could: Sustaining the Success of the Tuberculosis Trials Consortium in Turbulent Times.

[13] U.S. Centers for Disease Control and Prevention. Landmark TB Trial Identifies Shorter-Course Treatment Regimen. National Center for HIV, Hepatitis, STDs, and Tuberculosis Pre-

In order to avert further devastating impacts on TB programs, prevention, care, and research, increased funding for CDC DTBE is critically important. TAG requests that the subcommittee appropriate $225 million—an increase of $90 million—to safeguard the lifesaving progress that DTBE has made against TB in the US, sustain and grow the government's vital TB research agenda at TBTC by retaining critical R&D expertise, and to bring us closer to the elimination of TB once and for all, here and abroad. We thank you for your support of public health programs and research, and we look forward to working with you to ensure the health of all those impacted by TB in the US and around the world.

PREPARED STATEMENT OF THE TREATMENT ACTION GROUP

Treatment Action Group (TAG) thanks the esteemed members of the subcommittee for the opportunity to submit testimony regarding funding for the government's End the HIV Epidemic (EHE) at the U.S. Centers for Disease Control (CDC) Division for HIV Prevention (DHAP) for fiscal year 2022 (FY22) appropriations. TAG is an independent, activist, and community-based research and policy think tank committed to racial, gender, and LGBTQ+ equity; social justice; and liberation, fighting to end HIV, tuberculosis (TB), and hepatitis C virus (HCV). We work closely with community partners and stakeholders in the jurisdictions funded by the federal government's EHE initiative towards an inclusive, community-centered approach to end the HIV epidemic across our country.

TAG requests that the Subcommittee exceed the President's budget proposal for the CDC EHE initiative of an $100 million increase in FY22 with an additional increase of $96 million to a total of $196 million for DHAP ETE. In particular these resources would be critical to expand EHE efforts, advance and expand vital community partnership activities, and mitigate the impact of the COVID–19 pandemic among the hardest-hit jurisdictions.

While there has been immense progress in the HIV epidemic with rates declining from 37,500 new infections in 2015 to 34,800 infections in 2019—much work remains on truly ending the epidemic in the hardest-hit jurisdictions and populations in the U.S.[1] HIV rates are not evenly distributed across the nation and continue to be primarily skewed towards the Southern states as the bulk of new diagnoses.[2] Even more concerning, HIV disparities continue to severely persist among the Black and Latinx communities. We see these troublesome trends particularly among Black and Latinx gay and bisexual men, as well as Black women. Black communities represent 13% of the U.S. population, but make up 44% of new diagnoses.[3] Similarly, Latinx communities represent 18% of the U.S. population and account for 30% of new HIV diagnoses.[4] HIV comparably disparages Native American community, people of trans experience, and people who use drugs with stark disparities.

It is of no surprise that social determinants of health deeply impact these communities. These include housing, food security, employment and economic justice, as well as undoing numerous policies that violate the human rights of these communities and limit their ability to seek treatment and care. Criminalization for example is intertwined with the HIV epidemic, with many states continuing to have arcane laws that do not align with science and only further stigmatize communities of people living with, and vulnerable to HIV. Without addressing the myriad of social, economic and legal needs of communities impacted by HIV through a combination of targeted resources and a human-rights policies, reaching the vision for ending the epidemic across all communities will remain unclear and unattainable.

The previous administration ambitiously approached this challenge of ending the HIV epidemic once and for all, by redoubling U.S. efforts and formulating the landmark EHE initiative that would direct federal resources towards 57 jurisdictions hardest-hit by HIV through CDC and HRSA. While Congress, has responded in lockstep with bipartisan increases to EHE since its inception, we believe that the COVID–19 pandemic has significantly impacted efforts at the community-level, requiring a significant scale up in assistance to these jurisdictions.

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vention—Newsroom. 21 October 2020 https://www.cdc.gov/nchhstp/newsroom/2020/landmark-tb-trial-media-statement.html.

[1] Health Resource and Services Administration. HIV Data and Trends. HIV.gov. https://www.hiv.gov/hiv-basics/overview/data-and-trends/statistics.

[2] Ibid.

[3] U.S. Centers for Disease Control and Prevention. Racial and Ethnic HIV Rates—African Americans and Hispanic/Latinos. Division of HIV/AIDS Prevention. https://www.cdc.gov/hiv/group/racialethnic/africanamericans/index.html.

[4] Ibid.

Organizations and partners involved in the ACT NOW:END AIDS coalition—of which TAG is a cofounder—report significant impact upon services and outreach efforts to communities impacted by HIV. The lack of swift and robust federal guidance on COVID–19 to HIV organizations in the early stages of the pandemic led to many organizations having to decide between either risking the safety of their staff by continuing essential services, or temporarily closing programs. Additionally, many already financially strained organizations struggled to obtain the technologies necessary for telemedicine and many reported that clients—especially low-income, and unstably housing individuals—could not access these tools. Such delays led to clients missing care and contributed to an overall sense of burnout among HIV professionals.

In addition to the direct impact upon services for PLHIV and communities vulnerable to HIV, we have noted a significant shift in human resources and public health personnel detailed to the COVID–19 pandemic. CDC HIV program staff are also contributing significantly to the nation's COVID–19 response. The pandemic has caused severe disruptions to care and treatment activities of the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP). According to research from the Kaiser Family Foundation, nearly 700 CDC staff (with 1,125 cumulative deployments) from NCHHSTP have been detailed and deployed to the COVID response since the early days of the pandemic.[5] This is primarily due to the Center staff's expertise in infectious diseases. HIV public health practitioners from the CDC are drawn upon for the COVID–19 pandemic, primarily for their expertise in centering communities in prevention efforts and their ability to form key relationships, conduct outreach, while grounding public health prevention work in respect for human rights. However, scarce public health resources and personnel corresponds to a shift away from EHE efforts.

Furthermore, HIV community contributions to the COVID–19 response have been significantly extended through HIV/AIDS research investments at the National Institutes of Health (NIH) as well. For example, HIV research first piloted the of use mRNA as a vaccine platform for HIV prevention. These previous investments in HIV vaccine research boosted the development of widely disseminated COVID–19 vaccines that increasingly leveraged the well-developed research infrastructure of HIV research.[6]

In sum, the programmatic and research contributions of HIV have been invaluable to the nation's COVID–19 response. But the shift in HIV sector resources leaves EHE efforts in peril and limited in reaching its ambitious goals for treatment and prevention of HIV. Due to the our weakened public health infrastructure that COVID–19 leaves in its wake, without significantly targeted and expanded resources, HIV disparities will continue to be deeply entrenched in our nation's historically disenfranchised and marginalized communities. We urge the subcommittee to maximize resources to backfill the contributions of the HIV sector and launch our HIV response with the same level of vigor that we saw with the COVID–19.

To that end, we request an allocation of at least $196 million in FY22 for CDC DHAP EHE Plan to begin to align the necessary resources to mitigate the effects of COVID–19 upon struggling HIV programs and shore-up the necessary HIV infrastructure. We applaud the administration's and Congressional attention towards rooting out systemic racism, and believe that these investments will go a long way to begin addressing HIV as health disparity that primarily effects communities of color.

Thank you for the members of the subcommittee for this opportunity to submit testimony in support of CDC DHAP ETE initiative. We hope you will take action and recommit to realizing the end of the HIV epidemic with urgent, new resources.

PREPARED STATEMENT OF TRUST FOR AMERICA'S HEALTH

Trust for America's Health (TFAH) is pleased to submit this testimony on the fiscal year (FY) 2022 Labor, Health and Human Services, Education, and Related Agencies (LHHS) appropriations bill. TFAH is a non-profit, non-partisan organization that promotes optimal health for every person and community. Communities across the country are overwhelmed with responding to the Coronavirus Disease 2019 (COVID–19) pandemic with a depleted public health infrastructure and work-

[5] Dawson L, Kates J. Issue Brief: Key Questions on HIV and COVID–19. Kaiser Family Foundation. 20 May 2021. https://www.kff.org/coronavirus-covid-19/issue-brief/key-questions-hiv-and-covid-19/.

[6] Chibbaro L. HIV Research Sped the Develop of the COVID–19 Vaccine. Washington Blade. 23 June 2021 https://www.washingtonblade.com/2021/06/23/hiv-research-sped-development-of-covid-vaccine/.

force, while also responding to longstanding issues due to increases in chronic diseases, substance misuse and suicide, health disparities, and environmental health risks. TFAH's recent report, The Impact of Chronic Underfunding on America's Public Health System, finds that although health threats continue to increase, core public health budgets at the federal and state levels remain stagnant.[1] While Congress has allocated billions of dollars to address COVID–19, this funding is short-term and largely for use in response to the pandemic. It follows a similar pattern since 9/11 of annually underfunding core public health and then providing significant infusions of emergency funding for a short time when a disaster hits. This is like building a house on a shaky foundation. Without an investment in public health year in and year out, problems cannot be prevented, or emergencies reduced. While many thanks are due for your support during COVID, now is the time to fix an underfunded system so we can ensure every resident of the nation has the chance for optimal health and wellbeing. Bold action is needed to strengthen and modernize public health. TFAH urges Congress to fund the Centers for Disease Control and Prevention (CDC) at $10 billion for the FY2022 budget, including investing in these effective public health programs (unless otherwise noted, all programs are in CDC):

EMERGENCY PREPAREDNESS

The COVID–19 response was weakened because the CDC's emergency preparedness funding had been repeatedly cut, reducing essential training and eliminating expert personnel. The CDC's Public Health Emergency Preparedness (or PHEP) cooperative agreement has been reduced by a quarter since FY2003 (48 percent when inflation is considered). PHEP grants support 62 state, territorial, 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. TFAH recommends at least $824 million for the PHEP (CDC), the level authorized in 2006.

The pandemic has also demonstrated 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 FY2003 (62 percent when inflation is considered). HPP provides critical funding and technical assistance to health care 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 plans; 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

Not all federal emergencies are caused by infectious disease. Many occur due to environmental factors. Here, too, core funding has been insufficient. Since CDC's National Environmental Public Health Tracking Network began in 2002, grantees have taken over 400 data-driven actions to eliminate risks to the public. 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 health care savings for every dollar invested, the Tracking Network is a cost-effective program that examines and combats harmful environmental factors.[2] Yet only half the states receive funding. 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.

[1] The Impact of Chronic Underfunding of America's Public Health System. Trust for America's Health 2021. https://www.tfah.org/report-details/pandemic-proved-underinvesting-in-public-health-lives-livelihoods-risk/.

[2] Return on Investment of Nationwide Health Tracking, Washington, DC: Public Health Foundation, 2001.

OBESITY AND CHRONIC DISEASE PREVENTION

The COVID–19 pandemic has been exacerbated by preventable, chronic health conditions, including obesity. In 2017–2018, 42.4 percent of adults had obesity.[3] Even though obesity accounts for nearly 21 percent of U.S. healthcare spending, funding for CDC's Division of Nutrition, Physical Activity, and Obesity (DNPAO) is only equal to about 31 cents per person.[4] This Division funds state health departments to protects the health of all Americans by promoting healthy eating, active living, and obesity prevention in early care and education facilities, hospitals, schools, and worksites and neighborhoods; building capacity of state health departments and national organizations to prevent obesity; and conducting research, surveillance, and evaluation studies. However, 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 to allow CDC to continue building its capacity and scaling its interventions.

Additionally, this year we once again saw the impact of inequities in social and economic conditions facing people of color and tribal nations. Among the programs at CDC that are effective in reducing racial and ethnic health disparities are Racial and Ethnic Approaches to Community Health (REACH) program and Good Health and Wellness in Indian Country (GHWIC). CDC's 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 effect 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 $102.5 million for REACH (CDC) to restore funds historically diverted from core REACH programs. Within that total, TFAH recommends at least $27 million for the Good Health and Wellness in Indian Country (GHWIC) program. Also within DNPAO, GHWIC works with 21 tribes directly and funds 15 Urban Indian Health Centers and 12 Tribal Epidemiology Centers (TECs). GHWIC supports healthy behaviors in Native communities by supporting coordinated and holistic approaches to chronic disease prevention, continuing to support culturally appropriate, effective public health approaches, and expanding the program's reach and impact by working with more tribes and tribal organizations, including Urban Indian Organizations. In addition, these GHWIC funds support the Tribal Epidemiology Centers for Public Health Infrastructure (TECPHI).

Healthy Outcomes in Schools: Specialized efforts are needed within certain age groups as well. 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.

Age-Friendly Public Health: The COVID–19 outbreak has shown that collaboration between the public health and aging sectors is vital. Every day 10,000 Americans turn 65 years of age, yet there have been limited collaborations between the public health and aging sectors. 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 health care services, coordinating existing multi-sector efforts, and identifying gap areas, as well as disseminating and implementing evidence-based policies. Yet as of now, there is no comprehensive health promotion program for older adults. We recommend the Committee provide CDC at least $50 million to administer and evaluate an Age Friendly Public Health program to promote and address the public health needs of older adults and collaborate with partners in the aging sector.

Social Determinants of Health: Social determinants of health (SDOH) such as housing, employment, food security, and education have a major influence on individual and community health,[5] as illustrated by disparate outcomes and risk from

[3] State of Obesity 2020. Trust for America's Health. Sept 2020. https://www.tfah.org/report-details/state-of-obesity-2020/.

[4] 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.

[5] 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

COVID–19. Public health agencies 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 and are limited by disease-specific federal funding. TFAH thanks for the Committee for $3 million in FY2021 to establish a new CDC SDOH program. 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 and improve community social and economic conditions that promote health. Aligned with the President's budget request, TFAH recommends at least $153 million to further develop CDC's Social Determinants of Health Program and enable grants to states and localities.[6] More than 200 organizations have endorsed this funding level.[7]

SUICIDE PREVENTION

In 2019, suicide took 47,500 lives, and rates increased by 33 percent between 1999 and 2019.[8] The complex nature of this issue requires a comprehensive program that focuses on vulnerable populations, data collection to inform efforts, and research on risk factors. CDC's work helps identify and disseminate effective strategies for preventing suicide, from strengthening access and delivery of suicide care to promoting policies and programs that reduce the risk. The programs consist of multisector partnerships, use of data to identify vulnerable populations and risk and protective factors, leveraging existing suicide programs and filling gaps through complementary strategies and effective communications. TFAH recommends at least $36 million to expand innovative prevention activities to an estimated 25 sites from its current number of nine, and to support state health departments as they develop and implement comprehensive suicide prevention plans.

ADVERSE CHILDHOOD EXPERIENCES

CDC estimates that if Adverse Childhood Experiences (ACEs) such as abuse and neglect were prevented, there would be 21 million fewer cases of depression, 1.9 million fewer cases of heart disease, and 2.5 million fewer cases of obesity.[9] Preliminary evidence suggests the pandemic is likely to increase children's exposure to ACEs due to economic hardship, increased stresses on families, and reduced access to school-based services and supports.[10] CDC's approach to ACEs prevention involves translating research into action and helping states identify and implement effective prevention strategies. In 2020, four state health departments were awarded funding to enhance or build infrastructure for ACEs surveillance, implement strategies to prevent ACEs, and leverage multisector partnerships to coordinate prevention activities. TFAH recommends at least $7 million to expand innovative ACEs prevention activities to four additional state health departments and to build upon CDC's work on preventing early adversity in life and mitigating the impact of ACEs on healthy child development.

CONCLUSION

The COVID–19 pandemic has underscored the dangers of the chronic underfunding of public health. It has also exposed and exacerbated longstanding disparities that have plagued our nation for far too long. It is imperative that we not wait for the next emergency to fix this problem. Instead, now is the time to invest in public health and fund CDC at $10 billion in FY 2022, to become a more resilient and healthy nation. Thank you for the opportunity to present this testimony to the Committee.

[This statement was submitted by J. Nadine Gracia, MD, MSCE, President & CEO, Trust for America's Health.]

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[6] The President's request for fiscal year (FY) 2022 discretionary funding. (2021). Executive Office of the President. https://www.whitehouse.gov/wp-content/uploads/2021/04/FY2022–Discretionary-Request.pdf.

[7] Letter to House Appropriations LHHS Subcommittee. April 26, 2021. https://www.tfah.org/wp-content/uploads/2021/04/CDC__SDOHFunding__SignOn.pdf.

[8] Suicide Prevention, CDC. https://www.cdc.gov/suicide/.

[9] BRFFS 2015–2017, 25 states, CDC Vital Signs, November 2019. https://www.cdc.gov/vitalsigns/aces/index.html.

[10] MMWR 2021, https://www.cdc.gov/mmwr/volumes/69/wr/mm6949a1.htm.

PREPARED STATEMENT OF UNITED FOR CHARITABLE ASSISTANCE

SUMMARY OF FISCAL YEAR 2022 APPROPRIATIONS RECOMMENDATIONS

—Please continue to support and advance committee recommendations, as well as related funding and policy initiatives, which further encourage HHS and the Centers for Medicare and Medicaid Services (CMS) to address arbitrary barriers that disrupt patient access to essential charitable assistance in a meaningful and timely way.
—Please work with your colleagues to encourage HHS to establish a transparent and patient-centered regulatory system formally governing charitable assistance programs that is consistent with the current framework of OIG opinions and ensures all policymakers and stakeholders have appropriate mechanism to address challenges and opportunities in this space.
—Please provide meaningful funding increases for medical research and public health progress to initiate further progress and improve outcomes for the patient community.

Chairwoman Murray, Ranking Member Blunt, and distinguished members of the Subcommittee, thank you for your leadership on patient care, and coverage and access issues. On behalf of United for Charitable Assistance (UCA), we deeply appreciate the opportunity to provide a critical, patient-centered perspective as you consider FY 2022 appropriations issues that impact healthcare coverage and patient access. Most notably, we urge you to continue to advance committee recommendations that feature and emphasize the need to quickly restore access to critical charitable assistance programs that serve patients with no other options. Moreover, please continue the investment in medical research and public health activities. The COVID–19 pandemic has hit the patient community hard and identified a litany of reasons to enhance resources for medical research and public health while addressing critical coverage and access challenges for those with the greatest need (such as due to pandemic related job loss). Thank you again for this important opportunity. Please consider UCA a resource on moving forward.

ABOUT UNITED FOR CHARITABLE ASSISTANCE

We are a growing ad hoc group of patient community leaders that seek to protect access to the charitable financial support programs, which serve as a crucial part of the healthcare safety net for individuals with rare, chronic, and life-threatening medical conditions. We work together to educate policymakers so they understand the value, impact, and vital nature of these programs and ultimately support efforts to actively defend the lives and livelihoods of those facing serious conditions that can now be better-managed through proper care and innovative therapies.

ABOUT CHARITABLE ASSISTANCE

Over recent years, CMS promulgated rules that effectively allow private insurance companies to simply deny (or reserve the right to deny at will) any premium or related healthcare payments made on behalf of a patient. While these restrictions initially started in marketplace plans, they have spread to Medigap plans, and various other forms of coverage. The tangible result of these policies is that patients are often denied access to mission-driven charitable support from non-profits, civic groups, and houses of worship. Ultimately, these restrictions form a back-door to pre-existing condition discrimination where they are targeted at the most vulnerable populations and patients lose their coverage due to an inability to utilize available support or are simply steered towards one of the few remaining plans that has not implemented restrictions (if they are available in their state). Recently, the practice of copay accumulators has taken hold where some assistance is accepted, but it is never applied to the patient's out-of-pocket limits, thus rendering the support inconsequential for the seriously ill. Finally, there is now an emerging practice for employer-provided insurance known as the "alternative funding model". This prescription drug procurement model improperly utilizes drug manufacturers' free assistance programs to the detriment of patients who are forced to continually switch drugs. Further, any costs associated with filling the prescriptions or obtaining the medications are not counted toward a patient's out-of-pocket insurance costs.

The situation is particularly dire for patients with rare, chronic, and life-threatening illness that rely on innovative life-sustaining medications and who occasionally turn to charities following a job loss or similar hardship to ensure there is no catastrophic disruption in access to care. Often times, when properly medicated,

these patients work and contribute to society, and they do not qualify for Medicaid or similar need-based programs. Further, despite the severity of their illness, the therapy or medical intervention likely blunts or slows the progression of their disease meaning they also do not readily qualify for disability programs. When assistance and access to proper care is lost, a dangerous situation is created where the dramatic decline in health rapidly outpaces the patient's ability to transition on to tax-payer funded safety net programs.

We cannot overlook the fact that many patients in the aforementioned situation also continue to turn to charitable assistance during the process of transitioning on to federal programs as their illness progresses. The disability waiting periods alone would be insurmountable for many without charitable assistance. In this regard, the need for charitable assistance is certainly not mitigated in Medicare and related programs with some patients utilizing charitable assistance to make ends meet and cover cost-sharing requirements.

CONTEMPORARY EXAMPLES OF CHARITABLE ASSISTANCE CHALLENGES

Ms. Lisa Wright is a patient advocate for the Fabry Disease Community. Fabry disease is a rare genetic disorder that prevents the body from making a certain enzyme called alpha-galactosidase A. The symptoms of Fabry Disease are varied and progressive including kidney, heart and neurological damage. There are several FDA approved treatments for Fabry Disease. However, those treatments are very expensive and as more and more costs are shifted to patients they need access to financial assistance programs. Lisa is a wonderful example of the importance of patient assistance. Lisa receives health insurance premium and copayment assistance from a charitable assistance program. This enables Lisa to remain working and volunteering for her community. Patient assistance groups help Lisa and many other Fabry disease patients obtain access to these expensive treatments and therapies which mitigate the symptoms of the disorder and keep patients living productive lives. Congress should work to ensure access to these programs.

The situation of Dr. Jeffrey Swigert is an example of the new Alternative Funding. Dr. Swigert is the father of two children with Cystic Fibrosis. Cystic Fibrosis is a progressive, genetic disease that causes persistent lung infections and limits the ability to breathe over time. Dr. Swigert's employer is a self-insured plan that has implemented a carve out for specialty treatments such as those for cystic fibrosis. The employer will not cover treatments but instead attempts to obtain them free of charge from manufacturer compassionate treatment programs. However, the manufacturer programs are individual with their own specific criteria. These programs are often time limited and reserved for patients who are uninsured. Congress needs to review this practice and potentially introduce legislation to modify.

RECOMMENDATION

Please include committee recommendations, similar to the language below, in the committee report accompanying the FY22 Senate L–HHS Appropriations Bill. Please also work through the annual appropriations process to facilitate a meaningful dialogue between the community and HHS on challenges, opportunities, and potential solutions. Thank you for your time and for your consideration of this request.

CENTERS FOR MEDICARE AND MEDICAID SERVICES PROGRAM MANAGEMENT

Charitable Assistance and the Healthcare Safety Net.—The Committee notes the important role that third-party charitable assistance plays in regards to maintaining access to care and therapies, particularly for patients impacted by life-threatening illness that have no other options. The Committee notes the current significance of premium assistance, co-pay assistance, travel assistance, and related programs due to COVID–19 related economic challenges and loss of employment, and their disproportionate role in ensuring access to care for those with health disparities and from underserved communities. CMS is encouraged to re-evaluate policies that facilitate pre-existing condition discrimination for patients with serious illness by allowing covering entities to reject or simply not apply assistance from independent charities.

[This statement was submitted by James Romano, Executive Director, United for Charitable Assistance.]

PREPARED STATEMENT OF THE UNITED STATES WORKFORCE ASSOCIATIONS

Dear Chairman Murray and Ranking Member Blunt:

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. As our country grapples with unprecedented demand for unemployment insurance and economic recession within the COVID–19 pandemic, the employer-led, local workforce development system continues to respond with critical supports and services. Adequate federal funding would ensure the system is poised to address these community needs as we continue to recover from the devastating health and economic effects of COVID–19.

As the Senate Appropriations Committee considers the Fiscal Year 2022 Labor-HHS Appropriations Bill, we urge you to support further federal investment into WIOA and fully fund the law beyond its FY2020 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 need to be implemented seamlessly to respond to the effects of COVID–19. The established local workforce system is well-positioned to enhance efforts for an equitable recovery; low wage, low skill workers and minority populations were hit hardest by COVID–19. The federal funding structure, which allows these funds to be invested locally, provides for intentional investments to help those most in need.

Local workforce development leaders are engaged directly with businesses to help keep individuals employed and design training/education programs to prepare the workforce for the future. We continue to work with unemployed individuals to help them stay connected to the workforce and evaluate other opportunities; recent BLS data suggests nearly 41% of those unemployed have been unemployed for at least 27 weeks (long-term unemployed).[1] Business services, especially for small and medium-sized enterprises, have been critical during the COVID–19 pandemic as employers sought to maintain payrolls and find workers as businesses began to reopen. Increased federal appropriations are greatly needed to address this unprecedented health, economic, and social destabilization.

The Fiscal Year 2022 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 FY2022 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

—$692,370,000 for Wagner-Peyser (FY2021 Enacted)

Title IV—Department of Education

—$3,675,021,000 for Vocational Rehabilitation Services (FY2021 Enacted)

This training, support and business partnership is vital to our country's economic prosperity. For further information, please contact Chris Andresen.

Sincerely,

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[1] https://www.bls.gov/charts/employment-situation/unemployed-27-weeks-or-longer-as-a-percent-of-total-unemployed.htm.

Bob Lanter
Executive Director
California Workforce Association

Luann Dunsford, CEO
Michigan Works! Association

Jennifer Meek Eels
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

Mari Kay-Nabozny
Chief Executive Officer
Northwest Wisconsin Workforce
Investment Board, Inc.

Tonja Mettlach, Executive Director
Massachusetts Workforce Association

Michelle Day, President
Maryland Workforce Association

Heather Ficht, Chair
Oregon Workforce Partnership

Robin King, President
Florida Workforce Development Association

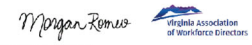
Teri Drew, Chairman
Arizona Workforce Association

Jeanna Fortney, Director
Minnesota Association of Workforce Boards

Angela Carr Klitzsch, Chair
Indiana Workforce Board Alliance

Carrie Amann, Executive Director
Pennsylvania Workforce Development Association

Sandra Miller, Executive Director
Washington Workforce Association



Morgan Romeo
Chair, Virginia Association of Workforce Directors

Kevin J. Kurdziel
President-Elect
Garden State Employment Training Association

PREPARED STATEMENT OF THE UNIVERSITY OF CALIFORNIA SAN FRANCISCO SCHOOL OF MEDICINE

Committee Members,

I am writing in support of a FY 2022 budget request for Department of Health and Human Services to develop a strategic plan and national strategy to improve the diagnosis, treatment and prevention of herpes simplex virus, types 1 and 2 (HSV). According to the Centers for Disease Control and Prevention, over half of Americans have been infected with HSV type 1 which can cause cold sores and genital ulcers, and one in eight Americans are currently infected with HSV type 2, which causes recurrent genital ulcers and is associated with significant stigma. There are significant disparities by race and sexual orientation, with HSV–2 impacting nearly half of all Black women, and approximately one in three men who have sex with men, with HSV being linked to HIV acquisition and transmission. Similar to HIV, HSV can be transmitted from mother to child during birth, which causes approximately 1,000 infant deaths annually. However, due to the poor quality of currently available antibody tests, routine testing in pregnancy or of the general population is not recommend by the United States Preventive Services Task Force. Finally, there is a growing body of evidence associating HSV to neurodegenerative diseases such as Alzheimer's, highlighting the urgency to develop better prevention and treatment strategies.

As a practicing clinician in the field of sexual health, I cannot overstate the negative impact of herpes simplex virus on patients' mental health. Countless studies have documented the mental health toll of an HSV diagnosis on a patient's well-being, and though not usually a fatal or serious infection itself, can lead to significant anxiety and depression given the burden of living with a chronic infection which must be disclosed to all future sex partners.

There is currently no national strategy to address HSV in the current Federal STI Strategic Plan (2021–2025). There is no surveillance for the condition, including its fatal outcomes among neonates. The majority of disease spread is via asymptomatic carriers unaware of their status. While antibody testing is readily available, it is prone to false positive results and there is poor access to confirmatory testing such as the Western Blot (previously used widely for confirmation of positive HIV results, but not widely available for herpes simplex virus). Given the implications for neonatal health, HIV transmission, and potential impact on general population of sexually active Americans, there is an urgent need for investment into the development of more accurate diagnostic testing, prophylactic and therapeutic vaccines, and antiviral medication that is more effective at viral suppression.

In short, if we care about maternal-child health, the health of communities of color, LGBTQ and other at-risk communities, and the mental health of Americans, we must prioritize funding to address herpes simplex virus infections.

Sincerely.

[This statement was submitted by Ina Park, MD, MS, Associate Professor, Departments of Family and Community Medicine & Obstetrics, Gynecology, and Reproductive Sciences, UCSF School of Medicine.]

PREPARED STATEMENT OF THE WASHINGTON STATE ASSOCIATION OF HEAD START AND ECEAP

Dear Chairman Murray, Ranking Member Blunt, and Members of the Subcommittee,

On behalf of the Head Start community, thank you for this opportunity to share the FY22 recommendation for Head Start funding.

I have the distinct pleasure of serving as the Executive Director of the Washington State Association of Head Start and ECEAP (WSA)—a statewide non-profit organization composed of representatives from Head Start, Early Head Start, Migrant/Seasonal Head Start, Native American Head Start and the Early Childhood Education and Assistance Program (ECEAP, the statewide early childhood program). WSA represents 52 Head Start programs from Bellingham to Walla Walla, including migrant and seasonal and tribal programs. We are immensely proud of our efforts to build early learners and support families facing financial hardships.

These past 16 months have been like none other. The COVID–19 pandemic has tested and challenged the nation's 1,600 Head Start programs and required program managers and directors to adapt overnight, think creatively, and juggle the complexities of supporting children and families while also protecting them as well as staff and meeting local, state, and federal guidelines. Last program year, little did we

know, social distancing, virtual learning, higher health and sanitation standards, and workforce safety would emerge as daily issues and priorities.

Thankfully, Congress and this Committee stood with us through this turbulent season. Because of you, Head Start programs by and large were able to return to services quickly, stay open, and support children with in-person learning. When the first major outbreak overtook Washington state, in-person services had to be rethought and virtual learning options made swiftly available. Quickly and competently, programs responded to emerging family needs including delivering food, learning materials, and cleaning supplies to doorsteps, holding Zoom dance parties with preschoolers, and supporting the mental health needs of parents and guardians. Several Head Start programs remained open onsite during the entirety of the pandemic including the Denise Louie Education Center in Seattle which provided childcare to many front line and essential workers and parents that needed to be at work in person.

These heroic efforts undertaken by the Head Start community this past year would not have been possible without COVID–19 relief funding from Congress. Thank you.

As Head Start increasingly returns to regular programming and doubles down on recruitment and enrollment, and the nation comes out from underneath the cloud of COVID–19, the National Head Start Association (NHSA) is seeking $12.1 billion in FY22. This level of funding will help Head Start programs get back on track in three distinct ways:

(1) by reassuring and bolstering the workforce ($247 million);

(2) by addressing growing and compounded childhood trauma through staff training and additional counseling support ($363 million); and

(3) by extending program duration for programs and families desperate for more hours of care and support ($730 million).

These are all long-standing priorities for NHSA and for programs across the country—workforce investment, Quality Improvement Funding for trauma-informed care, and extended duration—and we look forward to working with Congress to meet these goals. Addressing these critical needs is foundational to delivering the best results for children from at-risk backgrounds.

Equally important to the quality of our programs and the health, safety, and future success of Head Start is a long-overdue, often overlooked issue: infrastructure.

Five years ago, the US Department of Health and Human Services identified over $4.2 billion in Head Start capitalization needs, yet Head Start's facilities needs have largely gone unaddressed. Local programs are unable to afford critical health and safety updates, to support access and compliance with the Americans with Disabilities Act, to acquire licensable space in new neighborhoods, or to make modest updates to align with what we know is best for early childhood facilities. Head Start programs are serving children and families from the most at-risk backgrounds-those below the poverty line and a disproportionate share of children of color. In many cases, these children are in buildings that are a half-century old, crumbling, and out-of-date. Our Head Start programs, the children who spend most of their days in these centers, and the communities that house these facilities are in desperate need of long overdue investment.

In the state of Washington, our programs have persistently underfunded facility construction and classroom upgrades. Washington State Head Start programs are in desperate need of:

—HVAC systems and air filtration.

—Building repairs, including stairs and railings.

—Updated and/or new buses to ensure children can consistently get back and forth to school.

—New classrooms to handle an influx of children who need in person services; and

—Funds to build and construct new early learning facilities.

Please allow me to share specific examples from Head Start providers in my state:

Tulalip Tribe Head Start currently serves 74 Early Head Start children, 80 state funded preschool children, 112 child care spots, and 112 tribally funded kids. They need $1.6 million to add three classrooms to their Head Start/Child Care wing. This expansion project would address social distancing needs to meet licensing requirements and the influx of children moving from remote to in-person learning this fall as well as enable programing for another 30 children and families.

This year has highlighted the need for outdoor play and learning spaces. Family Services of Grant County in Moses Lake has active plans to acquire neighboring property to create outdoor classroom space for each preschool room. This expansion

would add gardens and make critical safety improvements. The cost of this project totals $1 million.

Moses Lake is also in immediate need for a larger transportation and maintenance building, additional parking, and improved drop-off vehicle access. The existing garage space is restrictive and lacks on-site storage. Moses Lake would like to turn the current garage into storage space, and build a new bus barn with more bays, so that the current space could be used as a small mechanical repair shop and perform preventative maintenance, reducing costs and extending the life of existing buses. They estimate that the cost for this project is about $1.7 million.

Finally, Okanogan County Child Development Association (OCCDA) in Northeast Washington has struggled to find long-term, sustainable educational space for five years and COVID–19 guidelines exacerbate this concern. OCCDA previously partnered with the Tonasket School District but after failed levy attempts, and the school district's own struggles for space, the lease was terminated in 2017. This forced OCCDA to relocate Tonasket Head Start and ECEAP programs to the building that was used for Early Head Start and subsequently relocate Early Head Start to a local church for a short period before landing at a workable, but not ideal downtown location. These moves have squeezed more children and staff into fewer and fewer square feet.

In 2018, OCCDA applied and was awarded and the Early Learning Facilities Technical Assistance Grant to plan for a potential future consolidated learning center; however, funds to purchase the property and build the facility are still lacking. The estimated cost for purchase and build at the time of our Feasibility Study was $1.5 million. For OCCDA, the pandemic has made a bad infrastructure concern far worse. As a result, current facility size and availability limits OCCDA's ability to conduct five-day per-week in-person classes to two days a week in Tonasket.

These examples are replayed over and over again in the 52 Head Start programs in the State of Washington. While there is a strong desire to return to pre-COVID–19 conditions, for Head Start programs, the road back is harder and longer. Candidly, we are not interested in simply "going back." We want to go forward. The pandemic has shone a bright light on deferred maintenance and strained or inadequate childcare facilities. Every Head Start program would welcome more children, however, the present-day constraints in many ways prevent expansion. Meaningful investments in our infrastructure—alongside funding for our workforce, sustained support for mental health and trauma response, and strengthening our existing program service hours—are critical in FY22 to helping children and families make a strong return.

In the days and weeks ahead, the Head Start community would appreciate Congress's full embrace of the NHSA FY22 Recommendation of $12.1 billion. The community also urges Congress to commit to an examination of Head Start's infrastructure constraints and how the federal government might partner with local programs to address these urgent needs.

Thank you for your consideration.

[This statement was submitted by Joel Ryan, Executive Director, Washington State Association of Head Start and ECEAP.]

PREPARED STATEMENT OF THE WOMEN FIRST RESEARCH COALITION

The Women First Research Coalition (WFRC) appreciates the opportunity to provide this outside witness testimony to the Senate Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies (Labor-HHS) for the Fiscal Year (FY) 2022 LHHS appropriations bill. As you begin work on FY 2022 appropriations, we respectfully request that you provide $46.11 billion for the National Institutes of Health (NIH) as well as additional emergency funds to support the biomedical research enterprise recover from the COVID–19 pandemic. We also request that you consider including our report language on "Diversity of the Biomedical Research Workforce" and the "BIRCWH Fellows Program" in the report that accompanies the final FY 2022 Labor-HHS appropriations bill.

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 to raise 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.

FUNDING FOR NIH

Robust, sustained and predictable funding is important for all biomedical research, particularly research on conditions that are unique to or predominately occur in women. As Congress appropriates funding for FY 2022, the WFRC is requesting that Congress provide $46.11 billion, an increase of $3.1 billion, to the NIH, which would allow for meaningful growth above inflation that would expand NIH's capacity to support promising science in all disciplines. Any funding increases should be allocated proportionately to all NIH institutes and centers to ensure that meritorious research in women's health is supported across the NIH. This would build on Congress' recent investments in NIH that have allowed for advances in discoveries toward promising therapies and diagnostics, supported current and new scientists nationwide and advanced the potential of medical research. It will also allow NIH to support meritorious research in women's health.

As the country continues to address the COVID–19 pandemic, WFRC also requests additional emergency supplemental funding for NIH to address the costs associated with restarting biomedical research including the increased costs of research related to personal protective equipment, reagents, and existing drugs in the COVID-era as well as ensure early stage and early established investigators remain part of the biomedical research workforce. We are deeply appreciative of the emergency funds Congress has already appropriated, but additional emergency funding is needed to enable a full recovery from the pandemic.

We urge Congress to designate a portion of these emergency funds for the Eunice Kennedy Shriver National Institute for Child Health and Human Development (NICHD), the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), and the National Institute on Aging (NIA), three institutes that support significant amounts of women's health research and have not yet received specific emergency funding. It is clear that there are significant impacts on patients with chronic conditions, as well as differences between how COVID–19 impacts women and men and the impact on older adults. We also must study the effects that COVID–19 has on conditions that are unique to or predominantly occur in women, such as pregnancy. Without additional funding, NICHD, NIDDK, and NIA will not have the capacity to continue adequately supporting existing research projects within their mission while also undertaking new research on COVID-related complications and comorbidities.

SUPPORT DIVERSITY OF THE BIOMEDICAL RESEARCH WORKFORCE

Recent reports demonstrate that women in the workforce have been disproportionately impacted during the COVID–19 pandemic. While women comprise 47 percent of the US labor force, they accounted for 54 percent of initial COVID-related job losses and continue to make up 49 percent of losses.[1] The recent May jobs report further emphasized this point, with unemployment among women showing little improvement.[2] During the COVID–19 pandemic, women in academia are balancing work with child care and virtual learning, financial issues, and other issues at a disproportionate rate to men. OBGYNs have been uniquely impacted during the pandemic since not only has their work not slowed down during the pandemic, but has become more complicated. For physician-researchers, there is little to no support currently in the system that addresses their situation. This is exacerbated for women of color, who are already underrepresented in obstetrics and gynecology. We are concerned that the losses we have seen thus far represent just the tip of the iceberg, and these inequities may result in loss of women from the research workforce for many more years to come even as the country continues to recover from the pandemic.

Therefore, the WFRC respectfully requests that you include the following report language in the report that accompanies the FY 2022 LHHS appropriations bill under the NIH Office of the Director:

> *Diversity of the Biomedical Research Workforce*.—The Committee is concerned with the impact of COVID–19 on the diversity of the biomedical research workforce, particularly women and women of color early stage and midcareer investigators. The Committee directs NIH to study the race and gender breakdown of the impact of COVID on participation in the workforce by monitoring the types of awards applied for and granted by gender and race for two years. If

[1] https://www.wsj.com/articles/how-the-coronavirus-crisis-threatens-to-set-back-womens-careers-11601438460#:~:text=Women%20have%20already%20lost%20a%20disproportionate%20number%20of%20jobs.&text=While%20women%20are%2047%25%20of,%2C%20according%20to%20McKinsey%20%26%20Co.

[2] https://www.bls.gov/news.release/empsit.nr0.htm.

the data demonstrate that less women are applying for grants, then it is imperative that NIH take steps to address this disparity. The Committee requests a status update from NIH on this research in the FY 2023 Congressional Justification as well as the steps being taken to maintain the diversity of the research workforce.

SUPPORT FOR THE BIRCWH FELLOWS PROGRAM

Administered by the NIH Office of Research of Women's Health (ORWH), the Building Interdisciplinary Research Careers in Women's Health (BIRCWH) program is a mentored career-development program designed to connect junior faculty, known as BIRCWH Scholars, to senior faculty with shared interest in women's health and sex differences research. There are currently 20 active BIRCWH programs across the country—each one is a 2-year program, and costs approximately $170,000 per fellow per year. BIRCWH research areas include cardiovascular disease, aging, cancer, neurosciences, musculoskeletal conditions, autoimmunity, mental health, reproductive health, health disparities, and infectious diseases/emerging infections & HIV/AIDS. Since its creation in 2000, the BIRCWH program has trained over 700 fellows and has an extremely strong track record of training successful women and URiM Scholars and preparing them for independence.

Approximately 70 percent of BIRCWH fellows supported during 2000–2018 received at least one successful R-level grant from the NIH and many received private grants as well. To continue this important work, more funding is necessary to support additional BIRCWH fellows at all existing sites with a goal of increasing the diversity of the scholars, sites, research areas supported by the program, and ultimately the diversity of the biomedical research workforce.

Therefore, the WFRC respectfully requests that you include the following report language in the report that accompanies the FY 2022 LHHS appropriations bill under the NIH Office of the Director:

> *BIRCWH Fellows Program*.—The Committee allocates $3 million to the ORWH's Building Interdisciplinary Research Careers in Women's Health (BIRCWH) program to fund additional BIRCWH fellows at all existing sites with a goal of increasing the diversity of the scholars, sites, and research areas supported by the program. These funds would support additional researchers focused on women's health and sex differences, which are priority research areas, as well as expand the program's work in the reproductive sciences. The Committee recognizes the effectiveness of the BIRCWH program, which is a mentored career-development program designed to connect junior faculty and senior faculty with shared interests.

CONCLUSION

Thank you again for the opportunity to submit testimony to the Committee as you begin your work on the FY 2022 appropriations bills. We look forward to working with you to ensure that there is appropriate funding for women's health research at the NIH, and to improve the diversity of the biomedical workforce.

PREPARED STATEMENT OF THE YALE SCHOOL OF PUBLIC HEALTH

To the Committee Members:

In my personal capacity, I am writing in support of a FY 2022 budget request for DHHS to develop a strategic plan and national strategy for treatment and prevention of Herpes Simplex Virus (HSV) Types 1 and 2. As you know, HSV is a chronic viral infection that disproportionately affects women of color, LGBTQ populations, and adolescents. HSV is well-known risk factor for HIV acquisition since it disrupts and is a widely recognized driver of the HIV epidemic. As a pediatrician, I wish to highlight the devastation that HSV causes through neonatal herpes, often fatal to newborns or the cause of overwhelming developmental abnormalities. Other neurodegenerative diseases have been linked to HSV.

There is currently no centralized national strategy to address HSV, it is not tracked or tested for, and the majority of spread is via asymptomatic carriers unaware of their status. We can and should be doing more to stop the spread and provide better treatment to the 1 in 3 Americans with this chronic condition.

I chaired a recent Committee for the National Academies of Sciences, Engineering, and Medicine that produced a 2021 report for the CDC entitled: Sexually Transmitted Infections: Advancing a Sexual Health Paradigm. This report highlights the crisis of rising rates of sexually transmitted infections in the United States. I hope that you support the HSV Strategic Plan mandate for DHHS. Thank you.

Sincerely yours.

[This statement was submitted by Sten H. Vermund, Anna M.R. Lauder Professor of Public Health, and Dean of the Yale School of Public Health, and Professor in Pediatrics at the Yale School of Medicine.]