

**DEPARTMENT OF LABOR, HEALTH AND
HUMAN SERVICES, AND EDUCATION, AND
RELATED AGENCIES APPROPRIATIONS FOR
FISCAL YEAR 2019**

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

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

DEPARTMENTAL WITNESSES

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

On behalf of America's 170 public television licensees, we appreciate the opportunity to submit testimony for the record on the importance of Federal funding for local public television stations and PBS. We urge the Subcommittee to support funding of at least \$455 million in 2-year advance funding for the Corporation for Public Broadcasting (CPB) in fiscal year 2021, \$20 million for the Public Television Interconnection System in fiscal year 2019 and \$30 million for the Ready To Learn program at the Department of Education in Fiscal Year 2019.

CORPORATION FOR PUBLIC BROADCASTING: AT LEAST \$455 MILLION (FISCAL YEAR 2021),
2-YEAR ADVANCE FUNDED

Local stations and PBS are committed to serving the public good in education, public safety, civic leadership, and other essential areas of society. Federal funding for CPB makes these services available to all Americans, including those in rural and underserved areas, and this funding enjoys the overwhelming support of the American people.

In a January 2017 bipartisan Hart Research Associates/American Viewpoint poll, 76 percent of American voters, including majorities of Republicans, Independents, and Democrats, support Federal funding for public television and want it maintained at current levels or increased. Over 70 percent of Federal funding for CPB goes directly to local stations, creating a successful public-private partnership of locally-controlled, broadly trusted, highly valued community servants.

Education

Local public television stations are America's largest classroom, meeting their communities' lifelong learning needs by providing the highest quality educational content and resources on multiple media platforms and in-person. Public television's exceptional content is available to nearly every household in America and has helped more than 90 million pre-school age children get ready to learn and succeed in school.

PBS, in partnership with local public television stations, has created PBS LearningMedia, an online portal where almost 2 million K–12 educators and users employ more than 100,000 standards-based, curriculum-aligned interactive digital learning objects created from public television content, as well as material from the Library of Congress, National Archives and other high-quality sources.

Overall, PBS LearningMedia helps teach an estimated 40 million students, including 33,000 homeschoolers, every day. Public television stations also provide distance

learning services that bring high-quality instruction in specialized fields to remote areas.

In January of 2017, local public television stations throughout the country partnered with PBS to bring a new, 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, day or night, over-the-air and streaming.

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

Partners in Public Safety

Public broadcasting stations throughout the country are leading innovators and essential partners to local public safety officers. In partnership with FEMA, the public television interconnection system provides the necessary redundant path for the Warning Alert and Response Network that enables cell subscribers to receive geo-targeted text messages in the event of an emergency—reaching citizens wherever they are.

This digital infrastructure and public television’s spectrum also enable stations 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 pilots in Houston, Chicago, Boston and Washington State, demonstrating the efficacy of this technology for expanding emergency communications capabilities.

The pilots were such a success that the DHS Science and Technology Directorate signed an agreement with America’s Public Television Stations to maximize and promote the technology and partnerships with local public television stations on a nationwide basis.

To support this nationwide effort, local public television stations have committed to reserve up to 1 megabit per second of their spectrum for the First Responder Network Authority (FirstNet). Additionally, stations are increasingly partnering with their local emergency responders to customize and utilize public television’s infrastructure for public safety in a variety of critical ways, with many serving as their States’ Emergency Alert Service (EAS) hub for weather and AMBER alerts.

Providing Civic Leadership

Public television strengthens the American democracy by providing citizens with access to the history, culture and civic affairs of their communities, their States and their country. Local public television stations often serve as the State-level “C-SPAN” covering State government actions. Local stations also provide more public affairs programming, 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 as consumers.

Public Broadcasting is a Smart Investment

All of this public service is made possible by the Federal funding to CPB that amounts to about \$1.35 per year, per American. 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 the Congress.

The need for Federal investment is particularly acute in small-town and rural America, where less 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 can be 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 this critical funding has remained flat for almost a decade, forcing stations to make difficult programming, staffing and service decisions as operational costs rose with inflation, while CPB funding did not. Despite this severe financial constraint, local public television stations have continued their deep commitments to the communities they serve. If CPB funding had kept up with the rate of inflation over this time period, CPB would be funded at more than \$500,000,000 annually.

In recognition of the fiscal austerity required of all Federal programs over the last several years, public television has never asked for an increase in CPB funding during this time. While public television recognizes continued budget constraints, the pressure on local public television stations after almost a decade of level funding necessitates the request of an increase of at least \$10 million, an important first step toward the eventual restoration of inflation-adjusted funding.

This request 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. For the fifteenth consecutive year, the American people have ranked PBS as one of the most trusted national institutions.

Local stations leverage the 2-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 2-year budget cycles.

Finally, the 2-year advance funding mechanism gives stations and producers, both local and national, the critical lead time needed to raise the additional funds necessary to sustain effective partnerships with local community organizations and engage them around high-quality programs. Producers like Ken Burns spend years developing programs like *The Vietnam War*, and future programs such as a 16-hour history of country music. It would be impossible to produce this in-depth programming and the curriculum-aligned educational materials that accompany it without the 2-year advance funding.

PUBLIC TELEVISION INTERCONNECTION: \$20 MILLION

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

Congress has always provided Federal funding for periodic improvements of the interconnection system. In fiscal year 2018, Congress moved to fund interconnection for public broadcasting on an annual, rather than decennial, basis to enable dynamic, incremental upgrades in accord with increasingly rapid advances in technology. Public television seeks level funding of \$20 million for interconnection in fiscal year 2019.

READY TO LEARN: \$30 MILLION (DEPARTMENT OF EDUCATION)

The 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 are delivering evidence-based, innovative, high-quality transmedia content to improve the math and literacy skills of high-need children. CPB and PBS, in partnership with local stations, have been able to ensure that the kids and families that are most in need have access to these groundbreaking and proven effective educational resources.

The additional funds will continue to help close a shortfall created when the Department of Education awarded grantees amounts that fully funded their submitted project budgets but exceeded annual appropriations levels, compromising grantees' abilities to execute on activities and fulfill the congressional intent of the program.

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. Highlights of recent studies show that:

- use of PBS KIDS content and games by low-income parents and their preschool children improves math learning and helps prepare children for entry into kindergarten;
- use of RTL content has been associated with a 29 percent improvement in reading ability in children grades K–2; and
- parents who used RTL math resources in the home became considerably more involved in supporting their children's learning outcomes.

In combination, RTL games, activities and videos provide early learners with the critical math and literacy skills needed to succeed in school.

An Excellent Investment

In addition to being research-based and teacher tested, RTL also provides excellent value for our Federal dollars. In the last 5-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 for content production. RTL exemplifies how the public-private partnership that is public broadcasting can change lives for the better.

CONCLUSION

Americans across the political spectrum rely on public broadcasting on television, on the radio, online, and in the classroom—because we provide essential local education, public safety, and informed citizenry services that are not available anywhere else. And none of this would be possible without the Federal investment in public broadcasting. A 2007 GAO report concluded that CPB's federally appropriated Community Service Grants to public television stations are an irreplaceable source of revenue for public broadcasting, and a 2012 study conducted by an independent third party for CPB at Congress's request came to the same conclusion.

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

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

Public broadcasters are the only broadcasters that reach nearly 99 percent of U.S. households, and it is CPB funding that makes this possible.

For all of these reasons we request that Congress continue its commitment to the highly successful, hugely popular public-private partnership that is public broadcasting by providing at least \$455 million in fiscal year 2021 for CPB, an incremental increase for the first time in almost a decade, in addition to \$20 million in fiscal year 2019 for the Public Television Interconnection system and \$30 million in fiscal year 2019 for the Ready To Learn Program.

PREPARED STATEMENT OF THE CORPORATION FOR PUBLIC BROADCASTING

Chairman Blunt, Ranking Member Murray and distinguished members of the subcommittee, thank you for allowing me to submit this testimony on behalf of America's public media service—public television and public radio—on-air, online and in the community. The Corporation for Public Broadcasting (CPB) requests funding of \$455 million for fiscal year 2021, \$20 million in fiscal year 2019 for the replacement of the public broadcasting interconnection system and \$30 million for the Department of Education's Ready To Learn program.

Fifty years after passage of the Public Broadcasting Act, this uniquely American public-private partnership continues to keep its promise—to provide high-quality, trusted content that educates, inspires, informs and engages in ways that benefit our civil society. Through the nearly 1,500 locally owned and operated public radio and television stations across the country, public media reaches 99 percent of the American people from big cities to small towns and rural communities. At approximately \$1.35 per citizen per year, it is one of America’s best infrastructure investments—paying huge dividends in education, public safety and civic leadership for millions of Americans and their families.

The Federal investment in public media enables universal access and is indispensable to sustaining the operations and public service mission of local public broadcasting stations. CPB serves as the steward of the Federal appropriation, ensuring that 95 cents of every dollar it receives goes to support local stations and the programs and services they offer to their communities; no more than five cents of every dollar goes to the administration of funding programs and overhead.

Education.—From early childhood through adult learning—is the heart of our mission. Through public television stations’ broadcast of the PBS 24/7 Kids Channel, 95 percent of all kids age two to eight receive educational content and services that are proven to prepare them for school, especially low-income and underserved children who do not attend or cannot afford pre-school. An excellent example of how public media brings together high-quality educational content with on-the-ground work in local communities is CPB’s work with the Department of Education’s Ready To Learn program. In addition to creating content for broadcast, Web and mobile platforms, local stations work with community partners to extend our high-quality children’s content through engagement with Head Start centers, daycare facilities, local health centers, faith-based organizations and others. No other media organization has both national reach coupled with local deployment of resources specifically charged with serving underserved, low-income and rural communities. In 2015, Congress reaffirmed its strong bipartisan support of Ready To Learn, furthering public media stations’ and producers’ work in connecting STEM and literacy learning experiences for children across multiple platforms and outlets.

Our work does not end with early learning. Through CPB’s “American Graduate” initiative, public media is addressing the crisis of one million young people failing to graduate from high school every year. Since 2011, more than 125 public media stations in 49 States have worked with 1,800 partners to raise awareness, attract mentors for young people and create local solutions for long-term success. Public media, with its unique position as a trusted resource and important partner in local communities, provides an important service helping youth stay on a path to graduation and post-graduation, job opportunities.

This year, American Graduate is addressing the Nation’s workforce skills gap. Through CPB support, local stations will partner with businesses, education and workforce related organizations to create content about the state of the workforce, identify job opportunities and skills required to meet local business and industry needs. In addition, we are continuing to work with local stations on behalf of veterans returning to civilian life who are seeking career and job training opportunities. CPB funding makes it possible for public television to operate the largest not-for-profit Graduate Equivalency Diploma program in the country, serving hundreds of thousands of second-chance learners and adult students.

CPB’s investments are guided by our commitment to innovation, diversity and engagement. As good stewards, we are always investing in innovation so that stations can deliver public media programming over multiple media platforms—free of charge and commercial free—available to our audience where, when, and how they choose to access our content. Our commitment to diversity includes geographic, socio-economic, political, ethnic, and cultural—at all levels of public media. Our stations, trusted in the community, also act as conveners, fostering constructive engagement on issues of importance locally and nationally.

Over the past 4 years CPB, working with public television and radio stations, launched Veteran’s Coming Home, an initiative designed to support veterans’ re-entry into civilian life. Public media recognizes the contribution and sacrifices of the men and women serving in our Armed Forces through content such as “Going to War,” which delivers an intimate look at a soldier’s combat experience and its aftermath told through the stories of veterans of various conflicts, as well as StoryCorps’ Military Voices initiative and the annual Memorial Day and Fourth of July concerts broadcast and streamed by PBS to millions.

Public broadcasters have retained the trust of the American people for accurate, balanced, objective, fair, transparent, and thoughtful coverage of news and public affairs—the essential resources for an informed citizenry and the foundation upon which a well-functioning democracy depends. In this disruptive and fragmented

media environment, public media's commitment to serving as a trusted source of information—providing more than a sound bite when it comes to news and fact-based information, as well as a civil place for the exchange of ideas locally and nationally—is more important and relevant to people's lives than ever.

CPB seeks to increase the capacity of public radio and television stations to create high-quality original and enterprise journalism by supporting collaborations that will establish reporting partnerships between multiple station newsrooms in a State or region. The objectives of these collaborations are to leverage public media's network of stations to provide a stronger local news service to the public media audience and to increase the flow of locally-produced content of general interest to the signature national programs.

When it comes to public safety, locally owned and operated public media stations are essential partners with public safety officials, schools, businesses and community leaders, providing real-time support in times of crisis. Public media stations broadcast crucial warnings about severe weather, send out AMBER alerts, and through data-casting capabilities, they work with first responders to deploy public media's infrastructure in a variety of life-saving ways. The Florida Public Radio Emergency Network (FPREN), a collaboration of 13 public radio stations, provides statewide multimedia updates during hurricanes or other emergencies to stations across the State, their websites, social media channels and on mobile devices via the Florida Storms app. In Houston, Texas, Houston Public Media, through its partnership with the U.S. Department of Homeland Security, proved it can deliver secure, encrypted IP data and communications to targeted, multiple emergency responders while continuing its television broadcast service.

INTERCONNECTION INFRASTRUCTURE

Interconnection is the backbone of the public media system, delivering content every day from public media producers to public television and radio stations in communities throughout the country. Without it, there is no nationwide public media service. Recognizing its importance, Congress has always funded public media's interconnection system; providing a separate, periodic appropriation for interconnection since fiscal year 1991. CPB appreciates Congress' support of moving the interconnection infrastructure to an annual, on-going funding cycle. This smaller, annual appropriation allows CPB the agility to contract for incremental upgrades as innovations in technology are realized and costs come down. These efficiencies and technological improvements will advance the public media system and benefit the American people.

CONCLUSION

CPB's fiscal year 2021 request of \$455 million and fiscal year 2019 requests of \$20 and \$30 million for interconnection and Ready To Learn, respectively, provides crucial support to stations—particularly those serving rural, minority and other underserved communities—and enables innovation and technological advances. Federal funding remains an irreplaceable part of the fabric of the national-local, public-private partnership that is the foundation of public media's success. With your support, CPB will continue to serve as a trusted steward of the Federal appropriation; by investing these taxpayer dollars in ways that strengthen the health of our civil society—helping to educate our youth, making Americans more aware of our Nation's challenges and opportunities, connecting to our history and engaging our citizens in their communities. Mr. Chairman and members of the subcommittee, thank you for allowing me to submit this testimony, and I appreciate your consideration of our funding request.

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

PREPARED STATEMENT OF THE RAILROAD RETIREMENT BOARD

Mr. Chairman and Members of the Committee:

The President's fiscal year 2019 proposed budget for the Railroad Retirement Board (RRB) is \$115.225 million. The RRB is requesting \$131.725 million. Appropriations for RRB operations are derived from the railroad retirement trust fund system and not the general fund. Appropriations language authorizes the RRB to access available funding from the trust funds to administer comprehensive retirement/survivor and unemployment/sickness insurance benefit programs for railroad workers and their families under the Railroad Retirement (RRA) and Railroad Un-

employment Insurance (RUIA) Acts. The RRB also administers certain benefit payments and Medicare coverage for railroad workers under the Social Security Act.

Last year, the RRB paid \$12.6 billion, net of recoveries and offsetting collections, in retirement/survivor benefits to about 548,000 beneficiaries, including \$1.6 billion in benefits paid to about 116,000 beneficiaries on behalf of the Social Security Administration. Further, the RRB paid \$104.6 million in unemployment-sickness benefits net of recoveries and offsetting collections to about 28,000 railroad workers.

The railroad employers and employee contributions are held in trust funds to pay railroad benefits and support RRB operations. Appropriations enacted for the RRB's administrative budget require no actual funds from the general fund. Enacted appropriations language authorizes the RRB to access the funds available in the railroad retirement trust fund system in order to finance operations. The Association of American Railroads and the Rail Labor Division of the Transportation Trades Department continue to support increased appropriations to address the urgent information technology and staffing needs of the agency.

PRESIDENT'S PROPOSED FUNDING FOR AGENCY ADMINISTRATION

The RRB's risk of mission failure is increasing substantially due to antiquated IT systems and insufficient staffing levels. The President's proposed budget would provide \$115.225 million for agency operations, to include IT initiatives, and support 757 full-time equivalents (FTEs). The RRB requests an additional \$16.5 million above the President's proposed \$115.225 million for a total of \$131.725 million to be derived from the railroad retirement trust fund system (not the general fund). Of the additional \$16.5 million, \$11.7 million would be used for continued IT investment initiatives and \$4.8 for increased staffing. The remainder of this testimony will focus on these critical priorities with a few additional topics in conclusion.

CRITICAL PRIORITY: INFORMATION TECHNOLOGY (IT)

We are grateful for the \$10 million designated for IT Investment Initiatives provided under Public Law 115-141, Consolidated Appropriations Act, 2018. These additional funds will allow the RRB to make significant progress on its top two mission critical IT investments (Mainframe Applications Re-platform Services and Legacy Systems Modernization Services), and to continue to work with GSA on contracts necessary to implement the mandated Enterprise Infrastructure Solutions.

For fiscal year 2019, the President's proposed budget provides \$115.225 million for normal agency operations and IT Modernization initiatives. The RRB's IT systems were built 40 years ago and support 200 mission-critical applications. The RRB's obsolete IT hardware and software systems are difficult to maintain and do not meet current Federal Information Security Modernization Act (FISMA) mandates, increasing the risk of a cybersecurity breach and mission failure. An additional \$11.7 million above the President's proposed amount of \$115.225 million, designated for IT initiatives will allow for continued progress on the RRB's ongoing critical modernization projects. Additional investment of \$11.7 million in the RRB's IT modernization efforts will facilitate compliance with cybersecurity and privacy mandates; improve and expand our data analytical capabilities to reduce the risk of fraud through stronger program integrity measures; and ultimately create a more effective and efficient organization capable of achieving the mission with fewer people.

CRITICAL PRIORITY: AGENCY STAFFING

For fiscal year 2019, the President's proposed budget provides \$115.225 million for normal operating costs of which seventy percent is for labor. From 1993 through 2017, the RRB has reduced staffing levels by half. Additionally, 58 percent of our current workforce will be eligible for retirement by fiscal year 2019. Under the President's proposed budget the RRB could fund 757 FTEs, which is 93 less than the minimum, 850 FTEs, needed to sustain mission critical operations.

Operating with less than 850 employees has and will continue to significantly decrease available customer service and office hours in the RRB's 53 field offices, resulting in unpredictable temporary office closures. As a result, railroad beneficiaries will continue to encounter significant delays in receiving assistance for benefits and counseling. Further, the growing backlog in retirement, survivor, and disability casework will continue to increase as a result of insufficient staffing. This will have a direct impact on payment of benefits. The \$4.8 million above the President's proposed budget will increase the staffing level to 850 FTEs that is necessary until modernized technology can sustain organization performance at lower staffing levels in the future.

LEGISLATIVE PROPOSALS

In connection with these workforce planning efforts, the President's budget request includes a legislative proposal to enable the RRB to utilize various hiring authorities available to other Federal agencies. Section 7(b) (9) of the Railroad Retirement Act contains language requiring that all employees of the RRB, except for one assistant for each Board Member, must be hired under the competitive civil service. We propose to eliminate this requirement, thereby enabling the RRB to use various hiring authorities offered by the Office of Personnel Management. Our budget request includes two additional legislative proposals. The first is to amend the RRA and the RUIA to include a felony charge for individuals committing fraud against the agency. The second is to amend the Social Security Act to provide access for the RRB to the National Directory of New Hires (NDNH). Access to NDNH supports the RRB's program integrity efforts to prevent improper payments.

FINANCIAL STATUS OF THE TRUST FUNDS

Railroad Retirement Accounts.—The RRB continues to coordinate its activities with the National Railroad Retirement Investment Trust (Trust), which was established by the Railroad Retirement and Survivors' Improvement Act of 2001 (RRSIA) to manage and invest railroad retirement assets for the payment of benefits. Pursuant to the RRSIA, the RRB has transferred a total of \$21.276 billion to the Trust. All of these transfers were made in fiscal years 2002 through 2004. The Trust has invested the transferred funds, and the results of these investments are reported to the RRB and posted periodically on the RRB's website. The net asset value of Trust-managed assets on September 30, 2017, was approximately \$26.5 billion, an increase of almost \$1.35 billion from the previous year. Through January 1, 2018, the Trust had transferred approximately \$21.920 billion to the RRB for payment of railroad retirement benefits.

The RRB's latest report required by the Railroad Retirement Act of 1974 and Railroad Retirement Solvency Act of 1983 was released in June 2017. The overall conclusion is, barring a sudden, unanticipated, large decrease in railroad employment or substantial investment losses, the railroad retirement system will experience no cash flow problems during the next 25 years. The report recommended no change in the rate of tax imposed on employers and employees. The tax adjustment mechanism will automatically increase or decrease tax rates in response to changes in fund balance. Even under a pessimistic employment assumption, this mechanism is expected to prevent cash flow problems for at least 25 years.

Railroad Unemployment Insurance Account.—The RRB's latest annual report required by Section 7105 of the Technical and Miscellaneous Revenue Act of 1988 was issued in June 2017. The report indicated that even as maximum daily benefit rates are projected to rise approximately 46 percent (from \$72 to \$105) from 2016 to 2027, experience-based contribution rates are expected to keep the unemployment insurance system solvent. Unemployment levels are the single most significant factor affecting the financial status of the railroad unemployment insurance system. However, the system's experience-rating provisions, which adjust contribution rates for changing benefit levels, and its surcharge trigger for maintaining a minimum balance, help to ensure financial stability in the event of adverse economic conditions. No financing changes were recommended at this time by the report.

Thank you for your consideration of our budget request. We will be happy to provide further information in response to any questions you may have.

[This statement was submitted by Vacant, Chairman, Walter A. Barrows, Labor Member, and Steven J. Anthony, Management Member, Railroad Retirement Board.]

PREPARED STATEMENT OF THE INSPECTOR GENERAL, RAILROAD RETIREMENT BOARD

Mr. Chairman and Members of the Subcommittee:

My name is Martin J. Dickman, and I am the Inspector General for the Railroad Retirement Board. I would like to thank you, Mr. Chairman, and the members of the Subcommittee for your continued support of the Office of Inspector General.

BUDGET REQUEST

The President's proposed budget for fiscal year 2019 would provide \$8,437,000 to the Office of Inspector General (OIG) to ensure the continuation of the OIG's independent oversight of the Railroad Retirement Board (RRB). During fiscal year 2019,

the OIG will focus on areas affecting program performance; the efficiency and effectiveness of agency operations; and areas of potential fraud, waste and abuse.

OPERATIONAL COMPONENTS

The OIG has three operational components: the immediate Office of the Inspector General, the Office of Audit (OA), and the Office of Investigations (OI). The OIG conducts operations from several locations: the RRB's headquarters in Chicago, Illinois; an investigative field office in Philadelphia, Pennsylvania; and four domicile investigative offices located in Virginia, Florida, Texas, and California. These domicile offices provide more effective and efficient coordination with other Inspector General offices and traditional law enforcement agencies, with which the OIG works joint investigations.

OFFICE OF AUDIT

The mission of OA is to promote economy, efficiency, and effectiveness in the administration of RRB programs and detect and prevent fraud and abuse in such programs. To accomplish its mission, OA conducts financial, performance, and compliance audits and evaluations of RRB programs. In addition, OA develops the OIG's response to audit-related requirements and requests for information.

During fiscal year 2019, OA will focus on areas affecting program performance; the efficiency and effectiveness of agency operations; and areas of potential fraud, waste, and abuse. OA will continue its emphasis on long-term systemic problems and solutions, and will address major issues that affect the RRB's service to rail beneficiaries and their families. OA has identified six broad areas of potential audit coverage: financial accountability; Railroad Retirement Act and Railroad Unemployment Insurance Act benefit program operations; RRB contracts and contracting activities; Railroad Medicare program operations; security, privacy, and information management; and Improper Payments Elimination and Recovery Act of 2010 (IPERA) oversight.

OA must also accomplish the following mandated activities in fiscal year 2019: audit RRB's financial statements pursuant to the requirements of the Accountability of Tax Dollars Act of 2002; audit RRB's compliance with IPERA; audit RRB's compliance with the Digital Accountability and Transparency Act of 2014 (DATA Act); evaluate RRB's risk in compliance with the Government Charge Card Abuse and Prevention Act of 2012; identify performance and management challenges for fiscal year 2019; conduct applicable semiannual reporting in accordance with the Inspector General Act of 1978, as amended; and evaluate information security pursuant to the Federal Information Security Management Act (FISMA). Beginning in fiscal year 2018, OA began utilizing contract services to conduct the annual FISMA evaluation.

During fiscal year 2019, OA will complete the audit of the RRB's fiscal year 2018 financial statements and begin its audit of the agency's fiscal year 2019 financial statements. OA contracts with a consulting actuary for technical assistance in auditing the RRB's "Statement of Social Insurance," which became basic financial information effective in fiscal year 2006. OA also conducts audits of individual computer application systems, which are required to support the annual FISMA evaluation. OA's work in this area is targeted toward the identification and elimination of security deficiencies and system vulnerabilities, including controls over sensitive personally identifiable information.

The portion of OA resources dedicated to conducting mandated audits continues to increase substantially. In fiscal year 2017, over 65 percent of direct audit time was spent completing mandated audits, which increased by over 15 percent from the prior fiscal year; largely attributable to the DATA Act mandated audit conducted in fiscal year 2017, another of which is required in fiscal year 2019. While mandated work results in important audit findings and increased agency oversight, it also limits other audits that can be undertaken without an increase in resources. Increased resources will make it possible for OA to provide additional oversight of RRB programs that represent billions in taxpayer dollars, while still meeting the important mandates of the Congress.

OA undertakes additional projects with the objective of allocating available audit resources to areas in which they will have the greatest value. In making that determination, OA utilizes a strategic planning process to focus on areas affecting program performance, the efficiency and effectiveness of agency operations, and areas of potential waste, fraud and abuse. OA also considers staff availability, current trends in management, and Congressional and Presidential concerns.

OFFICE OF INVESTIGATIONS

OI focuses its efforts on identifying, investigating, and presenting cases for prosecution, throughout the United States, concerning fraud in RRB benefit programs. OI conducts investigations relating to the fraudulent receipt of RRB disability, unemployment, sickness, and retirement/survivor benefits. OI investigates railroad employers and unions when there is an indication that they have submitted false reports to the RRB. OI also conducts investigations involving fraudulent claims submitted to the Railroad Medicare program. These investigative efforts can result in criminal convictions, civil penalties, or administrative recoveries/actions.

OI initiates cases based on information from a variety of sources including through RRB computer matching programs. OI also receives allegations of fraud through the OIG Hotline; contacts with State, local, and Federal agencies; and information developed through fraud detection projects initiated by investigative staff. The OIG will continue their commitment to proactively design projects aimed at promoting economy, efficiency, and effectiveness in the RRB's program and operations. In addition to identifying potential targets previously undetected through the RRB's standard program integrity measures, OIG will make the necessary recommendations to resolve identified program weaknesses and prevent future occurrences.

OI INVESTIGATIVE RESULTS FOR FISCAL YEAR 2017

| Civil Judgments | Indictments/Informations | Convictions | Financial Accomplishments |
|-----------------|--------------------------|-------------|----------------------------|
| 11 | 29 | 39 | ¹ \$149,800,000 |

¹The total amount of financial accomplishments reflect fraud amounts related to programs administered exclusively by the RRB and fraud amounts from other Federal programs such as Medicare or Social Security that were included in investigative dispositions.

OI anticipates an ongoing caseload of approximately 275 investigations in fiscal year 2019. During fiscal year 2017, OI opened 213 new cases and closed 155. As of March 31, 2018, OI had 281 cases open with an estimated fraud loss of more than \$552 million. Disability and Railroad Medicare fraud cases represent the largest portion of OI's total caseload. These cases involve more complicated schemes and often result in the recovery of substantial amounts for the RRB's trust funds. They also require considerable resources such as travel by special agents to conduct surveillance, numerous witness interviews, and more sophisticated investigative techniques. Additionally, these fraud investigations are extremely document-intensive and require forensic financial analysis.

The OI continues to work joint cases with other Inspector General offices and Federal law enforcement agencies that have responsibility for healthcare fraud matters. Railroad Medicare fraud investigations currently represent approximately 23 percent of OI's total caseload and more than \$334 million in potential fraud losses.² OI's collaborative joint investigative efforts ensure that RRB beneficiaries are protected from sham medical practitioners, and that the Railroad Medicare program's interests are safeguarded from fraudulent schemes.

OI will also investigate retirement fraud which typically involves the theft and fraudulent cashing of U.S. Treasury checks or the withdrawal of electronically deposited RRB benefits. OI will continue their use of the Department of Justice's Affirmative Civil Enforcement program to recover trust fund monies from cases that do not meet U.S. Attorney's guidelines for criminal prosecution.

During fiscal year 2019, OI will continue to coordinate its efforts with agency program managers to address vulnerabilities in benefit programs that allow fraudulent activity to occur and will recommend changes to ensure program integrity. OI plans to continue proactive projects to identify fraud matters that are not detected through the agency's program policing mechanisms. Findings will be conveyed to agency management to alert officials of operational weaknesses that may result in fraud against RRB programs. OI will also continue to work with RRB program managers to ensure appropriate and timely referral of fraud matters to the OIG.

CONCLUSION

In fiscal year 2019, the OIG will continue to focus its resources on the review and improvement of RRB operations and will conduct activities to ensure the integrity of the agency's trust funds. This office will continue to work with agency officials to ensure the agency is providing quality service to railroad workers and their fami-

²This reflects potential fraud amounts related to the Railroad Medicare program and other healthcare related programs, such as Medicare, which have been identified during OI's joint investigative work.

lies. The OIG will also aggressively pursue individuals who engage in activities to fraudulently receive RRB funds. The OIG will continue to keep the Subcommittee and other members of Congress informed of any agency operational problems or deficiencies.

[This statement was submitted by Martin J. Dickman, Inspector General, Railroad Retirement Board.]

NONDEPARTMENTAL WITNESSES

PREPARED STATEMENT OF THE ACADEMY FOR RADIOLOGY & BIOMEDICAL
IMAGING RESEARCH

Mr. Chairman and Members of the Subcommittee, my name is Dr. Hedvig Hricak, and I am privileged to serve as the President of the Academy for Radiology & Biomedical Imaging Research (“the Academy”), formerly known as the Academy of Radiology Research. I am testifying today to thank you for your dedicated support to medical imaging, and to strongly support an increase in funding for the National Institutes of Health to no less than \$39.3 billion, with a proportionate increase for the National Institute of Biomedical Imaging and Bioengineering (NIBIB).

In my “day job” I am the Chair of the Department of Radiology at Memorial Sloan-Kettering Cancer Center in New York City, New York. I also hold a senior position within the Program of Molecular and Pharmacology Therapeutics at the Sloan-Kettering Institute and am a Professor of Radiology at the Weill Medical College of Cornell University as well as a Professor at the Gerstner Sloan Kettering Graduate School of Biomedical Sciences. I have helped develop applications in ultrasound, MR, and CT for gynecological cancers as well as MR and MR spectroscopy for prostate cancer. I continue to investigate diagnostic methods for cancer detection, staging, and management, including approaches for molecular imaging of cancer.

On behalf of the Academy, I would like to begin by thanking you for your generous support for the National Institutes of Health in the recently passed bipartisan fiscal year 2018 omnibus appropriations bill. This money will contribute to the important work of improving our biomedical research infrastructure while also ensuring that the United States remains the leader in medical innovation and technology.

As this subcommittee knows well, funding for NIH is spread throughout the country. Approximately 84 percent of the amount appropriated is used for peer-reviewed intramural grants to researchers at universities, hospitals, and institutes in all 50 States. Another 9 percent funds very high-end research and patient care on the NIH campus. Only about 7 percent of funding is used for administrative purposes, maximizing the return on the investment. Nowhere is the return on investment more significant than in the growing field of biomedical imaging.

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

—Please fund the NIH at not less than \$39.3 billion for fiscal year 2019.

—Please increase NIBIB funding by not less than a proportionate amount.

Mr. Chairman, medical imaging plays a unique role in the healthcare delivery process, both as an instrumental part of the medical delivery and management ecosystem and as a catalyst for innovation and technological advancement in service of patient care. Imaging performs central and irreplaceable roles in early disease detection, diagnosis, treatment planning and monitoring. Precise and personalized care and treatment plans are often developed based on decisions made through imaging analysis and review. The Subcommittee’s investment in NIH and, in NIBIB in particular, helps make this possible. NIBIB’s imaging and bioengineering research and development create the vital methodology and tools utilized in so many areas of biomedical research by other institutes, let alone in America’s healthcare delivery system. Imaging research is a significant component of the work of many institutes of the NIH, including the National Cancer Institute, National Institute of Diabetes, Digestive and Kidney Diseases, and the National Institute of Neurological Disorders and Stroke, among others. NIBIB research itself has led to an impressive number of patents. In a study covering the 14-year period from 2000 to 2013, Battelle et al. found that for every \$100 million of research funding, NIBIB generated 25 patents and more than \$575 million in resulting economic activity and growth.

For nearly every patient—nearly every constituent—who receives a cancer diagnosis, suffers a head injury, or experiences any of thousands of other medical issues, or who cares for family members experiencing such difficulties, the health benefits of imaging research are profoundly felt. Few medical conditions do not already benefit from any of the wide range of clinical imaging modalities, from x-rays to MRI, CT, PET, fluoroscopy, angiography, and ultrasound. Furthermore, scientific discoveries and technological innovations are rapidly expanding the power of biomedical imaging to improve medical care. In the area of cancer, for example, emerging techniques for molecular imaging will play a key role in realizing the dream of molecularly targeted treatment, as, unlike biopsies, they can give a picture of the biological heterogeneity of cancer within and across all tumors in a patient. Moreover, progress is accelerating in the use of computer tools to analyze both anatomical and

molecular images and identify mathematically defined features, not perceptible to the human eye, which can predict the presence of cancer, its genetic profile, and how well it is likely to respond to specific treatments.

The Academy is involved in a broad effort to help maximize the efficiency with which medical imaging is applied in research and patient care. In 2015, we were privileged to work with the Office of Science Technology Policy (OSTP) in the White House to help develop the Interagency Working Group on Medical Imaging (IWGMI). The IWGMI was formed to coordinate the Federal investment in medical imaging research and develop a strategic plan for future development. Last year, the Working Group published a roadmap focused on “advancing high-value imaging” through four key objectives:

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

The Academy is working closely with allies across academia, government, and industry to develop steps to implement the Working Group’s roadmap. As part of this effort, the Academy has convened leaders in biomedical imaging and bioengineering to work together to develop a “Diagnostic Cockpit” that integrates advanced imaging and other diagnostic tools to improve diagnosis and thereby enhance the precision and efficiency of care delivery. These necessary investments will be made possible by a consistent and robust investment in biomedical imaging research. The sooner we invest, the sooner your constituents benefit.

Mr. Chairman, innovation is what keeps America healthy—both physically and economically—and the NIH is a major contributor to our strength. Since its creation, NIBIB has proven itself to have a significant impact on real people and the American economy.

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

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

PREPARED STATEMENT OF THE ACADEMY OF NUTRITION AND DIETETICS

The Academy of Nutrition and Dietetics appreciates the opportunity to submit outside witness testimony for the fiscal year 2019 appropriations bill. The Academy, which represents over 100,000 credentialed professionals throughout the Nation and is the world’s largest organization of food and nutrition professionals, is committed to improving the Nation’s health through healthy and safe food choices. As Congress begins work on fiscal year 2019 appropriations, we urge you to invest in Federal nutrition programs, which will provide an investment that will help prevent costly healthcare expenses due to chronic diseases.

ADMINISTRATION FOR COMMUNITY LIVING FUNDING

The Academy supports the appropriation of \$996.7 million for the Title III Nutrition Programs of the Older Americans Act, which is a \$100 million increase from the fiscal year 2018 omnibus levels. These nutrition services help millions of older adults receive the necessary meals to help them stay healthy and decrease the risk for disability.

The Academy also supports allocating \$19.8 million for Preventive Health Services under the Older Americans Act. These services support activities that educate older adults on the importance of healthy lifestyles and promote healthy behaviors. We also support the appropriation of \$8 million from the Prevention and Public Health Fund for Chronic Disease Self-Management Programs within the Administration on Aging, which is a low-cost, evidence-based disease prevention model that engages older Americans to be able to manage their diseases, which improves their health statuses and reduces more costly care such as hospital care and readmissions.

The Academy supports allocating \$31.2 million for Alaska Natives and Native American Nutrition and Supportive Services, the same as the fiscal year 2017 enacted level. These funds will provide approximately 6.1 million meals and 760,000 rides for Alaska Natives and Native American seniors to critical daily activities such as meal sites, medical appointments, and grocery stores.

The Academy supports the appropriations of \$12 million for Elder Rights Support Activities. This will allow for the expansion of ACL's Elder Justice/Adult Protective Services activities to help fulfill the promise of the Elder Justice Act of 2009. Funding will support the implementation of a nationwide Adult Protective Services data system, and fund research and evaluation activities. This program also provides funding for resource centers and activities that provide information, training, and technical assistance on elder rights issues to the national Aging Services Network.

CENTERS FOR DISEASE CONTROL AND PREVENTION FUNDING

The Academy supports a funding level of \$8.445 billion to the Centers for Disease Control and Promotion. Investing in evidence-based nutrition and public health programs is vital to our Nation's security, and the Federal investment in public health has failed to keep pace with inflation. Increasing CDC's budget is critical to ensuring that the Nation's health is protected from both communicable and non-communicable disease threats.

Chronic diseases, due in part to lifestyle choices, account for seven out of 10 causes of death in the U.S. As of 2012, almost half of adults had one or more chronic health conditions. We encourage funding the Division of Nutrition, Physical Activity and Obesity at \$92.420 million, which would allow the 18 remaining States and Washington D.C. to receive enhanced Section 1305 funding, and would fund two additional High Obesity sites. This funding level includes \$8 million for breastfeeding support efforts, and \$4 million for Early Child Care initiatives.

NATIONAL INSTITUTES OF HEALTH FUNDING

The Academy supports allocating \$2.165 billion to the National Institute of Diabetes and Digestive and Kidney Diseases. NIDDK supports discovery, clinical and translational research, as well as targeted training, aimed at understanding the impact of nutrition on diabetes, kidney and digestive diseases. The requested funding increases show a commitment to investing in nutrition research to prevent chronic diseases, and we applaud this commitment. NIDDK also is leading the Nutrition Research Task Force, and the Academy applauds this continued partnership.

PREPARED STATEMENT OF THE AD HOC GROUP FOR MEDICAL RESEARCH

The Ad Hoc Group for Medical Research is a coalition of more than 200 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).

The Ad Hoc Group is deeply grateful to the Subcommittee for its long-standing and bipartisan leadership in support of NIH, as demonstrated by the consecutive above-inflation increases for NIH in the final fiscal year 2017 and 2018 spending bills, and by the Subcommittee's tireless efforts to continue this budget trajectory with the historic \$3 billion increase for NIH in fiscal year 2018.

In fiscal year 2019, the Ad Hoc Group recommends at least \$39.3 billion for the NIH, including funds provided to the agency through the 21st Century Cures Act for targeted initiatives. This funding level, supported by more than 225 stakeholder organizations, would continue the momentum of recent years by enabling meaningful base budget growth above inflation to expand NIH's capacity to support promising science in all disciplines, and also would ensure that the Innovation Account supplements the agency's base budget, as intended, through dedicated funding for specific programs. Given the abundance of scientific opportunity, this recommendation represents a minimum investment to sustain progress that only would be amplified through an even more robust commitment.

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. As the Subcommittee has recognized, to remain a global leader in accelerating the development of life-changing cures, pioneering treatments, and innovative prevention strategies, it is essential that Congress sustain robust increases in the NIH budget.

NIH: A Partnership to Save Lives and Provide Hope. The partnership between NIH and America's scientists, medical schools, teaching hospitals, universities, and research institutions is a unique and highly-productive relationship, leveraging the full strength of our Nation's research enterprise to translate this knowledge into the next generation of diagnostics, therapeutics, and other clinical innovations. More

than 80 percent of the NIH's budget is competitively awarded through more than 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 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, and reduce illness and disability for more than 100 years. The following are a few of the many examples of how NIH research has contributed to improvements in the Nation's health.

- NIH-supported researchers continue to work toward strategies to better prevent, identify, and treat pain and substance use disorders. These efforts build on past NIH-supported work, such as the development of a naloxone nasal spray, the first easy-to-use, non-injectable version of a life-saving treatment for opioid or heroin overdoses, and development of the drug buprenorphine, the first drug for opioid addiction that could be prescribed in a doctor's office instead of requiring daily visits to a clinic.
- The death rate for all cancers combined has been declining since the early 1990s for adults and since the 1970s for children. Overall cancer death rates have dropped by about 1.5 percent per year, or nearly 15 percent in total from 2003—2012. Research in cancer immunotherapy has led to the development of several new methods of treating cancer by restoring or enhancing the immune system's ability to fight the disease.
- Deaths from heart disease fell 67.5 percent from 1969 to 2013, through research advances supported in large part by NIH. The Framingham Heart Study and other NIH-supported research have identified risk factors for heart disease, such as cholesterol, smoking, and high blood pressure. This work has led to new strategies for preventing heart disease.
- Since 1950, the stroke mortality rate has decreased by 79 percent, due in part to NIH-funded research on treatments and prevention.
- Despite the increasing prevalence of diabetes in the U.S., from 1969 to 2013 the death rate for adults with diabetes declined by 16.5 percent. Between 1990 and 2010, the rates of major diabetes complications dropped dramatically, particularly for heart attacks, which declined by 68 percent, and stroke, which declined by 53 percent. These improvements are due largely to clinical trials supported by NIH.
- Today, treatments can suppress HIV to undetectable levels, and a 20-year-old HIV-positive adult living in the United States who receives these treatments is expected to live into his or her early 70s, nearly as long as someone without HIV.
- In 1960, 26 of every 1,000 babies born in the United States died before their first birthday. By 2013, that rate had fallen to under 6 per 1,000 babies, thanks in large part to NIH research on reducing preterm births, neonatal mortality, and other complications.
- The haemophilus influenza type B (Hib) vaccine has reduced the cases of Hib, once the leading cause of bacterial meningitis in children, by more than 99 percent.
- In the mid-1970s, burns that covered even 25 percent of the body were almost always fatal. Today, people with burns covering 90 percent of their bodies can survive. NIH-funded research on wound cleaning, skin replacement, infection control, and other topics has greatly improved the chances of surviving catastrophic burns and traumatic injuries.

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

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

One long-lasting potential impact of investments in NIH is on the next generation of scientists. The Federal commitment to NIH sends a strong signal to these aspiring researchers about the stability of a long-term career in medical research. Of particular interest is maintaining a cadre of clinician-scientists to facilitate translation of basic research to human medicine. Additional funding is needed if we are to strengthen our Nation's research capacity, ensure a biomedical research workforce

that reflects the racial and gender diversity of our citizenry, and inspire a passion for science in current and future generations of researchers.

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. The research supported by NIH drives local and national economic activity, creating skilled, high-paying jobs and fostering new products and industries. Multiple studies have found that NIH investments catalyze increases in private sector investment. For example, a \$1 increase in public basic research stimulates an additional \$8.38 investment from the private sector after 8 years. Similarly, a \$1 increase in public clinical research stimulates an additional \$2.35 investment from the private sector after 3 years. Additionally, according to a report released by United for Medical Research, in 2017, NIH-funded research supported an estimated 380,000 jobs all across the United States and generated more than \$65 billion in new economic activity.

The Ad Hoc Group's members recognize the tremendous challenges facing our Nation and acknowledge the difficult decisions that must be made to restore our country's fiscal health. Strengthening our commitment to medical research, through robust funding of the NIH, is a critical element in ensuring the health and well-being of the American people and our economy.

Therefore, for fiscal year 2019, the Ad Hoc Group for Medical Research recommends that NIH receive at least a \$39.3 billion to continue the momentum in our Nation's investment in medical research.

PREPARED STATEMENT OF THE ADOPTION EXCHANGE

The Adoption Exchange offers the following testimony requesting increased funds for the following five programs under the supervision of the Administration for Children and Families (ACF): Child Welfare Services (CWS), Promoting Safe and Stable Families (PSSF), the Adoption and Kinship Incentives Fund, and the Adoption Opportunities Act.

In February, Congress passed the Family First Prevention Services Act (P.L. 115-123). The legislation has potential to expand services that can prevent the placement of children into foster care. It challenges States to reduce the number of children and youth in congregate placements. It will be a challenge to States to build the capacity and access to services (mental health, substance use, and in-home services) and to build the infrastructure of services and providers.

The challenge is against a backdrop of ever increasing foster care numbers driven by the opioid epidemic in parts of the country. Since 2012 the number of children in foster care has increased by 10 percent to 437,000 in 2016. The Adoption Exchange believes it is critical for Congress to fully fund six programs to both build capacity to effectively implement the Family First Act and help address the crisis many communities are facing as foster care placement demands explode.

The Family First Act provides funding for services to prevent the placement of children in foster care, but does not fund services to prevent child abuse and neglect. Child welfare strategy must significantly increase funding for child abuse prevention.

The Adoption Exchange calls on Congress to fully fund Child Welfare Services from \$269 million to \$325 million and Promoting Safe and Stable Families from \$99 million in discretionary funding to \$200 million; increase funding to the Adoption Opportunities Act to \$60 million; fully fund the Adoption and Kinship Incentives Fund at \$75 million.

IMPACT OF OPIOIDS ON CHILD ABUSE AND NEGLECT AND FOSTER CARE

Earlier this year HHS through the Secretary of Planning and Evaluation conducted an analysis of child welfare data and supplemented that work with field level research. Some of the key findings included:

—A 10 percent increase in overdose death rates correspond to a 4.4 percent increase in the foster care entry rate, and a 10 percent increase in the hospitalization rate due to drug use corresponds to a 3.3 percent increase in the foster care entry rate.

- While in past, drug epidemics family and communities could fill some of the gaps, today agencies report that family members across generations may be experiencing substance use problems forcing greater reliance on State custody and non-relative care.
- Parents using substances have multiple problems including domestic violence, mental illness, trauma history, and addressing substance abuse alone is unlikely to be effective.
- Substance use assessment is haphazard and there is a lack of “family-friendly” treatment that includes family therapy, child care, parenting classes and developmental services.
- There is a shortage of foster homes and this is exacerbated by the need to keep children longer in care which keeps existing homes full and unable to accept new placements.

FAMILY FIRST ACT

In fiscal year 2020, Families First will allow States to draw funds for children and families at risk of foster care. States taking the optional services will be limited to evidence-based services for families that need intervention, post-adoption, and reunification services. States must engage in and coordinate public-private agencies experienced with providing child and family community-based services, including mental health, substance use, and public health providers. There is a limited supply of foster homes and family-based aftercare support that can provide for post-discharge services for children leaving institutional care. Child welfare agencies need to find and support more family-based foster care homes. These four funds can help States develop evidence-based services that will meet the laws “well-supported,” “supported,” and “promising” standards and can assist the coordination of community based behavioral health and human services.

CHILD WELFARE SERVICES, TITLE IV–B PART 1

We ask for \$325 million for Child Welfare Services, the full authorization and above the current total of \$269 million. Starting in fiscal year 2020, the Families First Act will allow States to draw funds for children and families at risk of foster care. CWS is flexible enough to allow States to test out and develop these services and provide the research required to meet these evidence standards.

PROMOTING SAFE AND STABLE FAMILIES, TITLE IV–B PART 2

We also asking for full funding of \$200 million for Promoting Safe and Stable Families. Currently this appropriations is set at \$99 million despite being authorized at \$200 million. These funds supplement \$345 million in mandatory funds divided between services, the courts, substance use treatment grants and workforce development. Appropriations to \$200 million could be used for the four key services under PSSF: family reunification, adoption support, family preservation and family support. There are limited services for reunification services for children who return to their families and the same is true of post adoption services. These will all be eligible services under Family First but there are few models now eligible for funding.

THE ADOPTION OPPORTUNITIES ACT

The Adoption Opportunities program is the Nation’s oldest adoption program created to develop adoption promotion, post adoption services, and strategies. It has funded grants to reduce barriers to adoption, reduce disproportionality, and more recently, to promote adoptions of older youth in foster care, and develop post-adoption services. It is funded at \$39 million. We ask for funding at \$60 million to develop evidence-based models for post adoption services to families.

THE ADOPTION AND KINSHIP INCENTIVE FUND

We ask for a continued funding level of \$75 million for the adoption incentive fund. The fund was created in the Adoption and Safe Families Act (ASFA). In 2014, it became the Adoption and Legal Guardianship Incentive Payments Program. We thank the Appropriations Committee for partially addressing a recent shortfall in this incentive fund with the 2018 appropriations of \$75 million. In recent years HHS has not been able to fully award States because of a reduced appropriation. As a result, HHS has made up the previous year’s shortfall with the following year’s appropriations. The \$75 million for fiscal year 2018 was a significant step in addressing the shortfall of 2017. In the beginning years Congress would recognize this and provide an extra amount of appropriation. Your 2018 appropriation reestab-

lished this practice. When HHS issues the latest awards for fiscal year 2018, this September, there will be \$25 million remaining. That will likely fall short to fully fund the incentives. And we again ask for an appropriation of \$75 million to fully fund 2018 awards and have enough in place for fiscal year 2019.

These funds are reinvested by States into adoption services. These funds can be used by States to build both the evidence-based adoption services including post-adoption counseling and services that can prevent and reduce adoption disruption. The Adoption Exchange thanks you for this consideration and stands ready to respond to your questions and concerns.

[This statement was submitted by Lauren Arnold, CEO, The Adoption Exchange.]

PREPARED STATEMENT OF ADVANCE CTE

This testimony was prepared for the Senate Subcommittee on Labor, Health and Human Services, Education and Related Agencies regarding the fiscal year 2019 Federal Investment in the Perkins Basic State Grant Administered by the U.S. Department of Education

Advance CTE is the longest-standing national non-profit that represents State Directors and State leaders responsible for secondary, postsecondary and adult Career Technical Education (CTE) across all 50 States and U.S. territories. Advance CTE works to support an innovative CTE system that prepares individuals to succeed in education and their careers and poises the United States to flourish in a global, dynamic economy through leadership, advocacy and partnerships. On behalf of our members, Advance CTE is pleased to submit written testimony about the Federal investment in the Perkins Basic State Grant (authorized under Title I of the Carl D. Perkins Career and Technical Education Act (Perkins)) for fiscal year 2019 (fiscal year 2019) that is administered through the U.S. Department of Education. In order to meet the increased demand for CTE and fully support the CTE system and the 11.8 million learners it serves across the Nation, we request that Congress double the Federal investment in the Perkins Basic State Grant to \$2.4 billion.¹

Now is the right time to invest in CTE.

In fiscal year 2018 (fiscal year 2018), the Perkins Basic State Grant was increased by \$75 million to nearly \$1.2 billion. This is a very welcome step in the right direction and reflects Congress' understanding of the critical role CTE plays in helping our Nation's learners and employers close the skills gap. However, this was the first significant increase in CTE funding in nearly 30 years and there is a long way to go to restore all previous cuts to the Federal investment in CTE and meet today's demand for CTE. Furthermore, this increase still left six States and two territories behind: Iowa, Louisiana, Mississippi, Nebraska, Oklahoma, West Virginia, Puerto Rico and the Virgin Islands will receive the same size Perkins Basic State Grant for fiscal year 2018 as they did in fiscal year 2017.² This is in part due to the fact that the Federal investment in Perkins has not kept pace with increasing demand in a growing economy. In fact, over 600,000 additional secondary learners were enrolled in CTE in 2015–2016 compared to 2011–2012 and a 2017 survey of school districts offering CTE found that the top barrier to offering CTE in high school was "lack of funding or high cost of programs".^{3,4}

As the chart below demonstrates, between fiscal year 2004 and fiscal year 2017, Perkins funding 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 fiscal year 2018, Perkins had been relatively flat funded since 1991, and without being tied to inflation, the program's buying power had fallen by approximately \$933 million in inflation-adjusted dollars since 1991—a 45 percent reduction over a quarter century.⁵ This trend must be reversed if we are to make progress toward closing the skills gap.

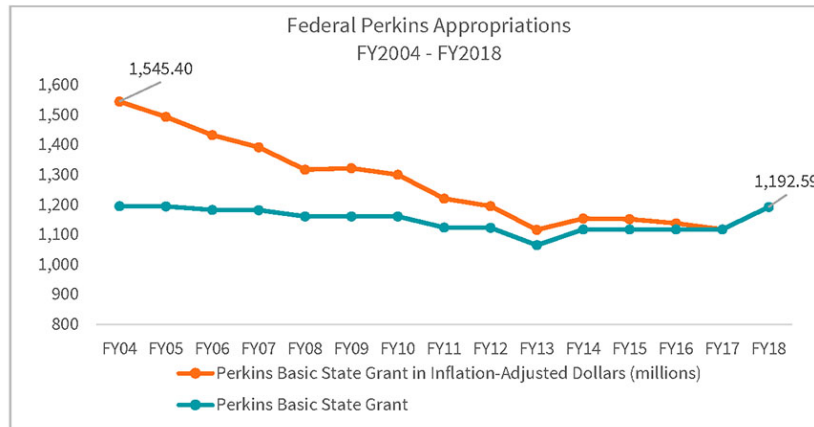
¹Refers to Program Year 2015–16. Source: <https://perkins.ed.gov/pims/DataExplorer/CTEParticipant>.

²Refers to 2017 and 2018 State Allocations. Source: <https://cte.ed.gov/grants/state-allocations>.

³Refers to Program Years 2011–2012 and 2015–16. Source: <https://perkins.ed.gov/pims/DataExplorer/CTEParticipant>.

⁴<https://nces.ed.gov/pubs2018/2018028.pdf>.

⁵Calculated using the Bureau of Labor Statistics' CPI Inflation Calculator. Source: <https://data.bls.gov/cgi-bin/cpicalc.pl>.



An Investment in CTE is an Investment in America's Economy.

By doubling the investment in the Perkins Basic State Grant, more resources would be directed to high-quality CTE programs that can strengthen the talent pipeline by supporting a workforce that is ready to meet the demands of tomorrow's jobs. More than half of all jobs (53 percent) in the U.S. today are middle-skill jobs—they require education beyond high school like certificates, associates degrees or some college. Yet only 43 percent of workers are trained to the middle-skill level, leading to a skills gap that leaves employers searching for qualified talent and many workers without job opportunities.⁶ In fact, in 2016, 46 percent of employers cited difficulty finding skilled talent, and six out of the ten hardest-to-fill positions are in technical fields or require a CTE background.⁷ Furthermore, businesses forego 11 percent of earnings and 9 percent of revenue because they can't find qualified workers.⁸ High-quality CTE programs directly connect learners in high school and post-secondary with employers, providing a clear pipeline of talent and unique opportunities for students to engage in internships, apprenticeships and other meaningful on-the-job experiences.⁹ By doubling the Federal investment in Perkins, these opportunities can be continued and expanded to serve more learners.

The Investment in CTE is Worth It.

Learners enrolled in CTE are increasingly high performers, with higher than average graduation rates and impressive postsecondary enrollment rates. The graduation rate for CTE concentrators is about 93 percent, approximately 10 percentage points higher than the national average.¹⁰ For example, in Massachusetts, students who were admitted to a vocational/technical high school had a nearly 100 percent probability of graduating on time compared to a rate of about 60 percent for students who just missed the admission cutoff and attended traditional high schools.¹¹

Not only are students who concentrate in CTE more likely to graduate from high school, they find success afterward as well. In Missouri, 96 percent of students who concentrated in a CTE program were enrolled in college, enlisted in the military or working within 6 months of graduation.¹² And a recent study in Arkansas found that, "Students with greater exposure to CTE are more likely to graduate from high

⁶ <http://www.nationalskillscoalition.org/resources/publications/2017-middle-skills-fact-sheets/file/United-States-MiddleSkills.pdf>.

⁷ <http://www.manpowergroup.com/talent-shortage-2016>.

⁸ <http://aedfoundation.org/wp-content/uploads/2017/01/AEDF-CollWMStudyII-Part1.pdf>.

⁹ For examples of high-quality CTE programs, see <https://careertech.org/excellence-action-award>.

¹⁰ U.S. Department of Education, Perkins Data Explorer. <https://perkins.ed.gov/pims/DataExplorer/Performance>.

¹¹ <http://www.doe.mass.edu/research/reports/2014/03EdLines-CTEImpact.pdf>.

¹² U.S. Department of Education, Perkins Data Explorer. <https://perkins.ed.gov/pims/DataExplorer/Performance>.

school, enroll in a 2-year college, be employed, and earn higher wages.”¹³ It is also important to highlight that CTE learners are not the only ones accruing the many benefits of CTE—taxpayers are also seeing a high return on investment (ROI). For example, in Washington, secondary CTE sees a ROI of \$7 for every one dollar of investment.¹⁴ In fact, the estimated impact of achieving a 90 percent graduation rate nationwide (calculated for the Class of 2015) is a \$5.7 billion increase in economic growth and \$664 million in additional Federal, State and local taxes.¹⁵ With double the Federal investment in CTE, these types of outcomes and more would be possible across the country.

CTE Parents and Students See the Value and Promise of CTE.

With the many opportunities and benefits that CTE offers, it is no surprise that CTE parents and students are highly satisfied with their CTE experience.¹⁶ Research commissioned by Advance CTE in 2017 found that:

- Students in CTE programs and their parents are three times as likely to report they are “very satisfied” with their and their children’s ability to learn real-world skills as part of their current education compared to parents and students not involved in CTE.
- 80 percent of parents of students in CTE are satisfied with their ability to participate in internships, compared to only 30 percent of prospective parents.
- 91 percent of parents of students in CTE believe their child is getting a leg up on their career, compared to only 44 percent of prospective parents.
- 86 percent of parents and students want real-world, hands-on opportunities as part of their high school experience.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 double the Federal investment in the Perkins Basic State Grant for fiscal year 2019.

Please feel free to contact Kimberly A. Green (kgreen@careertech.org), Advance CTE’s Executive Director, should you have any questions about our written testimony.

[This statement was submitted by Kimberly A. Green, Executive Director, Advance CTE.]

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

Dear Chairman Blunt and Members of the Subcommittee: AIDS Alliance for Women, Infants, Children, Youth & Families was founded in 1994 to help respond to the unique concerns of HIV-positive and at-risk women, infants, children, youth, and families. AIDS Alliance conducts policy research, education, and advocacy on a broad range of HIV/AIDS prevention, care, and research issues. We are pleased to offer written testimony for the record as part of the fiscal year 2019 Labor, Health and Human Services, Education, and Related Agencies appropriations measure.

RYAN WHITE PART D FUNDING REQUEST

Sufficient funding of Ryan White Part D, the program funded solely to provide family-centered primary medical care and support services for women, infants, children, and youth with HIV/AIDS has successfully identified, linked, and retained these vulnerable populations in much needed care and treatment, resulting in optimum health outcomes. We thank the Subcommittee for its continuous support of the Ryan White Program and respectfully request that the Subcommittee maintain its commitment to the Ryan White Part D and increase funding for Part D of the Ryan White Program by \$9.9 million in fiscal year 2019.

RYAN WHITE PART D BACKGROUND AND HISTORY

Congress first acted to address pediatric cases in 1987 by providing \$5 million for the Pediatric AIDS Demonstration Projects in the fiscal year 1988 budget. Those

¹³ <https://edexcellence.net/publications/career-and-technical-education-in-high-school-does-it-improve-student-outcomes>.

¹⁴ <http://www.wtb.wa.gov/CTE2018Dashboard.asp>.

¹⁵ Refers to the Graduating Class of 2015: <http://graduationeffect.org/US-GradEffect-Infographic.pdf>.

¹⁶ <https://careertech.org/recruitmentstrategies>.

¹⁷ https://cte.careertech.org/sites/default/files/Value%26Promise_FastFacts.pdf.

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

In 2017, Part D provided funding to 116 community-based organizations, academic medical centers and hospitals, federally qualified health centers, and health departments in 39 States and Puerto Rico. These federally, directly-funded grantees provide HIV primary care, specialty and subspecialty care, oral health services, treatment adherence monitoring and education services pertaining to opportunities to participate in HIV/AIDS-related clinical research. These grantees also provide support services which include case management (medical, non-medical, and family-centered); referrals for inpatient hospital services; treatment for substance use, and mental health services. Part D grantees receive assistance from other parts of the Ryan White Program that help support HIV testing and linkage to care services; provide access to medication; additional medical care, such as dental services; and key support services, such as case management and transportation, which all are essential components of the highly effective Ryan White HIV care model. This model has continuously provided comprehensive quality healthcare delivery systems that have been responsive to women, infants, children, youth and families for two decades.

A RESPONSE TO WOMEN, INFANTS, CHILDREN, AND YOUTH

The Ryan White Program has been enormously successful in meeting its mission to provide life-extending care and services. Yet, even though we have made significant progress in decreasing HIV-related morbidity and mortality, much work remains to be done. While accounting for less than 5 percent of Ryan White direct care dollars (minus ADAP and Part F), Ryan White Part D programs have been extremely effective in bringing our most vulnerable populations into care and developing medical care and support services especially designed to reach women, children, youth, and families.

Part D funded programs played a leading role in reducing mother-to-child transmission of HIV—from more than 2,000 newborn infections annually more than a decade ago to an estimated 174 in 2014 through aggressive efforts to reach out to pregnant women. Appropriate funding is critical to maintain and improve upon this success, as there are still approximately 8,500 HIV-positive women giving birth every year in the United States that need counseling, services and support to prevent pediatric HIV infections. According to the Centers for Disease Control and Prevention (CDC), Black women represented 59 percent of women living with HIV infection at the end of 2014 and 61 percent of HIV diagnosis among women in 2015. Additionally, youth aged 13–24 accounted for more than 1 in 5 new HIV diagnoses in the US in 2014. Most new HIV infections in youth (about 55 percent) occur in young Black gay and bisexual males. Of the new HIV infections among youth, 80 percent are among young women of color. Ryan White Part D programs are the entry point into medical care for many of these HIV positive women and youth and lead the Nation's effort in recruiting and retaining these populations in comprehensive medical care and support services.

According to the Health Resources and Services Administration, more than 27 percent of women living with HIV infection were served by the Ryan White program in 2016. Ryan White Part D provides medical and supportive services to a significant number of these women as well as a large number of women over 50 who are heading into their senior years as HIV survivors. This is a testament to the high standard of care provided to Ryan White Part D programs. Support and care

through the Ryan White Part D program was and continues to be funding of last resort for the most vulnerable women and children, who often have fallen through the cracks of other public health safety nets.

EFFECTIVE MODEL OF CARE

Ryan White Part D programs have been extremely effective in retaining our most vulnerable populations in care and treatment. The comprehensive coordinated medical care and supportive services provided by Part D are uniquely tailored to address the needs of women, including HIV positive pregnant women, HIV exposed infants, children and youth living with HIV/AIDS and are central components of a highly effective model of care designed to achieve optimal health outcomes. The family-centered primary medical and supportive services provided by Part D funded programs have enabled these funded programs to successfully engage and retain vulnerable populations in much needed care and treatment, resulting in positive health outcomes.

Part D is extremely cost effective relative to the care and treatment services provided to populations highly impacted by HIV and AIDS and is a critical component of the Ryan White Program. Additionally, Part D funded programs across the country and their vast networks of service providers are fully engaged in addressing and meeting the critical healthcare needs of women, infants, children and youth with HIV/AIDS.

CONCLUSION

While we recognize the considerable fiscal constraints Congress faces in allocating limited Federal dollars, the requested increase of \$9.9 million in fiscal year 2019 will enable Ryan White Part D programs to continue to deliver life-saving HIV/AIDS care and treatment to women, infants, children and youth with HIV infection to ensure that these populations are recruited and retained in care thereby closing the existing gaps in the HIV Care Continuum. Without the Ryan White Part D program, many medically-underserved women, infants, children and youth with HIV would not receive the vital medical care and support services provided to them for the last two decades.

On behalf of the women, infants, children, and youth living with HIV/AIDS and the Ryan White Part D funded programs across the country that serve them we sincerely thank the members of the Subcommittee for all that you do to ensure that our most vulnerable populations receive the much needed medical care, treatment and supportive services needed to sustain their lives.

Thank you.

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

PREPARED STATEMENT OF THE AIDS INSTITUTE

Dear Chairman Blunt and Members of the Subcommittee:

The AIDS Institute, a national public policy, research, advocacy, and education organization, is pleased to offer testimony in support of domestic HIV and hepatitis programs in the fiscal year 2019 Labor, Health and Human Services, Education, and Related Agencies appropriation measure. We thank you for your continued support and respectfully request \$873 million for the CDC's HIV Prevention Programs; \$134 million for CDC's Viral Hepatitis Programs; \$2.465 billion for the HRSA's Ryan White HIV/AIDS Program; \$105 million for the HHS Secretary's Minority AIDS Initiative Fund; \$160 million for SAMHSA's Minority AIDS Initiative Program; \$3.45 billion for HIV/AIDS research at the NIH; \$130.0 million for the Teen Pregnancy Prevention Program; and \$327 million for the Title X Program.

HIV/AIDS IN THE UNITED STATES

Over 1.1 million people in the U.S. are living with HIV, only about half of whom are virally suppressed, and there are an estimated 38,500 new infections each year. While there are decreasing rates of new HIV infections among most populations, increases are occurring in others. In 2016, African Americans accounted for 44 percent of HIV diagnoses, though they comprise only 12 percent of the U.S. population, and between 2010 and 2015, there was a 22 percent increase in new HIV infections among gay and bisexual Hispanic/Latino men. The South has been particularly impacted, accounting for 51 percent of estimated infections. There is also a rise in new HIV infections in certain areas due to the opioid crisis and injection drug users.

The vast majority of the discretionary programs supporting domestic HIV efforts are funded through this Subcommittee. Programs that prevent and treat HIV are in the Federal interest as they protect the public health against a highly infectious virus. HIV is now a treatable chronic disease for those with access to consistent and affordable healthcare and medications. HIV treatment also prevents someone from spreading the virus to others if they are virally suppressed. Therefore, HIV treatment is also HIV prevention. Diagnosing, treating, and achieving viral suppression for all individuals living with HIV are critical to achieve the goals of our National HIV/AIDS Strategy and reaching an AIDS-free generation. Sustained Federal investments in prevention, care and treatment, and research are necessary if we are to make additional advancements in combatting HIV.

VIRAL HEPATITIS IN THE UNITED STATES

Currently, there is an estimated 1.4 million people living with hepatitis B (HBV) and 3.9 million living with hepatitis C (HCV) in the U.S., and the numbers are rising. The CDC estimates that there was a 350 percent increase in new infections of HCV between 2010 and 2016, with an estimated 41,200 new cases in 2016. HBV infections also increased, with approximately 20,900 new cases occurring in 2016, up from an estimated 18,800 cases in 2011. Much of these increases have been driven by the ongoing opioid crisis. Additionally, more than 50 percent of people currently living with HBV or HCV remain undiagnosed. Left untreated, viral hepatitis can cause liver damage, cirrhosis, and liver cancer—one of the most lethal, expensive, and fastest growing cancers in the U.S. Viral hepatitis mortality rates have increased over the past decade, and there are nearly 20,000 HCV-related deaths each year, which is more than the 60 other notifiable infectious diseases combined.

Due to advances in medical science, there is now a highly effective treatment for HCV that can cure the disease in as little as eight weeks with few to no side effects. There are also vaccines for children and adults that protect against HBV. The National Academies of Science, Engineering, and Medicine has released a report outlining how increasing HBV vaccination and HCV treatment efforts, along with an investment in viral hepatitis testing, education, and surveillance can put the U.S. on the path to eliminating viral hepatitis as a public health threat.

INFECTIOUS DISEASE IMPACT OF THE OPIOID CRISIS

The recent explosion of opioid use in the U.S. has created tremendous risk for HIV and HCV outbreaks. Outbreaks related to the shared use of syringes have already occurred in Indiana, San Diego, Kentucky, and elsewhere in the past 3 years. The CDC has identified 220 counties across 26 States that are vulnerable to outbreaks and has estimated that at least seventy percent of new HCV infections are among people who inject drugs. The increasing HIV infection rates among people who inject drugs risks undoing the Nation's decades-long progress toward curbing transmissions. The skyrocketing increases in new viral hepatitis cases caused by injection drug use not only pose a serious public health threat, but also moves the country further away from eliminating viral hepatitis. A comprehensive response to the opioid crisis must include efforts to reduce the infectious disease consequences of the crisis.

In his fiscal year 2019 Budget, the President proposed a new \$40 million "Infectious Disease Elimination Initiative" at the CDC, and a new \$150 million "Reducing Injection Drug Use, HIV/AIDS, and Hepatitis" program at SAMHSA. While The AIDS Institute is highly supportive of these initiatives they are coupled with a \$40 million reduction to CDC's HIV Prevention programs and a complete elimination of SAMHSA's Minority AIDS Initiative program. We urge the Subcommittee to fund these new initiatives but not at the expense of cutting existing programs.

Additionally, both the House and Senate are advancing legislation that authorizes \$40 million in additional funding for the CDC to address opioid related infectious diseases, including Hepatitis and HIV ("Eliminating Opioid Related Infectious Diseases Act" (H.R. 5353), "Opioid Crisis Response Act of 2018" (S. 2680, Section 512)). The AIDS Institute strongly urges the Subcommittee to fully fund this program at the authorized level if it were to become law.

CDC VIRAL HEPATITIS PREVENTION

Despite the large increase in the number of cases and the estimated level of resources needed to eliminate the disease, the CDC's Division of Viral Hepatitis funding is only \$39 million. This is far from the estimated \$312 million a December 2016 CDC professional judgment budget describes as being necessary for a national viral hepatitis program focused on decreasing mortality and reducing the spread of the disease. Unfortunately, the President's fiscal year 2019 Budget reduces funding to

the \$34 million fiscal year 2017 level. Only with increased funding can we begin to address the rise in viral hepatitis and combat the impact of the opioid crisis. The AIDS Institute recommends \$134 million for CDC viral hepatitis activities in order to address this epidemic. This will provide an adequate level of education, screening, treatment, and the surveillance needed to reduce new infections and eventually eliminate hepatitis in the U.S.

CDC HIV PREVENTION

The CDC is focusing resources on those populations and communities most impacted by investing in high-impact prevention. With one in seven people living with HIV in the U.S. unaware of their infection, the CDC is also increasing access to HIV testing. 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 pre-exposure prophylaxis (PrEP), a once a day pill that effectively prevents HIV infection.

We were extremely disappointed that the President has proposed a \$40 million cut to HIV prevention programs. A cut this size would reverse the progress we have made in preventing new infections, and especially strain resources that are needed to fight the infectious disease impacts of the opioid crisis. We urge the Subcommittee to fund CDC's HIV Prevention program at \$872.7 million, including \$50 million for school-based HIV prevention efforts. One in five new HIV infections are among young people between the ages of 13 and 24.

THE RYAN WHITE HIV/AIDS PROGRAM

The Ryan White HIV/AIDS Program, acting as the payer of last resort, provides medications, medical care, and essential coverage completion services to approximately 550,000 low-income individuals with HIV, many of whom are uninsured or underinsured. With people living longer and continued new diagnoses, the demands on the program continue to grow. The Ryan White Program successfully engages individuals in care and treatment, increases access to HIV medications, and helps over 85 percent of clients achieve viral suppression compared to just 49 percent of all HIV-positive individuals nationwide. Part of the Ryan White Program, the AIDS Drug Assistance Program, provides funding for States to assist more than 250,000 people access lifesaving medications and helps enrollees afford insurance premiums, deductibles, and high cost-sharing of their medications. It is an important component in the successful health outcomes of Ryan White clients. With a changing and uncertain healthcare landscape and more need for comprehensive HIV care as a result of the opioid crisis, increased funding for the Ryan White Program is critically important now and in the future to ensure access to healthcare, medications, and other life-saving services for people with HIV.

In the President's fiscal year 2019 Budget Request, the AIDS Education and Training Centers (AETCs) and the Special Projects of National Significance (SPNS) were proposed for elimination. These two programs are integral pieces of the Ryan White HIV/AIDS Program and help to address the unique needs of hard to reach people living with HIV, including those who are co-infected with HCV. We urge your Subcommittee to reject these proposed cuts as was done in the fiscal year 2018 Omnibus.

The AIDS Institute requests that the Subcommittee fund the Ryan White HIV/AIDS Program at a total of \$2.465 billion in fiscal year 2019, distributed in the following manner: Part A at \$686.7 million; Part B (Care) at \$437 million; Part B (ADAP) at \$943.3 million; Part C at \$225.1 million; Part D at \$85 million; Part F/AETC at \$35.5 million; Part F/Dental at \$18 million; and Part F/SPNS at \$34 million.

MINORITY AIDS INITIATIVE (MAI)

As racial and ethnic minorities in the U.S. are disproportionately impacted by HIV, it is critical that the Subcommittee reject the President's proposal to completely eliminate the HHS Secretary's Minority AIDS Fund and Minority AIDS programs at SAMHSA. The Secretary's MAI Fund supports cross-agency demonstration initiatives to support HIV prevention, care and treatment, and outreach and education activities. SAMHSA's Minority AIDS programs target highly effected populations and provide prevention, treatment, and recovery support services, along with HIV testing for people at risk of mental illness and/or substance abuse. We urge the Subcommittee to appropriate \$105 million for the HHS Secretary's Minority AIDS Initiative Fund; and \$160 million for SAMHSA's Minority AIDS Initiative Program.

HIV/AIDS RESEARCH AT THE NIH

The NIH has supported innovative HIV research for better drug therapies, behavioral and biomedical prevention interventions, and has saved the lives of millions around the world. Research coordinated by the NIH's Office of AIDS Research (OAR) is vital in our efforts to end the epidemic. OAR ensures that funding for HIV/AIDS research is directed toward the most promising medical innovations. Continued research is necessary to learn more about the disease and to develop new treatments, prevention tools, and ultimately a cure. The NIH is currently studying new HIV treatment options, innovative delivery methods for PrEP, the possibility of an HIV vaccine, and novel medical research that may lead to a cure. We urge the Subcommittee to support AIDS research at \$3.45 billion, a figure that is based on the NIH's fiscal year 2018 Trans-NIH AIDS By-Pass Budget Estimate.

THE TEEN PREGNANCY PREVENTION PROGRAM

Young people under the age of 25 account for one in five new HIV infections in the U.S. We must ensure that they, especially those disproportionately impacted by HIV, have access to high quality evidence-based sexual health programs. The Teen Pregnancy Prevention Program (TPPP) funds innovative community-driven projects aimed at reducing unplanned pregnancies and increasing access to sexual health education such as HIV prevention information. TPPP is a key tool in our HIV prevention work with young people, and we urge the Subcommittee to reject the President's proposal to eliminate the program. Instead, we request the Subcommittee fund TPPP at \$130 million in fiscal year 2019.

SEXUAL RISK AVOIDANCE/ABSTINENCE-ONLY EDUCATION

Our Nation has wasted billions of dollars funding ineffective and harmful abstinence-only programs, now rebranded as "sexual risk avoidance." We urge the Subcommittee to fully defund these programs, saving taxpayer \$25 million a year, and ensuring that young people are not withheld from sexual health information, including HIV prevention tools.

TITLE X FAMILY PLANNING PROGRAM

The Title X family planning program provides family planning and sexual health services to over 4 million low income people across the Nation. Title X clinics are essential to ensuring access to family planning and sexual health services, including HIV prevention education and testing. In 2015, 1.2 million HIV tests and 5 million STD tests were provided by Title X clinics. In order to ensure that Title X has the necessary funds to administer high quality sexual health services, we request that the Subcommittee appropriate \$327 million for Title X in fiscal year 2019.

[This statement was submitted by Carl Schmid, Deputy Executive Director, The AIDS Institute.]

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[This statement was submitted by Carl Schmid, Deputy Executive Director, The AIDS Institute.]

PREPARED STATEMENT OF AIDS UNITED

As the Committee begins its important deliberations on the fiscal year 2019 Labor, Health and Human Services, Education, and Related Agencies appropriation bill, we thank you for your continued commitment to addressing HIV/AIDS in the United States and ask that you maintain the Federal Government's commitment to safety-net programs that protect public health. Specifically, we ask that you adequately fund the CDC Division of HIV prevention and surveillance activities at \$872.7 million to prevent new infections, AIDS research at the NIH at \$3.45 billion to find a cure and address other research priorities, and the Ryan White HIV/AIDS Program at \$2.465 billion to better ensure that all people living with HIV receive treatment and are retained in care.

Research has shown that we can achieve the goal of ending the HIV epidemic by diagnosing and treating all cases of HIV and by helping people at risk access means to protect themselves, including through pre-exposure prophylaxis (PrEP), but reaching this goal requires the Federal Government to continue to commit and even increase resources. While we have seen progress in the fight to end HIV in the United States, programs are not fully resourced to actually reach the end of the epidemic. Additionally, new, intersectional threats such as the opioid epidemic have emerged and must also be addressed within the context of infectious disease as well.

Due to austere budgets, domestic HIV/AIDS programs and other non-defense discretionary programs have been cut in recent years, even as new HIV infections continue at 37,600 per year and disproportionately impact disenfranchised communities including people of color, gay men, women, people living in the South, and young people. We appreciate that the subcommittee has recognized this need in the past and ask that you increase funding for domestic HIV/AIDS programs as you formulate the fiscal year 2019 funding measures.

The Ryan White HIV/AIDS Program

The Ryan White HIV/AIDS Program (“Program”) is a system of care that provides medications, medical care, and essential coverage completion services to approximately 550,000 low-income, uninsured, and underinsured individuals living with HIV/AIDS in the United States. Early and reliable access to HIV care and treatment, such as what the Program provides, is cost effective and helps people with HIV live healthy and productive lives. As the CDC recognized last year, when people living with HIV adhere to treatment regimens to maintain sustained viral suppression, there is effectively zero risk of transmitting the virus to an HIV-negative sexual partner. To achieve an undetectable viral load, people living with HIV must have consistent access to high-quality care and affordable medications. With the number of people living with HIV in the United States at 1.1 million, the demands on the Ryan White Program, which now covers nearly 60 percent of all people diagnosed with HIV in the U.S., continue to grow while funding does not keep pace, leaving many needs unmet.

As a payer of last resort, the Ryan White Program works in conjunction with Medicaid, Medicare, and the Affordable Care Act (ACA) to help with out-of-pocket costs and to support access to critical medical and coverage completion services not covered by traditional health insurance. The Ryan White Program also will continue to be the primary source of HIV/AIDS care and treatment for the millions who will not be eligible for health coverage under the ACA, including low-income people who live in non-Medicaid-expansion States. Sustained and increased funding of primary care, medications, and coverage completion services as well as education and training for medical providers in the Ryan White Program continues to be necessary to move towards ending the epidemic. We urge you to maintain all parts of the Program.

Racial and ethnic minority populations, and particularly African Americans/Black Americans, continue to bear the disproportionate burden of HIV prevalence and new diagnoses. To decrease these health outcome disparities, the Minority AIDS Initiative (MAI) was created in 1999 to fund parts of the Program to serve minority populations specifically as well as to support innovative projects and research that would produce sustainable change in the Federal HIV response to better serve racial and ethnic minorities. As one such administrator of MAI funds, the HHS Secretary’s Minority AIDS Initiative Fund (SMAIF) has supported projects in over 40 States, Puerto Rico, and the District of Columbia that directly impact the health and well-being of people of color living with or affected by HIV. Projects supported by SMAIF generally take a broad, intersectional approach to addressing these racial health disparities, tackling such topics as intimate partner violence, the leadership of people of color, pre-exposure prophylaxis (PrEP) access, and Hepatitis C (HCV) comorbidity in minority groups most affected by HIV. Sustained funding of these initiatives brings us closer to ending the HIV epidemic through a commitment to the wellbeing of those most impacted.

As exemplified by the evidence that someone whose viral load is undetectable cannot transmit HIV to a partner, scientific knowledge and medical best practices regarding HIV have advanced exponentially in the nearly four decades since the epidemic began in the United States. Medical professionals of all scopes and practices encounter patients living with HIV; with such rapidly developing standards, however, many struggle to provide their patients with the best care. In order to end the HIV epidemic, medical personnel must be provided the highest quality of continuing professional education. The AIDS Education and Training Centers (AETCs), under Part F of the Ryan White Program, are a network of HIV experts who train and provide consultation to medical professionals serving people living with HIV to ensure the highest standards of provider competency and comfort with the unique clinical and social challenges that can accompany an HIV diagnosis. The AETCs work regionally, able to meet providers where they are in terms of their location and knowledge about HIV care. Without the intervention of the AETCs, access to HIV care would decrease significantly. AETCs are often the “first responders” to new facets of the HIV epidemic, including training providers in behavioral and mental health comorbidities, addressing the impact of the opioid crisis on the HIV epidemic, and creating pathways for providers to become HIV specialists when the need arises

in their area. Continued support of the AETCs is vital to achieving the goal of the National HIV/AIDS Strategy of ensuring people living with HIV are diagnosed, linked to, and retained in care by starting with the source: highly trained medical professionals. Similarly, we urge you to increase critical practical research funds that produce cutting-edge knowledge through the Special Projects of National Significance at \$34 million.

Funding for the Ryan White Program is critical to improving health coverage and outcomes for people living with HIV. Therefore, we urge you to fund the Ryan White Program at a total of \$2.465 billion in fiscal year 2019, an increase of \$145.8 million over fiscal year 2018, distributed as follows: Part A, \$686.7 million; Part B/Care, \$437 million; Part B/ADAP, \$943.3 million; Part C, \$225.1 million; Part D, \$85 million; Part F/AETC, \$35.5 million; Part F/Dental, \$18 million; Part F/SPNS, \$34 million; Minority AIDS Initiative, \$610 million.¹

HIV Prevention—CDC HIV Prevention and Surveillance

Although the United States has significantly reduced the number of infections over 30 years of fighting HIV, there still are 37,600 new infections annually and about 1 in 7 people living with HIV do not know they have the virus. In 2016, approximately 63 percent of Ryan White Program clients were living at or below the Federal poverty level. In 2016, nearly three-quarters of Ryan White HIV/AIDS Program clients were from racial or ethnic minority populations, with approximately 47 percent identifying as Black/African American and approximately 23 percent identifying as Hispanic/Latinx. In the same year, more than 71 percent of Program clients were male, more than 27 percent were female, and slightly more than 1 percent were transgender.

AIDS United is pleased that the CDC has targeted funds to fight HIV among gay and bisexual men and transgender people including funding for PrEP—a highly effective prevention tool for people who are HIV-negative but at substantial risk—plus ongoing medical care and antiretroviral treatment for people with HIV. While we are making progress in decreasing new infections among women, women of color are still disproportionately affected: Black women accounted for 61 percent of women infected in 2016, and the HIV diagnosis rate among Hispanic/Latinx women in 2015 was more than three times that of white women.

Investing in HIV prevention today translates into less spending in the future on care and treatment. We are at a critical juncture in the fight against HIV/AIDS: we have the tools to end the epidemic, but we must invest the resources now to bring the vision of ending the epidemic to reality. In order to achieve the goals of reducing new infections, increasing knowledge of HIV status, and minimizing HIV transmission, funding for the CDC is needed to carry out its High-Impact Prevention activities. For fiscal year 2019, we request increases of \$84 million over fiscal year 2018 for a total of \$872.7 million for the CDC Division of HIV prevention and surveillance activities. [Note: This request does not include the request for DASH]

Combating Viral Hepatitis and Protecting Access to Sterile Syringes

AIDS United strongly urges the Committee to maintain current language allowing the use of Federal funds for syringe services programs in eligible jurisdictions experiencing or at risk for an HIV outbreak or elevated levels of HCV and where local public health or local law enforcement authorities deem a site to be appropriate. People with HIV infection in the United States are often affected by chronic viral hepatitis; about one-third are coinfecting with either Hepatitis B (HBV) or HCV, and viral hepatitis progresses faster and causes more liver-related health problems among people with HIV than among those who do not have HIV. Over the last several years, the opioid crisis has led to concerning numbers of new infections tied to injection drug use, resulting in nearly 55,000 new hepatitis cases each year. At just \$39 million a year, CDC's viral hepatitis programs do not have the needed resources to combat the infectious diseases associated with the opioid epidemic. The CDC has identified 220 counties that are most vulnerable to outbreaks of HCV and HIV related to injection drug use. These counties are spread across 26 States and represent only the top 5 percent of vulnerable counties overall. At present, more than 93 percent of those 220 counties vulnerable to HIV/HCV outbreaks do not have comprehensive syringe service programs. Over the past 30 years, the CDC has collected compelling evidence of syringe services programs' effectiveness, safety, and cost-effectiveness for HIV prevention among program participants and for reductions in HIV, HCV, and HBV incidence rates community-wide. Syringe services programs in-

¹Total MAI funding is distributed through multiple programs and, in most instances, is included in the funding requests for those programs. (Federal AIDS Policy Partnership. ABAC fiscal year 2019 Requests. April 16, 2018).

crease access to comprehensive resources such as HIV and Hepatitis testing and linkage to treatment, referral to substance use treatment and assistance, behavioral health services, primary care, overdose treatment and education, Hepatitis A and B vaccinations, and other ancillary services.

More than forty new comprehensive syringe services programs have been implemented since the CDC released its program guidance in 2016, and existing syringe services programs are experiencing high demand for services, yet funding has not increased proportionally. Syringe services programs are recommended by AIDS United as a key component of the Department of Health and Human Services' response to the opioid crisis in CDC, HRSA, and SAMHSA appropriations. AIDS United urges the Committee to adequately fund the CDC Division of HIV prevention and surveillance activities at \$872.7 million and to increase funding for the CDC Division of Viral Hepatitis activities to \$134 million for the purpose of ensuring appropriate levels of testing, education, screening and linkage to care, surveillance, and on-the-ground syringe service programs that reduce the infectious disease consequences of the Nation's opioid crisis.

HIV/AIDS Research at the National Institutes of Health (NIH)

Building on recent progress, robust support for HIV research must continue until better, more effective and affordable prevention and treatment regimens—and eventually a cure—are developed and universally available. For the U.S. to maintain its position as the global leader in HIV/AIDS research for the 36.7 million people globally and 1.1 million people in our Nation living with HIV, we must invest adequate resources in HIV research at the NIH. NIH research has produced promising recent advances, including the study of the prevention effects of treatment, improved treatment programming, and the first partially effective HIV vaccine. In order to realize similar breakthroughs in the future and improve the HIV care continuum, continued robust AIDS research funding is essential. We ask that you request \$3.45 billion for HIV research at the NIH, an increase of \$0.45 billion over fiscal year 2018.

AIDS United looks forward to a positive outcome for the funding request for HIV/AIDS domestic programs, and 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. For questions, please contact Carl Baloney, Jr., Director of Government Affairs, at cbaloney@aidsunited.org.

Sincerely,

[This statement was submitted by William D. McColl, Vice President of Policy and Advocacy, 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 testify on the fiscal year 2019 appropriations for Alzheimer's research, education, outreach and support at the U.S. Department of Health and Human Services.

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

ALZHEIMER'S IMPACT ON THE AMERICAN PEOPLE AND THE ECONOMY

The most important reason to address Alzheimer's is because of the human suffering it causes to millions of Americans. 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. According to recent data from the National Center for Health Statistics, deaths from Alzheimer's disease increased 123 percent between 2000 and 2015. Currently, Alzheimer's is the sixth leading cause of death in the United States and the only one of the top ten without a means to prevent, cure or slow its progression. Over five million Americans are living with Alzheimer's, with 200,000 under the age of 65.

In addition to the human suffering caused by the disease, however, Alzheimer's is also creating an enormous strain on the healthcare system, families, and Federal and State budgets. Alzheimer's is the most expensive disease in America. In fact, a study funded by the National Institutes of Health (NIH) in the *New England Journal of Medicine* confirmed that Alzheimer's is the most costly disease in America, with costs set to skyrocket at unprecedented rates. If nothing is done, as many as 14 million Americans will have Alzheimer's by 2050 and costs will exceed \$1.1 trillion (not adjusted for inflation).¹ As the current generation of baby boomers age, near-term costs for caring for those with Alzheimer's will balloon, as Medicare and Medicaid will cover more than two-thirds of the costs for their care.

Caring for people with Alzheimer's will cost all payers—Medicare, Medicaid, individuals, private insurers and HMOs—\$20 trillion over the next 40 years. As noted in the 2018 Alzheimer's Disease Facts and Figures report, in 2018 America will spend an estimated \$277 billion in direct costs for those with Alzheimer's, including \$186 billion in costs to Medicare and Medicaid. Average per person Medicare costs for those with Alzheimer's and other dementias are more than three times higher than those without these conditions. Average per senior Medicaid spending is 23 times higher.²

CHANGING THE TRAJECTORY OF ALZHEIMER'S

Until recently, the Federal Government did not have a strategy to address this looming crisis. In 2010, thanks to bipartisan support in Congress, the National Alzheimer's Project Act (NAPA) (Public Law 111-375) passed unanimously, requiring the creation of an annually-updated strategic National Plan to Address Alzheimer's Disease (National Plan) to help those with the disease and their families today and to change the trajectory of the disease for the future. The National Plan must include an evaluation of all federally-funded efforts in Alzheimer's research, care and services—along with their outcomes.

If America is going to succeed in the fight against Alzheimer's, Congress must continue to provide the resources scientists need to do their work. Understanding this, in 2014 Congress passed the Consolidated and Further Continuing Appropriations Act of 2015 (Public Law 113-235), which included the Alzheimer's Accountability Act (S. 2192/H.R. 4351). The Alzheimer's Accountability Act requires NIH to develop a Professional Judgment Budget focused on the research milestones established by the National Plan. This provides Congress with an account of the resources that NIH has confirmed are needed to reach the lead goal of the National Plan: to effectively treat and prevent Alzheimer's by 2025.

Recent funding increases have been critical to accelerate progress toward the National Plan's 2025 goal. Among other advances, this additional funding has already enabled important research advances into new biomarkers to detect the disease before the onset of symptoms, help to build better animal models to replicate the disease and enable preclinical testing of promising therapeutics, and has increased data sharing.

For example, the Alzheimer's Disease Neuroimaging Initiative (ADNI), which tracks how neuroimaging and fluid biomarkers change with disease onset and progression, has moved into a critical new phase of discovery with ADNI3. ADNI3 focuses on brain scans that detect the amount and location of tau protein tangles, one of the hallmark brain changes of Alzheimer's disease. The discovery of novel biomarkers for Alzheimer's disease is critically needed for detection of disease-related changes years before the symptoms of memory loss appear.

Additionally, increased NIH funding has enabled the Accelerating Medicines Partnership-Alzheimer's Disease (AMP-AD) knowledge portal, a vibrant public-private partnership bringing together the NIH, pharmaceutical companies, and non-profits like the Alzheimer's Association. This important data portal allows the researcher community to access and analyze data on a scale that would not be possible by individual research teams, academic institutions, or pharmaceutical companies. This broad and rapid sharing of biological data and analytical results has already allowed researchers to discover more than 100 novel candidate targets.

Another exciting development is the publication last month of a new research framework developed between the National Institute on Aging (NIA) and the Alzheimer's Association, "NIA-AA Research Framework: Towards a Biological Definition of Alzheimer's Disease." This new framework shifts the definition of Alzheimer's disease in a research context from one based on cognitive changes and be-

¹2018 Alzheimer's Disease Facts and Figures:https://www.alz.org/documents_custom/2018-facts-and-figures.pdf.

²ibid.

havioral symptoms with biomarker confirmation, to a strictly biological construct as we have for other major diseases. This framework provides researchers a roadmap that circumvents many of the pitfalls that have crippled so many high-profile clinical trials in recent years. By recognizing the onset of Alzheimer's disease many years before the presentation of symptoms, it directs the research community's focus on overcoming specific hurdles to faster progress in addressing this disease.

It is vitally important that NIH continues to build upon these and many other promising advances. The Alzheimer's Association and AIM urge Congress to fund the research targets outlined in the Professional Judgment Budget by supporting an additional \$425 million for NIH Alzheimer's funding in fiscal year 2019.

A disease-modifying or preventive therapy would not only save millions of lives but would save billions of dollars in healthcare costs. Specifically, if a treatment became available in 2025 that delayed onset of Alzheimer's for 5 years (a treatment similar in effect to anti-cholesterol drugs), savings would be seen almost immediately, with Medicare and Medicaid saving a cumulative \$535 billion in the first 10 years.³

CONCLUSION

The Alzheimer's Association and AIM appreciate the steadfast support of the Subcommittee and its priority setting activities. We thank the Subcommittee and Congress for including an historic \$414 million increase for Alzheimer's research activities at NIH in fiscal year 2018. However, the current funding level is still short of the total funding scientists believe is needed to meet the goal of finding a treatment or cure for Alzheimer's and other dementias by 2025. We look forward to continuing to work with Congress in order to address the Alzheimer's crisis. We ask Congress to address Alzheimer's with the same bipartisan collaboration demonstrated in the passage of the National Alzheimer's Project Act (Public Law 111-375) and enactment of the Alzheimer's Accountability Act (Public Law 113-235) with an additional \$425 million for Alzheimer's research activities at NIH in fiscal year 2019.

[This statement was submitted by Robert Egge, Chief Public Policy Officer, Alzheimer's Association and Alzheimer's Impact Movement.]

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF FAMILY PHYSICIANS

On behalf of the American Academy of Family Physicians, representing 131,400 family physicians and medical students, I submit this testimony. Family physicians conduct approximately one in five of the total medical office visits in the United States annually—more than any other specialty. Family physicians provide comprehensive, evidence-based, and cost-effective care and are essential to improving the health of patients, families and communities.

Family physicians depend on your Committee to provide funding levels necessary for the essential public health programs which support family physician workforce development, provide access to primary care to patients of all ages, generate the primary care research needed to improve efficacy and safety, and strengthen our Nation's disease prevention and health promotion efforts. We recommend that the Committee provide the following appropriations for programs important to family physicians and our patients.

We strongly urge that you restore the discretionary budget authority for the Health Resources and Services Administration (HRSA) to the fiscal year 2010 level adjusted for inflation of \$8.56 billion; provide \$454 million in budget authority for the Agency for Healthcare Research and Quality (AHRQ); \$4 billion to the Centers for Medicare & Medicaid Services (CMS) for program management; \$8.445 billion to the Centers for Disease Control and Prevention (CDC); and at least \$5.2 billion to the Substance Abuse & Mental Health Services Administration (SAMHSA).

We will highlight the following HRSA programs which are priorities for the AAFP:

Title VII, § 747 Primary Care Training & Enhancement—\$59 Million

The AAFP is grateful to the Committee for increasing by \$10 million in fiscal year 2018 the appropriation for the Primary Care Training & Enhancement (PCTE) program authorized by Title VII, of the Public Health Service Act of 1963 and administered by HRSA. PCTE grants were found to be "a crucial, but often overlooked, factor in facilitating scholarly activity in departments of family medicine" in a study

³ Changing the Trajectory of Alzheimer's Disease: How a Treatment by 2025 Saves Lives and Dollars: http://www.alz.org/documents_custom/trajectory.pdf.

published in *Family Medicine* [<http://www.stfm.org/FamilyMedicine/Vol48Issue6/Morley452>]. These grants are essential to meeting the increased demand for family physicians and other primary care physicians. The AAFP urges the Committee to increase the appropriation to \$59 million in fiscal year 2019.

National Health Service Corps—\$330 Million

The National Health Service Corps (NHSC), administered by HRSA, plays a vital role in addressing the challenge of regional health disparities arising from physician workforce shortages by offering financial assistance to recruit and retain primary care physicians and other healthcare clinicians to meet the workforce needs of communities designated as health professional shortage areas. The Bipartisan Budget Act (PL 115–123) extended the trust fund for the NHSC of \$310 million in fiscal year 2019. We commend the Committee for providing the NHSC with an additional discretionary appropriation of \$105 million in fiscal year 2018 to expand substance use disorder (SUD) treatment and support the Rural Communities Opioid Response initiative. The AAFP is committed to supporting the objectives of the NHSC in assisting communities in need of family physicians for their comprehensive primary care including appropriate SUD treatment, and we ask that the Committee support a program level, either appropriated or mandatory funding, of at least \$330 million for the NHSC.

Office of Rural Health Policy—\$175.3 Million

The programs administered by HRSA's Office of Rural Health Policy work to reduce the unique obstacles faced by physicians and patients in rural areas. Data from the U.S. Census Bureau's American Community Survey shows that 19.3 percent of the population (about 60 million people) lives in rural areas. Access to high quality healthcare services for rural Americans continues to be dependent upon an adequate supply of rural family physicians who perform about 42 percent of the visits that Americans in rural areas make to their physicians each year. The AAFP strongly supports an increased investment in the Office of Rural Health Policy. We ask that the Committee provide at least \$175.3 million for the Office of Rural Health Policy to support Rural Outreach Network Grants, Rural Health Research, State Offices of Rural Health, Rural Opioid Reversal Grants, Rural Hospital Flexibility Grants, and Telehealth.

Title X—\$286.5 Million

The AAFP supports continued funding for the Title X Federal grant program dedicated to providing women and men with comprehensive family planning and related preventive health services. The AAFP strongly recommends adequate funding to support Title X clinics which offer necessary screening for sexually transmissible infections, cancer screenings, HIV testing, and contraceptive care of \$286.5 million in fiscal year 2019.

Agency for Healthcare Research and Quality—\$454 Million

The Agency for Healthcare Research and Quality (AHRQ) has released early findings from EvidenceNOW, a multimillion dollar initiative to help primary care practices across the country more rapidly improve the heart health of Americans. This \$112 million grant-funded initiative is the largest primary care research investment in the agency's history. The *Annals of Family Medicine* [http://www.annfam.org/content/16/Suppl_1] April 2018 supplement published original research articles, an overview and rationale from AHRQ, and commentaries from nationally recognized experts. EvidenceNOW is aligned with the HHS Million Hearts® initiative and is aimed at reducing the research-to-practice delay in implementing best practices to deliver the ABCS of cardiovascular disease prevention: aspirin in high-risk individuals, blood pressure control, cholesterol management, and smoking cessation. The multi-State EvidenceNOW initiative engaged 1,500 small- to medium-sized primary care practices and nearly 8 million patients. AHRQ also convenes the U.S. Preventive Services Task Force which is vital in primary care in making evidence-based recommendations after a rigorous examination of peer-reviewed data. The AAFP urges budget authority of no less than \$454 million for AHRQ.

Centers for Medicare & Medicaid Services Program Management—\$3.7 Billion

CMS plays a crucial role in the healthcare of over 125 million Americans enrolled in Medicare, Medicaid, and in the Children's Health Insurance Program and also regulates private insurance coverage in the Marketplace. The AAFP recognizes the need for CMS to have adequate resources to manage these programs at a time when the agency continues to implement MACRA which prompted the ongoing transformation of the Medicare program to a system based on quality and healthy outcomes. The AAFP recommends that the Committee provide CMS with at least \$3.7

billion for program management to allow the agency to manage the complex implementation of MACRA.

Centers for Disease Control and Prevention—\$8.445 Billion

Family physicians are dedicated to treating the whole person to integrate the care of patients of all genders and every age. In addition to diagnosing and treating illness, they provide preventive care, including routine checkups, health risk assessments, immunization and screening tests, and personalized counseling on maintaining a healthy lifestyle. CDC Chronic Disease Prevention and Health Promotion funding helps with efforts to prevent and control chronic diseases and associated risk factors and reduce health disparities. We ask that the Committee provides at least \$1.17 billion for CDC Chronic Disease Prevention and Health Promotion.

The CDC also plays a pivotal role in increasing rates of immunization. Vaccines have proven to be a public health success by reducing the incidence of infectious disease and nearly eliminating many deadly threats. Recent outbreaks point to the need to remain vigilant regarding our Nation's infectious disease efforts. The AAFP supports programs, such as the CDC's National Center for Immunization and Respiratory Diseases (IRD) 317 immunization program, which provides surveillance, prevention, and outbreak support. We request at least \$798.4 million for CDC's IRD line.

The AAFP appreciates that the Committee clarified the CDC's authority to conduct research on the causes of gun violence, and we recommend that you provide the CDC with \$50 million in fiscal year 2019 to conduct public health research into firearm morbidity and mortality prevention.

Substance Abuse & Mental Health Services Administration—\$5.2 Billion

The AAFP is committed to addressing opioid misuse at both the national and grassroots levels and supports SAMHSA's mission to reduce the impact of substance abuse and mental illness on America's communities. Family physicians continue working to destigmatize medication-assisted treatment and supporting State and national partnerships to improve the functionality, utility, and interoperability of prescription drug monitoring programs (PDMP).

PROPOSED RESCISSIONS TO FISCAL YEAR 2018 APPROPRIATIONS

Last March, the AAFP commended the passage of the Consolidated Appropriations Act, 2018 (PL 115–141) which maintained the strength of the healthcare system's infrastructure by making an important investment of \$88 billion, an \$10 billion increase over fiscal year 2017, for the Department of Health and Human Services. However, we were deeply disappointed that the Administration proposed to rescind \$7 billion from the Children's Health Insurance Program (CHIP), \$800 million from the Center for Medicare and Medicaid Innovation (CMMI), and \$220 million from HHS departmental management.

CHIP is vital access to healthcare coverage for nearly 9 million children. Since its creation in 1997, CHIP has allowed States to expand health coverage voluntarily to children in families with incomes too high to qualify for traditional Medicaid but too low to afford private health insurance. Recently, the Congress allowed CHIP funding to lapse forcing States to request millions in emergency funding to keep children covered.

CMMI is uniquely charged with developing and piloting healthcare payment reforms to advance patient-centric care delivery to improve quality and lower costs for individuals and payers, which include the Federal Government. The AAFP believes a healthcare system built on a foundation of comprehensive and continuous primary care is best positioned to achieve these important goals. The work of CMMI is critical to moving toward Advanced Alternative Payment Models, as envisioned under the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA, PL 114–10), to test and prove the value of the Advanced Primary Care Alternative Payment Model (APC–APM).

The AAFP designed the APC–APM to improve patient choice, expand primary care physicians' access to APMs—including small, independent, and rural practices. The AAFP has submitted the APC–APM for consideration by the Physician-Focused Payment Model Technical Advisory Committee established by Congress in MACRA.

The model builds on the existing Comprehensive Primary Care (CPC) classic and CPC+ programs, moves further away from fee-for-service (FFS), better supports small and independent practices, and reduces administrative burdens.

We urge Congress to reject the Administration's proposed HHS rescissions which threaten the good and important work of the Department.

In conclusion, the AAFP thanks the Committee for its support for these key investments. They will make our country stronger by supporting our primary care workforce and public health system.

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

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF PEDIATRICS

The American Academy of Pediatrics (AAP), a non-profit professional organization of 66,000 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 2019 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: \$3 million for Reducing Underage Drinking Through Screening and Brief Intervention, \$10 million for Pediatric Mental Health Care Access Grants, \$5 million for Screening for Maternal Depression, \$24.506 million for Emergency Medical Services for Children, \$150.56 million for National Center for Birth Defects and Developmental Disabilities, \$35 million for Lead Poisoning Prevention, \$50 million for Gun Violence Prevention Research, \$120 million for Child Abuse Prevention and Treatment Act State Grants, \$226 million for Global Immunization including Polio and Measles/Other, and \$208.2 million for Global Public Health Protection including Global Health Security.

Adolescent Substance Use Screening and Brief Intervention (SAMHSA)

Adolescent substance use, including opioid use and underage drinking poses the risk of immediate, devastating consequences and the potential for long-term negative effects. New research clearly makes the case that the developing brains of adolescents make them particularly vulnerable to addiction. Opioid and alcohol use among adolescents is associated with violence, decreased academic performance, and risky sexual behaviors. Screening, brief intervention, and referral to treatment (SBIRT) specifically developed for the pediatric population has been shown to delay or reduce alcohol involvement in this population, and multiple agencies have recommended that SBIRT be a part of routine healthcare screening. This program provides grants to train pediatric providers to use screening and brief intervention to reduce underage drinking.

Fiscal Year 2019 Request: \$3 Million.

Pediatric Mental Health Care Access Grants (HRSA)

The AAP appreciates the \$10 million in the fiscal year 2018 omnibus and urges Congress to maintain funding at \$10 million in fiscal year 2019 for the Pediatric Mental Health Care Access Grants established in the 21st Century Cures Act. This grant program supports the development of new statewide or regional pediatric mental healthcare telehealth access programs, as well as the improvement of already existing programs. Research shows pervasive shortages of child and adolescent mental/behavioral health specialists throughout the U.S. Integrating mental health and primary care has been shown to substantially expand access to mental healthcare, improve health and functional outcomes, increase satisfaction with care, and achieve costs savings. For children, integrating mental telehealthcare into primary care settings simply makes sense, as it is a setting where families regularly obtain care for their children.

Fiscal Year 2019 Request: \$10 Million; Fiscal Year 2018 Level: \$10 Million.

Screening for Maternal Depression (HRSA)

The AAP thanks the committee for providing \$5 million in funding in fiscal year 2018 for the Screening and Treatment for Maternal Depression grant program authorized in the 21st Century Cures Act. These grants will serve to establish, improve, or maintain programs that increase screening, assessment, and treatment services for maternal depression for women who are pregnant or have given birth within the preceding 12 months. Maternal depression can lead to increased costs of medical care, inappropriate medical care, child abuse and neglect, discontinuation of breastfeeding, family dysfunction, and may adversely affect early brain development in children.

Fiscal Year 2019 Request: \$5 Million; Fiscal Year 2018 Level: \$5 Million.

Emergency Medical Services for Children (HRSA)

The AAP appreciates the \$2.172 million increase in funding for the Emergency Medical Services for Children (EMSC) Program in fiscal year 2018. Established by Congress in 1984 and last reauthorized in 2015 for 5 years, the EMSC Program is the only Federal program that focuses specifically on improving the pediatric components of the emergency medical services (EMS) system. EMSC aims to ensure that state of the art emergency medical care 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 children and adolescents no matter where they live, attend school, or travel. The EMSC program helps to address persistent gaps in providing quality care to children in emergencies, helps reduce pediatric mortalities due to serious injury, and supports rigorous multi-site clinical trials through the Pediatric Emergency Care Applied Research Network (PECARN).

Fiscal Year 2019 Request: \$24.506 Million; Fiscal Year 2018 Level: \$22.334 Million.

National Center for Birth Defects and Developmental Disabilities (CDC)

The AAP applauds the \$3 million increase in fiscal year 2018 for the National Center for Birth Defects and Developmental Disabilities (NCBDDD), a center within CDC that seeks to promote the health of babies, children, and adults and enhance the potential for full, productive living. According to the CDC, birth defects affect 1 in 33 babies and are a leading cause of infant death in the United States; the center has done tremendous work in the way of identifying the causes of birth defects and developmental disabilities, helping children to develop and reach their full potential. The center also 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. The Center is doing important work monitoring and tracking mothers and babies with confirmed exposure to the Zika virus and we believe this important work needs to be continued for the foreseeable future.

Fiscal Year 2019 Request: \$150.6 Million; Fiscal Year 2018 Level: \$140.56 Million.

Lead Poisoning Prevention Program (CDC)

The Academy appreciates the \$18 million increase for the Lead Poisoning Prevention Program, as there is no safe level of lead exposure in children. Lead damage can be permanent and irreversible, leading to increased likelihood for behavior problems, attention deficit and reading disabilities, and a host of other impairments to developing cardiovascular, immune, and endocrine systems. Today, approximately 500,000 children are exposed to unacceptably high levels of lead, and prevention efforts are critical to protect children from its harmful effects. The crisis in Flint, MI is a tragic inflection point in the ongoing issue of vulnerable communities facing lead exposure, with lifelong health effects. Adequate funding for prevention efforts can help screen more children, identify those in need of follow-up services, and help reduce the impact of lead on children.

Fiscal Year 2019 Request: \$35 Million; Fiscal Year 2018 Level: \$35 Million.

Gun Violence Prevention Research (CDC)

In 2016, there were over 38,000 U.S. firearm-related fatalities.¹ 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 dearth of research on how best to prevent morbidity and mortality from firearm-related injuries and deaths makes it difficult to implement a public health approach to addressing this public health problem. Without dedicated funding, CDC is unable to research solutions to prevent unintended firearm injuries and fatalities, firearm-related suicides, or the next school shooting. The request of \$50 million for fiscal year 2019 could support the creation of 10 to 20 new, large multi-year studies each year (or even

¹ https://www.cdc.gov/nchs/pressroom/sosmap/firearm_mortality/firearm.htm.

more single-year studies) and the rebuilding of a research community that has shrunk in the decades since the Dickey Amendment.

Fiscal Year 2019 Request: \$50 Million; Fiscal Year 2018 Level: N/A.

Child Abuse Prevention and Treatment Act (CAPTA) Title I State Grants (ACF)

CAPTA is the only Federal law dedicated to primary prevention of child abuse. This critical law is underfunded, and States need additional CAPTA resources to meet the needs of their communities. CAPTA also requires States to refer families to child welfare services if an infant is identified at birth as affected by prenatal substance exposure, withdrawal symptoms, or a Fetal Alcohol Spectrum Disorder. This provision was amended by the Comprehensive Addiction and Recovery Act of 2016, which expanded State reporting requirements but did not provide additional funds for development of plans of safe care. Implementation has had mixed results because of the lack of funding for these provisions. Plans of safe care follow the best evidence for treating maternal substance use, including early identification and screening, appropriate treatment, consistent hospital screening of mothers and their infants, consistent hospital notifications to the child welfare system, and information sharing and monitoring across systems. These expanded requirements represent a major opportunity to address the child health impact of the opioid epidemic.

Fiscal Year 2019 Request: \$120 Million; Fiscal Year 2018 Level: \$85.3 Million.

Global Immunization—Polio and Measles/Other (CDC)

Vaccines are one of the most cost-effective and successful public health solutions available, saving the lives of two to three million children each year. Vaccines are among the safest medical products 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, one of the top five diseases killing children, declined by 79 percent between 2000 and 2015 thanks to expanded immunization, saving an estimated 20.3 million lives. A global immunization campaign has reduced the number of polio cases by more than 99 percent since 1988. However, until the world is free of measles and polio, all children, even those in the United States, remain at risk. In 2014, the U.S. experienced 668 measles cases in 27 States, in part due to unvaccinated travelers importing the virus from parts of the world where it remains common. Only two countries had indigenous transmission of wild polio virus in 2017: Afghanistan and Pakistan. We must complete polio eradication or face a potential global resurgence, which could result in as many as 200,000 cases of polio annually within a decade.

Fiscal Year 2019 Request: \$226 Million Including \$176 Million for Polio and \$50 Million for Measles/Other; Fiscal Year 2018 Level: \$226 Million Including \$176 Million for Polio and \$50 Million for Measles/Other.

Global Public Health Protection, Including Global Health Security (CDC)

As pediatricians caring for America's children, we know that what happens in other countries has an impact on the health of children and families here at home, as well as on Americans living, traveling, and deployed overseas. U.S. programs help endemic countries build public health infrastructure and prepare for disease outbreaks before they reach the United States. For example, the CDC Global Disease Detection program has helped more than 55 countries respond to over 1,900 outbreaks and public health emergencies since 2006, including Ebola, Zika, and Pandemic Flu, and its emergency response centers have led to the detection of 12 previously unknown pathogens. We urge the Committee to strengthen its support for Global Health Security and to require agencies to continue to report on their progress, as directed in the fiscal year 2018 Omnibus.

Fiscal Year 2019 Request: \$208.2 Million; Fiscal Year 2018 Level: \$208.2 Million.

There are many ways Congress can help meet children's needs and protect their health and well-being. Adequate funding for children's health programs is one of them. The American Academy of Pediatrics looks forward to working with Members of Congress to prioritize the health of our Nation's children in fiscal year 2019 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 Colleen Kraft, MD, FAAP, President, American Academy of Pediatrics.]

PREPARED STATEMENT OF THE AMERICAN ALLIANCE OF MUSEUMS

Chairman Blunt, Ranking Member Murray, and members of the subcommittee, thank you for allowing me to submit this testimony. My name is Laura Lott and I serve as President and CEO of the American Alliance of Museums (AAM). I respectfully request that the subcommittee make a renewed investment in museums in fiscal year 2019. I urge you to provide the Office of Museum Services (OMS) within the Institute of Museum and Library Services (IMLS) with at least \$38.6 million, its most recent authorized level. I want to express gratitude for the \$34.7 million in funding for OMS in fiscal year 2018. This small program is a vital investment in protecting our Nation's cultural treasures, educating students and lifelong learners, and bolstering local economies around the country.

Representing more than 35,000 individual museum professionals and volunteers, institutions—including aquariums, art museums, botanic gardens, children's museums, cultural museums, historic sites, history museums, maritime museums, military museums, natural history museums, planetariums, presidential libraries, science and technology centers, and zoos—and corporate partners serving the museum field, the Alliance stands for the broad scope of the museum community.

Museums are economic engines and job creators: According to *Museums as Economic Engines: A National Report*, U.S. museums support more than 726,000 jobs and contribute \$50 billion to the U.S. economy per year. The economic activity of museums generates more than \$12 billion in tax revenue, one-third of it going to State and local governments. For example, the total financial impact that museums have on the economy in Missouri is \$852 million, including 13,653 jobs. For Washington it is a \$1.01 billion impact supporting 14,145 jobs. This impact is not limited to cities: more than 25 percent of museums are in rural areas.

Museums spend more than \$2 billion yearly on education activities; the typical museum devotes 75 percent of its education budget to K–12 students, and museums receive approximately 55 million visits each year from students in school groups. Children who visited a museum during kindergarten had higher achievement scores in reading, math and science in third grade than children who did not, including children most at risk for delays in achievement. Also, students who attended a half-day field trip to an art museum experienced an increase in critical thinking skills, historical empathy and tolerance. For students from rural or high-poverty regions, the increase was even more significant. Museums help teach the State and local curriculum in subjects ranging from art and science to history, civics, and government. Museums have long served as a vital resource to homeschool learners. For the approximately 1.8 million students who are homeschooled—a population that has increased by 60 percent in the past decade—museums are quite literally the classroom. It is not surprising that in a 2017 public opinion survey, 97 percent of respondents agreed that museums were educational assets in their communities. The results were statistically identical regardless of political persuasion or community size.

IMLS is the primary Federal agency that supports museums, and 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. The fiscal year 2018 appropriation of \$34.7 million, while a most welcome funding increase, still falls below its recent high of \$35.2 million in fiscal year 2010. We applaud the 40 bipartisan Senators who wrote to you in support of fiscal year 2019 OMS funding.

Here are just two examples of how IMLS funding was used in 2017 to support museums' work in your communities:

—*The Nelson-Atkins Museum of Art in Kansas City, Missouri*, received a \$384,532 Museums for America grant to research and implement a rich array of public offerings through the Deaf Culture Project, as well as to hire a Coordinator for the Deaf Culture Program. "One of the core principles of the Nelson-Atkins strategic plan is attracting all our constituents with focused and effective communications and outreach," said Julián Zugazagoitia, Menefee D. and Mary Louise Blackwell CEO & Director of the Nelson-Atkins in a recent press release. "Engaging our visitors who are Deaf or hard of hearing will deepen and broaden our mission, building relationships and expanding involvement."

The Nelson-Atkins will create a suite of interrelated activities designed to build engagement and learning among visitors who are Deaf, empowering them to participate in the museum's collections and programs. "We are excited to have the opportunity to collaborate with community stakeholders and partner organizations such as the Museum of Deaf History, Arts and Culture, The Whole Person, and the Kansas School for the Deaf," said Christine Boutros, Manager, Community & Access Programs. "This is a project that will not only increase access to

the collection for Deaf and hard of hearing populations in Kansas City, but will also build general audience understanding and appreciation for Deaf culture, American Sign Language, and the diversity of experiences and identities of people who are Deaf and hard of hearing.”

This program builds on a 2015 initiative, in which the Nelson-Atkins formed an Advisory Committee for Accessibility to work with people with disabilities. Other programs arising from this committee include Low Sensory Mornings and Relating to Art, and current tactile tours have been revamped. The Deaf Culture Project will be developed with Deaf and hard of hearing communities across greater Kansas City and will provide a model for museums around the country. Over the coming months, the museum will work to identify and understand what programs, approaches, and strategies would have the greatest and most positive impact. Focus groups will discuss opportunities, challenges, and benefits that will inform project planning and development.

—*The Children’s Museum of Tacoma, Washington*, received a \$499,994 Museums for America award to develop and pilot programs and fabricate exhibits for a satellite location on Joint Base Lewis-McChord. “Play is on Base” will strengthen the museum’s position as a community anchor by increasing its capacity to engage and serve the region’s military families. The museum and the military base will collaborate closely, engage additional community organizations, and work with the intended audience to create exhibits and programs tailored to meet the unique needs of military families, especially those whose children have special needs. Project activities also will include professional development for staff and volunteers to build the knowledge and strategies needed to work with the target audiences. An external evaluator will develop a comprehensive evaluation plan and related tools to ensure exhibits and programs are meeting organizational goals as well as audience needs. The project will contribute to the creation of a model for partnerships between children’s museums and military installations across the country.

In addition to these examples, I want to share with you an excerpt from the powerful live public witness testimony provided on April 26, 2018 to the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies by Dr. Michael A. Mares, Director of the Sam Noble Museum of Natural History at the University of Oklahoma:

“I am proud that my museum has benefitted from OMS grants: The museum was founded by the Territorial Legislature in 1899, 4 years after the last Land Run. The Legislature directed the museum to develop collections, interpret Oklahoma’s natural and cultural heritage, and bring the world to Oklahoma. The collections grew rapidly: dinosaurs, fossils, Native American artifacts, natural history specimens—a record of life over a billion years of time.

In 1981 the museum was struggling to survive, but there were people who believed that Oklahoma deserved better, including IMLS, which helped the museum with funding for personnel, collections, and programs over 4 decades. This support helped sustain the drive for a new museum that became a reality in 2000. In 2003, the museum was awarded the national award for conservation for saving the heritage of the State of Oklahoma.

With a recent award of \$123,132, the museum developed traveling Discovery Kits for students and teachers across cities and rural parts of Oklahoma. All curricula are aligned with educational standards and feature age-specialized K–12 content focusing on geologic, life and cultural sciences relevant to the State. The kits and curriculum feature museum teaching collections and specimens. Kits contain multimedia resources to engage students with local scientists including video of museum scientists in the field, scientific investigations and videos from inside the collections. In addition, all content has been digitized and made available to the public at no cost. Through this project, the museum addresses the lack of high-quality STEM curricula and natural history science available in Oklahoma. At the completion of the project, the museum will have produced a tested body of curricula relevant to Oklahoma’s K–12 teachers that will increase availability and accessibility of exceptional science resources for all students. Our programs are changing the lives of Oklahoma’s young people—children who would have had few opportunities to do something unique without the museum’s programs.

A recent OMS grant of \$128,863 allowed the museum to improve the stewardship and long-term preservation of its frozen tissue collection—a collection that was vulnerable to catastrophic loss in a disaster prone region. The project will facilitate the use of genetic resources in research and teaching worldwide, and

provide educational experiences for undergraduates, K–12 teachers and students through training and outreach.

Being recognized with an IMLS National Medal for Museum Service in 2014, the Nation’s highest honor for museums, has been a great honor for the Sam Noble Museum and for me as director. It has opened doors for the museum nationally and internationally. In 2015, the museum was inducted into the Club of Excellence by the European Heritage Association. And, in 2017, our Native American language program, which is saving Native languages, was selected as the outstanding international educational program by the University Museums and Collections association.”

IMLS grants to museums are highly competitive and decided through a rigorous peer-review process. Even the most ardent deficit hawks ought to view the IMLS grant-making process as a model for the Nation. It should be noted that each time a museum grant is awarded, additional local and private funds are also leveraged. In addition to the dollar-for-dollar match generally required of museums, grants often spur more giving by private foundations and individual donors. Two-thirds of Museums for America grantees report that their grant encouraged additional private funding. In fiscal year 2017, the OMS received 962 applications requesting nearly \$165 million, but current funding (\$31.7 in fiscal year 2017) has allowed the agency to fund only a small fraction of the highly-rated grant applications it receives.

Please consider this request in the context of the essential role that museums play in our Nation, as well as their immense economic and educational impact. In closing, I highlight 2017 national public opinion polling that shows that 95 percent of voters would approve of lawmakers who acted to support museums and 96 percent want Federal funding for museums to be maintained or increased. People love museums. 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 submitted by Laura L. Lott, President and CEO, American Alliance of Museums.]

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION FOR CANCER RESEARCH

The American Association for Cancer Research (AACR) is the world’s first and largest scientific organization focused on every aspect of high-quality, innovative cancer research. The mission of the AACR and its more than 40,000 members is to prevent and cure cancer through research, education, communication, collaboration, research funding and advocacy. The AACR calls on Congress to provide at least \$39.3 billion for the National Institutes of Health (NIH) in fiscal year 2019, including a commensurate increase for the National Cancer Institute (NCI). Furthermore, we encourage Congress to appropriate in full the \$400 million designated in fiscal year 2019 for the Beau Biden Cancer Moonshot through the 21st Century Cures Act. Keeping the NIH and the NCI on a path of sustained, robust, and predictable funding growth is the only way we will seize the unparalleled scientific opportunities in cancer research that lie before us, and the only way we will overcome the challenges we face in conquering this complex disease.

We thank the United States Congress for its longstanding, bipartisan support for the NIH and for its commitment to funding cancer research. We especially thank Senate Appropriations Subcommittee on Labor, Health and Human Services (HHS), and Education Chairman Roy Blunt and Ranking Member Patty Murray for their unwavering support for the NIH. Under their leadership for the past three fiscal years, the NIH budget has increased by a remarkable 23 percent. Because Congress has made medical research a national priority, Federal funding for this lifesaving work is increasing our ability to save and improve the lives and health of millions of Americans.

A Unique Moment for Cancer: Supporting the National Cancer “Moonshot” Initiative

We live in an extraordinary time of scientific opportunity in the field of cancer research. The AACR looks forward to continuing to work with Congress to accelerate progress against the more than 200 diseases we call cancer. To that end, the AACR continues to strongly support the Beau Biden Cancer Moonshot Initiative. With a bold goal to significantly speed progress against cancer, this initiative both supports and builds upon the strong, basic science foundation that has been established, and is helping to translate exciting scientific discoveries into improved therapies for cancer patients. Nowhere is this more evident than in genomics, immunoncology and precision medicine, areas in which cancer research has been leading the way for more than a decade. A continued commitment to the NIH and the NCI

is required to move this initiative forward, in addition to continued support for other cross-cutting NIH programs such as the All of Us Research Program.

Investments in Cancer Research are Saving and Improving Lives

Significant progress has been made against cancer because of decades of Federal investment in medical research and the dedicated work of researchers, physician-scientists, and patient advocates throughout the biomedical research ecosystem. Federal support has cultivated new and improved approaches to the prevention, detection, diagnosis, and treatment of cancer, and investments in basic research have enabled scientists to capitalize on our understanding of what causes and drives cancer. As is detailed in the AACR Cancer Progress Report 2017, support from the NIH and the NCI for basic, translational, and clinical research has led to decreases in the incidence of many cancers, cures for a number of these diseases, and higher quality and longer lives for many individuals whose cancers cannot yet be prevented or cured.

One of the most exciting recent breakthroughs in cancer research has been the ability to harness the power of a patient's own immune system to fight cancer, leading to the development of immunotherapies. The concept of immunotherapy as a means to target cancer cells is not new, but we now have achieved the ability to effectively translate decades of knowledge about the immune system into revolutionary advances in patient care. In 2017 alone, the FDA approved the first immunotherapy to treat liver cancer, as well as the first gene modification therapy that changes a patient's own T cells in the lab to make them more effective against cancer. NIH-funded research was integral to the development of these innovative new therapies.

Perhaps most illustrative of our progress is the fact that there are now an estimated 15.5 million cancer survivors living today in the United States, and this number is expected to grow to 20.3 million by the year 2026. These remarkable achievements would never have been possible without a national commitment to funding cancer research, screening, and treatment programs at the NCI, NIH, and other agencies. We can continue to make significant advances, but only if we redouble our efforts to ensure the Federal resources are there to continue, and increase, the pace of progress.

In addition to improving health and saving lives, cancer research and biomedical science also serves as one of our country's primary paths to innovation, global competitiveness, and economic growth. According to United for Medical Research, NIH funding directly and indirectly supported more than 402,000 jobs in 2017 alone, and generated more than \$68.8 billion in new economic activity.

Lastly, conquering cancer is important to the American public. In a poll of likely voters commissioned by the One Voice Against Cancer Coalition this year, 73 percent of respondents were supportive of Congress' decision to increase NIH funding by \$3 billion in fiscal year 2018, and 92 percent of those polled said it is extremely or very important for the Federal Government to support medical research to find cures for diseases like cancer.

Cancer Remains a Significant Public Health Challenge

Even in the face of the promise and progress highlighted above, cancer remains a formidable opponent. An estimated 1.7 million Americans will be diagnosed with cancer this year, and 1 in every 3 women and 1 in every 2 men will likely develop cancer in their lifetimes. It is also projected that more than 609,000 people will die this year in the U.S. from cancers. According to most recent NCI Report to the Nation, there are several cancers for which 5-year survival rates are still very low, including lung and bronchus cancer (18.6 percent), cancer of the liver and intrahepatic bile duct (17.7 percent) and pancreatic cancer (8.5 percent). Further, racial and ethnic minorities, as well as low-income, rural and elderly populations, continue to suffer disproportionately in cancer incidence, prevalence, and mortality. Because of the steady increase in cancer incidence rates, which is due in large part to our aging population, continuing and strengthening our Nation's commitment to cancer research and biomedical science is more critical now than ever. Increasing the Federal investment in cancer research and biomedical science will play a vital role in addressing the current challenges in cancer, while at the same time curbing the overall annual costs of this devastating disease. The cost of cancer care in the United States alone is projected to exceed \$157 billion in 2020, while the total economic cost including disability and lost productivity will be much greater.

Progress Against Cancer Requires a Sustained Commitment to Funding

Our Nation's ability to realize the exciting future that awaits us in cancer research depends on a continued, strong commitment by Congress to provide sustained, robust, and predictable funding increases for the NIH and the NCI. We have

reached a point of sustained progress, at which discoveries are being made at an ever-accelerating pace. These discoveries are saving lives and bringing enormous hope for cancer patients, even those with advanced disease. We must seize the opportunity to continue to invest in our Nation's medical research ecosystem by providing at least \$39.3 billion for the NIH in fiscal year 2019. This reflects an increase of at least \$2 billion for the NIH's base budget, in addition to funding designated under the 21st Century Cures Act in fiscal year 2019 for specific initiatives including the Beau Biden Cancer Moonshot. Fulfilling this request will ensure that we can continue to transform cancer care, spur innovation and economic growth, maintain our position as the global leader in science and medical research, and most importantly, bring hope to cancer patients and their loved ones everywhere. The AACR looks forward to working with you to ensure that researchers have the resources they need to continue to deliver hope to those who are confronting this dreaded disease.

[This statement was submitted by Margaret Foti, PhD, MD (hc), Chief Executive Officer, American Association for Cancer Research.]

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 2019, which include at least \$39.3 billion for the National Institutes of Health, including funds provided to the agency through the 21st Century Cures Act for targeted initiatives, and—within NIH—\$492 million for the National Institute of Dental and Craniofacial Research (NIDCR).

AADR is grateful to Congress for providing a substantial funding increase for federally-funded research, including for NIH and NIDCR, in fiscal year 2018. We recognize this increase was possible due to the generous new budget cap increases established within the Bipartisan Budget Act of 2018 passed earlier this year, and we greatly appreciate the work of members of Congress to enact that legislation and provide much-needed relief for non-defense programs. Over the years, the Federal research enterprise has seen losses in purchasing power due to inflationary losses, sequestration and budget cuts. Fortunately, by demonstrating the commitment to Federal research via the funding increases set forth in the fiscal 2018 omnibus, members of Congress are allowing members of the research community to begin to play catch up and build on the promise of their work.

NIDCR is the largest institution in the world dedicated exclusively to research to improve dental, oral and craniofacial health. The health of the mouth and surrounding craniofacial (skull and face) structures is central to a person's overall health and well-being. Left untreated, oral diseases and poor oral conditions make it difficult to eat, drink, swallow, smile, communicate and maintain proper nutrition. Scientists also have discovered important linkages between periodontal (gum) disease and heart disease, stroke, diabetes and pancreatic cancer. Investments in NIDCR funded research during the past half century have led to improvements in oral health for millions of Americans through its impact on areas such as community water fluoridation; the implementation of dental sealants to reduce cavities in children; and emerging opportunities to assess the efficacy of a human papilloma virus (HPV) vaccine for oral and pharyngeal cancers.

As a result of these investments, today over 210 million Americans are benefiting from community water fluoridation. Absent advances in oral health research in the fight against dental caries (tooth decay) and periodontal disease, there would be an additional 18.6 million Americans aged 45 or older who have lost all of their natural teeth. Perhaps most striking is that since the 1950s the total Federal investment in NIH-funded oral health research has saved the American public at least \$3 for every \$1 invested.

Despite these improvements, however, treating oral health conditions remains extremely costly—with the Nation spending \$124.4 billion on dental services in 2016. While tooth decay and gum disease are the most prevalent threats to oral health, complete tooth loss, oral cancer and craniofacial birth defects, such as cleft lip and palate, impose massive health and economic burdens on Americans.

Right now, NIDCR is funding research across a range of areas to continue improving Americans' oral and overall health. These include point-of-care diagnostics that use saliva to test for conditions and infections, such as HIV, HPV, substance abuse and oral cancer; e-cigarette studies to investigate the effects of aerosols from e-cigarette vapors on the oral microbiome, oral epithelia and wound healing; a diverse precision medicine portfolio that includes research on cancer, craniofacial develop-

mental disorders, and salivary diagnostics; research related to early detection, prevention and treatment of HPV-related oropharyngeal cancer; and much more.

From a patient perspective, the research at NIDCR has impacted millions of patients with a wide range of conditions that impede quality of life, are physically debilitating, and create a major financial and social burden. NIDCR conducts research on complex systemic diseases that have a major oral health component, including TMJ, ectodermal dysplasias and autoimmune disorders, such as Behcet's and Sjögren's Syndrome, as well as birth defects, such as cleft lip and cleft palate, which affect roughly 7,000 babies in the United States each year and are among the most common birth defects. Through its research into the basic science needed to better understand these diseases and conditions; the discovery of biomarkers for better diagnosis and clinical care; and the development of new and improved tools for management and treatment, NIDCR has provided hope for these patients and their families and is improving the outlook for future generations.

As we look toward the future, AADR asks Congress to build upon this foundation by continuing to provide sustained and adequate investments across the Federal research continuum. To do this effectively, Congress will need to work together to develop a long-term solution to our Nation's debt and deficit that does not rely on cuts to non-defense discretionary spending and, importantly, pass regular appropriations bills rather than to rely on the continuing resolutions that have become so commonplace in our Federal budget process. The increased dependence on these short-term spending measures not only undermines the budget process, but it also negatively affects Federal agencies and programs, including these Federal agencies' grant recipients.

There are a range of repercussions for Federal agencies and those who depend on them when continuing resolutions take effect. To begin, continuing resolutions affect Federal grants award funding. NIH, as one example, often issues non-competing research and research training grant awards "at a level below that indicated on the most recent Notice of Award (generally up to 90 percent of the previously committed level)." Additionally, according to a 2009 report on continuing resolutions from the Government Accountability Office, agencies reported that these short-term budget measures resulted in inefficiencies in their work. The inefficiencies cited included an inability to fill positions, the delay of contracts and increased workloads as a result of entering into new contracts or exercise contract options.

This trend—coupled with other macro budget issues, such as attempts to increase defense spending at the expense of non-defense discretionary spending—produces additional uncertainty in already uncertain times for Federal research spending. Our hope is that moving forward Congress will build on the unprecedented momentum generated in the fiscal year 2018 omnibus legislation and continue to provide NIH, NIDCR and other Federal research institutions with predictable and sustained funding.

Increasing the appropriation for NIDCR will improve the oral health of the Nation, reduce societal costs of dental care and enhance the scientific evidence base for the dental profession. Specifically, increased funding would enable NIDCR to expand its portfolio of work on immunotherapies for oral cancer; research on cleft lip and cleft palate; and address oral health disparities among the aging population.

In addition to the research being conducted at NIH, AADR urges you to fund the full continuum of Federal research—from discovery to delivery—that will allow us to maximize our investments. Our members urge you to provide \$20 million for the Centers for Disease Control and Prevention (CDC) Division of Oral Health, \$40.673 million for the Title VII Health Resources and Services Administration (HRSA) programs training the dental health workforce, \$454 million for the Agency for Healthcare Research and Quality (AHRQ), and \$175 million in budget authority for the National Center for Health Statistics (NCHS).

Thank you for the opportunity to submit this testimony. We stand ready to answer any questions you may have.

[This statement was submitted by Christopher H. Fox, DMD, DMSc, Chief Executive Officer, American Association for Dental Research.]

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF COLLEGES OF NURSING

As the national voice for academic nursing, the American Association of Colleges of Nursing (AACN) represents over 500,000 nursing students and more than 45,000 nurse faculty. On behalf of its 814 member schools across the country, AACN thanks the subcommittee for its leadership, which provided a strong investment in nursing education and research in the fiscal year 2018 Consolidated Appropriations Act [Public Law 115–141]. The association respectfully requests that the sub-

committee continue to invest in America's health in fiscal year 2019 by providing \$266 million for the Nursing Workforce Development programs (Title VIII of the Public Health Service Act [42 U.S.C. 296 et seq.]), administered by the Health Resources and Services Administration (HRSA), which include the following programs:

- Advanced Nursing Education (Sec. 811), which includes the Advanced Education Nursing Traineeships and Nurse Anesthetist Traineeships
- Nursing Workforce Diversity (Sec. 821)
- Nurse Education, Practice, Quality, and Retention (Sec. 831)
- NURSE Corps Loan Repayment and Scholarship Programs (Sec. 846)
- Nurse Faculty Loan Program (Sec. 846A)
- Comprehensive Geriatric Education Program (Sec. 855)

as well as \$170 million for the National Institute of Nursing Research (NINR), within the National Institutes of Health.¹

As the largest sector of the healthcare workforce, nurses provide care in a multitude of settings and collaborate with other professionals to improve health and wellness across the Nation. Registered Nurses (RNs) and Advanced Practice Registered Nurses (including Nurse Practitioners, Certified Registered Nurse Anesthetists, Certified Nurse-Midwives and Clinical Nurse Specialists) are critical to increasing access and reducing cost, particularly in rural and underserved areas.

The Demand for Care in Rural and Underserved Communities

As new models and fiscal constraints continue to complicate America's healthcare system, the need for accessible, high-quality, and affordable care intensifies. Quality of life for the individual and the family depends on access to primary care to ensure that basic and preventative services are met. However, rural and underserved communities face barriers to receiving the care that they need. HRSA's national data shows there are currently 7,226 Health Professional Shortage Areas that are designated as having a shortage of primary care providers. Additionally, there are 4,242 designated Medically Underserved Areas/Populations, which may include individuals and families who face economic, cultural, or linguistic barriers to healthcare.² A diverse and highly-educated nursing workforce is needed to match the Nation's cultural and economic trends and meet the demand for care in these high shortage areas.

The demand for care is amplified in these communities as the population continues to age. According to Pew Research Center, from January 1, 2011 to December 31, 2029, an estimated 10,000 baby boomers will turn 65 each day.³ This is of particular concern due to the rising rates of chronic illness associated with aging, including heart disease, stroke, cancer, diabetes, and arthritis. According to the Centers for Disease Control and Prevention (CDC), approximately half of all adults across the Nation (117 million individuals) have one or more chronic health conditions, and one in four adults have two or more.⁴ Moreover, rural and underserved populations are hit just as hard when dealing with public health crises like the opioid epidemic. The CDC states that the rate of drug overdose deaths in rural areas is higher than in urban areas. From 1999 to 2015, death rates due to opioid overdose in rural populations quadrupled among those 18–25 years old and tripled for females.⁵

¹For fiscal year 2019, the Ad Hoc Group for Medical Research, of which AACN is a member, requests at least \$39.3 billion for the NIH, including funds provided to the agency through the 21st Century Cures Act for targeted initiatives. The request level of \$170 million for NINR denotes the same percentage increase for NIH applied to NINR. The request of \$266 million for Title VIII and \$170 million for NINR is supported by 56 organizations within the Nursing Community Coalition.

²U.S. Department of Health and Human Services, Health Resources and Services Administration. (2018) HRSA Data Warehouse Shortage Areas. Retrieved from <https://datawarehouse.hrsa.gov/topics/shortageAreas.aspx>.

³Pew Research Center. (2010). Baby Boomers Retire. <http://www.pewresearch.org/fact-tank/2010/12/29/baby-boomers-retire>.

⁴U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. (2016). Chronic Diseases: The Leading Causes of Death and Disability in the United States. Retrieved from <https://www.cdc.gov/chronicdisease/overview/>.

⁵U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. (2017). Rural America in Crisis: The Changing Opioid Overdose Epidemic. Retrieved from <https://blogs.cdc.gov/publichealthmatters/2017/11/opioids/>.

Preparing a Workforce for Today and Tomorrow's Healthcare Needs

With over four million licensed RNs,⁶ the profession is poised to serve in rural and underserved communities and be on the frontlines of public, population, and personalized health. However, while the demand for nurses varies by State, the national need for RNs is projected to increase 28 percent by 2030. By that time, seven States (Alaska, California, Georgia, New Jersey, South Carolina, South Dakota, and Texas) are expected to have a nursing deficit, four of which will have a deficit of over 10,000 nurses.⁷ Adding complexity to the shortage is the fact that nursing schools across the country are struggling to meet the rising demand to educate all qualified applicants interested in the profession.⁸ This is why AACN members rely so heavily on the support of both the Title VIII programs and the NINR grants to bolster a robust nursing workforce able to implement new science that will impact positive health outcomes now and in the future.

The Title VIII Nursing Workforce Development Programs

For the nursing profession, the Title VIII programs have been effective in meeting their goals of workforce development, recruitment, retention, and faculty preparation. The programs help to ensure nurses are practicing in the most rural and underserved communities where care is in high demand. For example, the Title VIII Advanced Nursing Education (ANE) program supports graduate nursing education and practice by funding academic-practice partnerships between academic institutions and rural and/or underserved primary care practice sites. In Academic Year 2015–16, the grant supported 10,238 students and partnered grantees with 2,596 clinical training sites, of which 51 percent were in primary care settings.¹¹

Moreover, the Title VIII programs also help to grow a diverse workforce that helps to address health inequities. Significant ethnic and racial disparities in healthcare are the result of cultural differences, little to no access to healthcare, and high rates of poverty and unemployment. Research shows that health professionals from underrepresented populations are more likely to serve in underrepresented and medically underserved areas.⁹ The Title VIII Nursing Workforce Diversity program is critical in this effort. In Academic Year 2015–16 alone, the program's grantees provided 9,243 clinical training experiences to students, with approximately half of the training sites in underserved or primary care settings.¹⁰ The compilation of the Title VIII programs are the right programs at the right time to meet the care demands of the Nation.

The National Institute of Nursing Research

The healthcare community continues to investigate methods to improve the delivery of high-quality care in a financially sustainable manner. As one of the 27 Institutes and Centers at the NIH, the NINR is dedicated to providing the evidence base to support nursing practice and, in many cases, the care of the interprofessional team. Research conducted at NINR plays an indispensable role in improving the quality of life for those with chronic illness, and preventing illnesses that threaten to exacerbate an already over-burdened healthcare system. Additionally, NINR allocates a generous amount of its overall budget to the education of nurse researchers,¹¹ many of whom dually serve as nurse faculty within our Nation's nursing schools.

One example of innovative NINR-funded research focuses on improving health outcomes for older adults, 80 percent of whom live with at least one chronic condi-

⁶National Council of State Boards of Nursing. (2018). A Profile of Nursing Licensure in the U.S. Retrieved from <https://www.ncsbn.org/6161.htm>.

⁷U.S. Department of Health and Human Services, Health Resources and Services Administration. Supply and Demand Projections of the Nursing Workforce: 2014–2030. Retrieved from https://bhwh.hrsa.gov/sites/default/files/bhwh/nchwa/projections/NCHWA_HRSA_Nursing_Report.pdf?utm_campaign=enews08172017&utm_medium=email&utm_source=govdelivery.

⁸American Association of Colleges of Nursing. (2017). Nursing Shortage Fact Sheet as of May 18, 2017. Retrieved from <http://www.aacnnursing.org/Portals/42/News/Factsheets/Nursing-Shortage-Factsheet-2017.pdf>.

⁹The Sullivan Commission. (2004). Missing persons: Minorities in the health professions. A report of the Sullivan Committee on diversity in the healthcare workforce. Retrieved from <http://www.aacnnursing.org/Portals/42/Diversity/SullivanReport.pdf>.

¹⁰U.S. Department of Health and Human Services, Health Resources and Services Administration. (2018). Justification of estimates for appropriations committees. Retrieved from <https://www.hrsa.gov/sites/default/files/hrsa/about/budget/budget-justification-2018.pdf>.

¹¹National 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.

tion.¹² Nursing scientist Marilyn Rantz, PhD, RN, FAAN, and her team at the University of Missouri developed an intelligent sensor system that detects health-related symptoms of older adults and alerts healthcare providers of potential health issues. By providing early coordinated care of chronic illnesses, older adults can better maintain their health at home and in their community. Furthermore, the prospective cost savings of this research is evident, as early detection would delay the transition of older adults into nursing homes and reduce spending on hospital stays.

Strong investments in the nursing workforce and research that translates science into practice ensures that the next generation of nurses will be prepared for what our patients need most: accessible, high-quality, cost-effective care. AACN respectfully requests continued support of the Title VIII Nursing Workforce Development Programs and the National Institute of Nursing Research to improve America's health.

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF COLLEGES OF
OSTEOPATHIC MEDICINE

The American Association of Colleges of Osteopathic Medicine (AACOM) represents the 34 accredited colleges of osteopathic medicine in the United States. These colleges are accredited to deliver instruction at 51 teaching locations in 32 states. Six of the colleges are publicly controlled, and 28 are private institutions. In the current academic year, these colleges are educating nearly 29,000 future physicians—more than 20 percent of all U.S. medical students.

AACOM strongly supports restoring funding for discretionary Health Resources and Services Administration (HRSA) programs to \$8.56 billion; funding for key priorities in HRSA's Title VII programs under the Public Health Service Act, including adequate funding for the Centers for Excellence (COE), Health Careers Opportunity Program (HCOP), Scholarships for Disadvantaged Students (SDS) Program, Geriatrics Education Centers (GECs); \$40 million for the Area Health Education Centers (AHECs) Program; \$59 million for the Primary Care Training and Enhancement (PCTE) Program; \$4 million for the Rural Physician Training Grants; long-term sustainable funding for the Teaching Health Center Graduate Medical Education (THCGME) Program; at least \$330 million in funding for the National Health Service Corps (NHSC), either appropriated or mandatory funding; a minimum of \$39.3 billion for the National Institutes of Health (NIH), including funds provided to the agency through the 21st Century Cures Act for targeted initiatives; and \$454 million in base discretionary funding for the Agency for Healthcare Research and Quality (AHRQ).

The Title VII health professions education programs, authorized under the Public Health Service Act and administered through HRSA, support the training and education of health practitioners to enhance the supply, diversity, and distribution of the healthcare workforce, acting as an essential part of the healthcare safety net and filling the gaps in the supply of health professionals not met by traditional market forces. Title VII programs are the only Federal programs designed to train primary care professionals in interdisciplinary settings to meet the needs of medically underserved populations, as well as increase minority representation in the healthcare workforce. AACOM supports total funding of \$690 million for Title VII and Title VIII programs.

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

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

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

¹²National Institutes of Health, National Institute of Nursing Research (2014). Because of Nursing Research: Supporting Technologies for Healthy Independent Living. Retrieved from <https://www.ninr.nih.gov/newsandinformation/because-of-nursing-research-eldertech#—edn1>.

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

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

The AHEC Program provides funding for interdisciplinary, community-based, primary care training programs. Through a collaboration of medical schools and academic centers, a network of community-based leaders works to improve the distribution, diversity, supply, and quality of health personnel, particularly primary care personnel in the healthcare services delivery system, specifically in rural and underserved areas. AACOM supports a request of \$40 million for the AHEC Program and strongly opposes any effort to eliminate this critical program.

The PCTE Program provides funding to support awards to primary care professionals through grants to hospitals, medical schools, and other entities. AACOM supports a request of \$59 million for this important program.

The Rural Physician Training Grants will help rural-focused training programs recruit and graduate students most likely to practice medicine in underserved rural communities. Health professions workforce shortages are exacerbated in rural areas, where communities struggle to attract and maintain well-trained providers. According to HRSA, approximately 59 percent of primary care health professional shortage areas are rural. AACOM supports the inclusion of \$4 million for the Rural Physician Training Grants.

AACOM continues to strongly support the long-term sustainment of the THCGME Program, which provides funding to support primary care medical and dental residents training in community-based settings. The majority of currently-funded medical residency programs are osteopathic or dually-accredited (DO/MD). Currently, there are more than 730 residents being trained in 57 HRSA-supported THC residencies in 24 States. According to HRSA, physicians who train in teaching health centers (THCs) are three times more likely to work in such centers and more than twice as likely to work in underserved areas. The continuation of this program is critical to addressing primary care physician workforce shortages and delivering healthcare services to underserved communities most in need. AACOM is pleased that Congress supported this highly successful bipartisan program by extending it for fiscal years 2018 and fiscal year 2019 through the Bipartisan Budget Act of 2018 (PL: 115–123). However, stable funding is necessary for the THCGME Program to continue to expand and increase the number of physicians that work in communities of need. AACOM strongly supports the continuation of and permanent funding for the THCGME Program and will continue to work with Congress to support a sustainable and viable funding mechanism for the continuation beyond fiscal year 2019. Furthermore, we strongly support the program's funding continue as mandatory funding beyond fiscal year 2019.

The NHSC supports physicians and other health professionals who practice in health professional shortage areas across the U.S. The NHSC projects that a field strength of more than 15,000 primary care clinicians will be in health professional shortage areas in fiscal year 2018. While we were pleased to see a 2-year extension of this program per the Bipartisan Budget Act of 2018 (PL: 115–123), stable funding is necessary for the continuation of this critically effective program. Therefore, AACOM supports the stability of the NHSC by requesting either appropriated or mandatory funding, of at least \$330 million for the NHSC.

Research funded by the NIH leads to important medical discoveries regarding the causes, treatments, and cures for common and rare diseases, as well as disease prevention. These efforts improve our Nation's health and save lives. To maintain a robust research agenda, further investment will be needed. AACOM supports a funding level of at least \$39.3 billion for the NIH, including funds provided to the agency through the 21st Century Cures Act for targeted initiatives.

AHRQ plays an important role in producing the evidence base research needed to improve our Nation's health and healthcare. The incremental increases for AHRQ's Patient Centered Health Research Program in recent years will help AHRQ generate more of this research and expand the infrastructure needed to increase capacity to produce this evidence; however, more investment is needed. AACOM recommends \$454 million in base discretionary funding for AHRQ, consistent with fiscal year 2010 levels. This investment will preserve AHRQ's current programs while helping to restore its critical healthcare safety, quality, and efficiency initiatives. Additionally, AACOM opposes the consolidation of AHRQ into the NIH.

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

[This statement was submitted by Stephen C. Shannon, DO, MPH, 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 society of research scientists and physicians who study the immune system, respectfully submits this testimony regarding fiscal year 2019 appropriations for the National Institutes of Health (NIH). AAI recommends an appropriation for NIH of at least \$39.3 billion for fiscal year 2019 to enable NIH to fund critically important new and ongoing biomedical research, support the next generation of biomedical researchers, and ensure continued robust investment in this national priority area. As a result of generous support from this subcommittee and Congress in recent years, NIH has continued to make great strides in advancing urgently needed medical research, supporting talented scientists and trainees who want to pursue research careers in the United States, and providing hope to all who are afflicted by illness or disability.

WHY THE IMMUNE SYSTEM MATTERS—AND WHY IMMUNOLOGISTS ARE ESSENTIAL

The immune system is the body's primary defense against viruses, bacteria, parasites, toxins, and carcinogens. When it performs optimally, it can protect its host from a wide range of infectious diseases, including influenza virus, and from chronic illnesses, such as cancer. But the immune system can underperform, leaving the body vulnerable to disease, such as the common cold, measles, pneumonia, and AIDS; and it can "overperform," attacking normal organs and tissues and causing autoimmune diseases/conditions such as allergy, asthma, inflammatory bowel disease, lupus, multiple sclerosis, rheumatoid arthritis, and type 1 diabetes. Immunologists study how the immune system works, including ways it can be harnessed to help prevent, treat, or cure disease; and how it can be used to protect people and animals from infectious organisms (including antibiotic resistant bacteria) and other bacteria (like anthrax and plague) and viruses (like smallpox and Ebola) that could also be used as bioweapons.

RECENT IMMUNOLOGICAL DISCOVERIES AND THEIR IMPACT ON PREVENTING AND FIGHTING DISEASE

Cancer immunotherapy—Cancer immunotherapy, which harnesses the immune system to fight tumors, is revolutionizing cancer treatment. Because of NIH-funded research, several new immuno-therapeutic agents have recently been developed that offer great hope for cancer patients.¹ In 2017, the Food and Drug Administration (FDA) approved the Nation's first gene therapy, CAR-T (chimeric antigen receptor T cell) therapy, tisagenlecleucel (Kymriah™), for treatment of acute lymphoblastic leukemia.² In a key clinical trial, this highly effective therapy showed an overall remission rate of 83 percent. Subsequently, axicabtagene ciloleucel (Yescarta®) received FDA approval for the treatment of B cell lymphoma following a clinical trial that showed a complete remission rate of 51 percent.³ These therapies using engineered immune cells offer exciting new approaches to tailoring treatments to individuals (known as "precision medicine").

Another type of immunotherapy (checkpoint inhibitors), previously FDA-approved for the treatment of some solid tumors and blood cancers, was also recently approved for treatment of cancers with a specific genetic feature (biomarker). This recent approval of pembrolizumab (Keytruda®) is significant not only because of the responses that are being achieved (~40 percent complete or partial response), but also because this was the first FDA approval given to a therapy based on a bio-

¹Maude, S. L. et al. 2014. Chimeric antigen receptor T cells for sustained remissions in leukemia. *N. Engl. J. Med.* 371: 1507–1517; Zhong, X. S. et al. 2010. Chimeric antigen receptors combining 4-1BB and CD28 signaling domains augment PI3kinase/AKT/Bcl-XL activation and CD8+ T cell-mediated tumor eradication. *Mol. Ther.* 18:413–420.; Rosenberg, S. A. et al. 1988. Use of tumor-infiltrating lymphocytes and interleukin-2 in the immunotherapy of patients with metastatic melanoma. *N. Engl. J. Med.* 319: 1676–1680.

²<https://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm574058.htm>.

³<https://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm581216.htm>.

marker rather than on the tumor's original location in the body.⁴ Subsequently, nivolumab (Opdivo®) received approval for treatment of colorectal cancer with a specific biomarker.⁵ These advances directly result from NIH-funded research demonstrating the sensitivity of tumors harboring these genetic features to immunotherapy.⁶

Hepatitis B vaccine.—Hepatitis B is a viral disease of the liver that can become chronic and lead to cirrhosis, liver cancer, and death. An estimated 850,000–2.2 million people in the U.S. have chronic hepatitis B, resulting in approximately 1,800 deaths every year.⁷ There is no cure, and infections are on the rise. Over the past decade, however, NIH has provided more than \$17 million toward the development of vaccine adjuvants (which enhance vaccine efficacy).⁸ In 2017, the FDA approved HEPLISAV-B, the first new vaccine for the hepatitis B virus (HBV) in 25 years.⁹ Because HEPLISAV-B requires only two doses over 1 month, in contrast to previously available vaccines, which require three doses over 6 months, this new vaccine may be a valuable tool in the effort to improve vaccination rates and therefore prevent infection with, and death from, HBV.

Artificial pancreas for type 1 diabetes.—Type 1 diabetes (T1D) is an autoimmune disease that affects over 1.25 million Americans, including 200,000 children.¹⁰ People with T1D are unable to produce insulin because their immune system has destroyed their insulin-producing (i.e., beta) cells, resulting in an uncontrolled rise in blood sugar levels. Complications from T1D include blindness, nerve damage, kidney failure, heart disease, and death. Because changes in diet or lifestyle alone will not treat the disease, diabetic patients must closely monitor their blood sugar levels to ensure that they are taking the needed dose of insulin.¹¹ Control of blood sugar levels is essential to preventing or delaying T1D complications. NIH-funded researchers from fields including immunology, endocrinology, bio-engineering, and computational biology have developed “closed-loop” artificial pancreas systems, which continuously monitor blood sugar and automatically administer the appropriate amount of insulin when needed; these systems have recently entered clinical trials, and if successful and approved by the FDA, will not only revolutionize T1D treatment, but also dramatically improve the quality of life of these patients.¹²

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

As the Nation's main funding agency for biomedical research, NIH distributes more than 80 percent of its budget through approximately 50,000 grants annually, supporting the work of more than 300,000 researchers at universities, medical schools, and other research institutions in all 50 States, the District of Columbia, and several U.S. territories.¹³ NIH also utilizes about 10 percent of its budget to support roughly 6,000 additional researchers and clinicians who work at NIH facilities in Maryland, Arizona, Massachusetts, Michigan, Montana, and North Carolina.¹⁴ NIH funding strengthens the economies of the States where its researchers live and work; in 2017, it supported more than 402,000 jobs across the U.S.¹⁵ NIH-funded research also propels the Nation's extraordinarily successful pharmaceutical industry: according to NIH Director Francis Collins, M.D., Ph.D., a recent study shows that “NIH contributed to published research that was associated with every single one of the 210 new drugs approved by the [FDA] from 2010 through 2016 [and that] [m]ore than 90 percent of that contributory research was basic—that is,

⁴ <https://www.fda.gov/Drugs/InformationOnDrugs/ApprovedDrugs/ucm560040.htm> [approval for two biomarkers: microsatellite instability high (MSI-H) and mismatch repair deficient (dMMR)].

⁵ <https://www.fda.gov/Drugs/InformationOnDrugs/ApprovedDrugs/ucm560040.htm> (approval for MSI-H and dMMR).

⁶ Le, D. T. et al. 2017. Mismatch repair deficiency predicts response of solid tumors to PD-1 blockade. *Science* 357: 409–413.

⁷ <https://www.cdc.gov/hepatitis/hbv/bfaq.htm>.

⁸ <http://investors.dynavax.com/releasedetail.cfm?releaseid=337232>.

⁹ <https://www.hhs.gov/hepatitis/blog/2017/11/29/fda-approves-new-hepatitis-b-vaccine>.

¹⁰ <http://www.jdrf.org/about/what-is-t1d/>.

¹¹ <https://www.cdc.gov/diabetes/basics/type1.html>.

¹² <https://www.nih.gov/news-events/news-releases/four-pivotal-nih-funded-artificial-pancreas-research-efforts-begin>.

¹³ <https://www.nih.gov/about-nih/what-we-do/budget>; <https://report.nih.gov/award/index.cfm>.

¹⁴ https://www.training.nih.gov/resources/intro_nih/other_locations.

¹⁵ http://www.unitedformedicalresearch.com/advocacy_reports/nih-role-in-sustaining-the-u-s-economy-2018-update/.

related to the discovery of fundamental biological mechanisms, rather than actual development of the drugs themselves.”¹⁶

NIH also provides invaluable scientific leadership both in the U.S. and abroad. The steward of more than \$37 billion in taxpayer dollars, NIH advises our Nation’s elected and appointed leaders on scientific advancements, needs, and threats, and works to ensure that its funds are properly and prudently spent. NIH not only governs the conduct of scientific research at academic institutions in the U.S., it also fosters collaborations between U.S.-based scientists and their invaluable international colleagues; and between government and the pharmaceutical, biotechnology and medical device industries, all of which benefit from NIH-supported research to fuel their own advances.¹⁷ These NIH leadership responsibilities, which include consultation with a broad and diverse stakeholder community, require a sufficient number of skilled personnel. Therefore, AAI urges that NIH be permitted to hire the scientific and administrative personnel needed to ensure the success of what is unquestionably an enormous and complicated enterprise.

RECENT FUNDING INCREASES HAVE EASED, BUT NOT ELIMINATED, THE EROSION OF NIH PURCHASING POWER

Strong, decisive action by this subcommittee and the full Congress has resulted in substantial funding increases for NIH over the last several years. With generous, needed increases of \$3 billion in fiscal year 2018 and \$2 billion each in fiscal year 2016 and fiscal year 2017 (including supplemental funding to support initiatives authorized by the 21st Century Cures Act and increased funding to support the development of a universal influenza vaccine), Congress has helped restore some of the purchasing power that NIH lost from years of insufficient budgets that were further eroded by biomedical research inflation; this gap, which once reached ~25 percent, has been reduced to ~11 percent. Continued efforts to close this gap, and to grow the research enterprise, are needed if we are to ensure a robust research environment that will both facilitate research on discoveries that might lead to new treatments or cures, and encourage promising young people to become the next generation of researchers, doctors, professors, and inventors. Predictable, ample funding increases for NIH, particularly through the timely passage of annual appropriations bills, would strengthen the Nation’s biomedical research enterprise and foster needed confidence within the scientific community.

CONCLUSION

AAI greatly appreciates this subcommittee’s longstanding leadership and strong bipartisan support for NIH and biomedical research through regular appropriations and supplementary funds to support 21st Century Cures Act initiatives. AAI urges the subcommittee to continue to strengthen NIH’s ability to support research that is critical to human health by appropriating at least \$39.3 billion for NIH for fiscal year 2019.

[This statement was submitted by Beth A. Garvy, Ph.D., American Association of Immunologists (AAI).]

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 fiscal year 2017 and fiscal year 2018, and for mandatory increases for the NIH as part of the 21st Century Cures Act and the Bipartisan Budget Act of 2018. These significant investments will help spur the development and implementation of medical innovations. To continue this important progress and ensure future medical research advancements in fiscal year 2019 and beyond, ACC urges members of Congress to appropriate the following funds toward agencies doing vital work in cardiovascular disease (CVD) treatment and prevention: \$39.3 billion for the NIH, with \$3.6 billion going toward the National Heart Lung & Blood Institute (NHLBI) and \$2.3 billion toward the National Institute of Neurological Disorders & Stroke (NINDS) to increase the NIH’s purchasing power and preserve U.S. leadership in research; \$160 million toward the CDC’s Division for Heart Disease and Stroke Prevention to strengthen heart disease prevention efforts at State and local levels, \$5 million toward CDC’s Million Hearts to prevent 1 million heart

¹⁶ <https://directorsblog.nih.gov/2018/02/27/basic-research-building-a-firm-foundation-for-bio-medicine/>.

¹⁷ http://conservativereform.com/wp-content/uploads/2016/09/CRN_MedicalResearch.pdf.

attacks and strokes by 2022, \$37 million toward CDC's WISEWOMAN to help uninsured or under-insured women prevent or control heart disease, \$7 million toward CDC congenital heart research to study its effects over the patient's lifespan, and \$216.5 million toward CDC's Office on Smoking and Health to maintain the program's cost-effective tobacco control efforts.

The ACC is the professional home for the entire cardiovascular care team. The mission of the College and its more than 52,000 members is to transform cardiovascular care and to improve heart health. The ACC leads in the formation of health policy, standards and guidelines. The College operates national registries to measure and improve care, offers cardiovascular accreditation to hospitals and institutions, provides professional medical education, disseminates cardiovascular research and bestows credentials upon cardiovascular specialists who meet stringent qualifications.

INCREASE FUNDING AT THE NATIONAL INSTITUTES OF HEALTH

Cardiovascular Disease (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 Despite reduced capacity to fund grants and new discoveries over the last decade, the NIH continues to enhance and save millions of lives. The heart disease death rate has continued to drop since the 1970s³ due to scientific advances and improved heart medications and procedures—but to meet the challenges of an aging population, rising obesity rates and unhealthy diets, the NIH must maintain its place at the forefront of medical innovation for years to come. Since many heart disease-related, life-saving interventions are a result of sustained commitment to investments in medical research, we recommend the NIH be funded at \$39.3 billion.

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 percent⁴ decrease in death rates due to cardiovascular disease. NHLBI's recent groundbreaking research found that more intensive management of high blood pressure in people 50 years and older reduces cardiovascular events by almost 25 percent.⁵ We recommend that NHLBI be funded at \$3.6 billion to maintain current activities and investment toward new research and emerging technologies related to heart disease.

NINDS conducts research on brain and nervous system disorders, including stroke prevention and treatment. Coronary heart disease and stroke share many of the same risk factors such as high cholesterol levels, high blood pressure, smoking, diabetes, physical inactivity, and being overweight or obese. The NINDS Stroke Clinical Trials Network develops high-quality, multi-site clinical trials focused on key interventions in stroke prevention, treatment and recovery. We recommend that NINDS be funded at \$2.3 billion to enhance its existing initiatives and explore new priorities in stroke prevention.

INCREASE FUNDING AT THE CENTERS FOR DISEASE CONTROL AND PREVENTION

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

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

²National 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.

³Heart Disease; National Institutes of Health Fact Sheets. <https://report.nih.gov/NIHfactsheets/ViewFactSheet.aspx?csid=96>.

^{4,5}HHS/NIH/NHLBI fiscal year 2017 Congressional Justification Report; https://www.nhlbi.nih.gov/sites/default/files/media/docs/Final%20NHLBI%202017%20CJ_R508_v1_0.pdf.

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

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

CDC's WISEWOMAN initiative provides more than 165,000 under-insured, low-income women ages 40–64 with services to help reduce heart disease and stroke risk factors. Heart disease ranks as the leading cause of death for women. Only 1 in 5 women⁶ believes heart disease is her greatest health threat, and 11 percent of women⁷ remain uninsured. We recommend that \$37 million be allocated for WISEWOMAN to provide preventive health services, referrals to local healthcare providers, lifestyle programs, and counseling.

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. We recommend that the CDC National Center for Birth Defects and Developmental Disabilities be funded at \$7 million for enhanced CHD surveillance and public health research.

Programs within CDC's Office on Smoking and Health (OSH) work to prevent smoking among young adults and eliminate tobacco-related health disparities in different population groups. In 2012, OSH launched the national tobacco education campaign, Tips from Former Smokers, which has motivated more than 5 million people to quit smoking, with at least 400,000 quitting permanently.^{8,9} 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 \$216.5 million to continue leading the nation's efforts in preventing chronic diseases caused by tobacco use.

CONCLUSION

On behalf of our 52,000 members who work to prevent and treat CVD, ACC would like to thank members of Congress for supporting medical innovation as we continue the fight against heart disease. Stable funding for research, surveillance, and healthy lifestyle promotion will not only save lives, but save healthcare costs in the long term. Medical research nurtures economic growth by creating jobs and new technologies, which will produce billions of dollars in Medicare and Medicaid savings over the next decade. Please help us secure robust NIH and CDC funding to protect the health of future generations.

[This statement was submitted by C. Michael Valentine, 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 58,000 physicians and partners dedicated to advancing women's health, is pleased to offer this statement to the Senate Committee on Appropriations, Subcommittee on Labor, Health and Human Services, Education, and Related Agencies. We thank Chairman Blunt, Ranking Member Murray, and the entire Subcommittee

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

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

^{8,9}Office on Smoking and Health; Centers for Disease Control and Prevention. <https://www.cdc.gov/tobacco/about/osh/>.

¹⁰At a Glance 2016 Tobacco Use; Centers for Disease Control and Prevention. <https://www.cdc.gov/chronicdisease/resources/publications/aag/pdf/2016/tobacco-aag.pdf>.

for this opportunity to provide comments on some of the most important programs to women's health.

ACOG commends Congress for passing the Consolidated Appropriations Act of 2018 (Public Law 115—141), which gives the Department of Health and Human Services (HHS) the budget relief provided by the Bipartisan Budget Act of 2018. It also provides much needed funding to combat the ongoing opioid crisis, which continues to plague communities across the country. Looking ahead, we urge you to make funding of the following programs and agencies a priority in fiscal year 2019:

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

The United States has the highest rate of maternal mortality and severe morbidity of any developed country. The Safe Motherhood Initiative at CDC works with State health departments to collect information on pregnancy-related deaths, give technical assistance to maternal mortality review committees, track preterm births, and improve maternal outcomes through Maternity and Perinatal Quality Collaboratives. Improvement to national data collection via State maternal mortality review committees is needed—only 33 States have maternal mortality review committees. ACOG requests you fund the Safe Motherhood Initiative at \$53 million, including \$7 million to help States expand or establish maternal mortality review committees.

Firearm Morbidity and Mortality Prevention (CDC):

In 2016, there were over 38,000 U.S. firearm-related fatalities. Federally funded public health research has a proven track record of reducing public health-related deaths, whether from motor vehicle crashes, smoking, or Sudden Infant Death Syndrome. This same approach should be applied to increasing gun safety and reducing firearm-related injuries and deaths, and CDC research will be as critical to that effort as it was to these previous public health achievements. The foundation of a public health approach is rigorous research that can accurately quantify and describe the facets of an issue and identify opportunities for reducing its related morbidity and mortality. For fiscal year 2019, ACOG requests \$50 million for CDC to conduct public health research into firearm morbidity and mortality prevention.

Data Collection and Surveillance at National Center for Health Statistics (NCHS):

Uniform, accurate, and comprehensive data is essential for addressing the rising rates of maternal mortality and severe maternal morbidity in the United States. NCHS is the Nation's principal health statistics agency and collects raw vital statistics from State records like birth and death certificates. This information provides key data about both mother and baby during pregnancy, labor, and delivery. ACOG requests funding to be used to support States in improving the quality and accuracy of vital statistics reporting. For fiscal year 2019, ACOG requests \$175 million for NCHS.

Biomedical, Social, and Behavioral Research at the National Institutes of Health (NIH):

Biomedical research is vital to understanding the causes maternal and infant mortality and morbidity and developing interventions to reduce these outcomes. The Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) has achieved great success in meeting the objectives of its biomedical, social, and behavioral research mission, including 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 their existing initiatives to produce new insights and solutions to benefit women and children. ACOG supports of \$39.2 billion for the National Institutes of Health (NIH) in fiscal year 2019, including a proportionate increase for NICHD. This amount would maintain a steady trajectory of \$2 billion annual increases for the NIH.

Title V Maternal and Child Health Block Grant at Health Resources and Services Administration (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, the Block Grant supports the Alliance for Innovation on Maternal Health (AIM)—a program that works with States and hospital systems to implement evidence-based toolkits, or bundles, to improve maternal outcomes and reduce rates of maternal mortality

and severe morbidity. For fiscal year 2019, ACOG requests \$880 million for the Block Grant to maintain its current level of services.

Title X Family Planning Program (HRSA):

Family planning and prepregnancy care are imperative to ensuring healthy women and healthy pregnancies. The Title X Family Planning Program provides essential services to over 4 million low income men and women who may not otherwise have access to these services. For many individuals, particularly those who are low-income, uninsured or adolescents, Title X is essential to their ability to affordably and confidentially obtain birth control, cancer screenings, STI tests and other basic care. Six in ten women seen at a Title X-supported healthcare center have reported that the center was their usual source of medical care, and in 2015 alone, the contraceptive services supported by Title X helped women avoid 822,000 unintended pregnancies. The Administration's recently-released proposed rule jeopardizes the success of the program, and we encourage Congress to call for its immediate withdrawal. ACOG requests \$327 million for Title X in fiscal year 2019 to sustain its level of services.

Advancing Maternal Therapeutics at the Department of Health and Human Services (HHS):

Each year, more than 4 million women give birth in the United States and more than 3 million breastfeed. However, little is known about the effects of most drugs on the woman and her child. ACOG strongly supports continued implementation of the Task Force on Research in Pregnant Women and Breastfeeding Women that passed as part of the 21st Century Cures Act (Sec. 2041 of Public Law 114–255). The Task Force will propel research in pregnancy and breastfeeding.

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

AHRQ is the Federal agency with the sole purpose of improving healthcare quality. AHRQ produces data with the mission of making healthcare safer, higher quality, more accessible, equitable, and affordable. AHRQ works with HHS and other partners to ensure that the evidence improves patient safety. ACOG supports \$454 million for AHRQ in fiscal year 2019, which is consistent with the fiscal year 2010 funding level for the agency adjusted for inflation.

Response to Zika Virus (HHS):

ACOG commends Congress for providing emergency supplemental funding in fiscal year 2017 to respond to the Zika virus. It is imperative that Congress sustain that investment in fiscal year 2019 and beyond to address the full span of activities necessary to track, treat, and ultimately prevent Zika infections, and improve our efforts to defend against future outbreaks. This includes a wide range of ongoing activities throughout HHS agencies, including vaccine research and development at NIAID; research into how the Zika virus affects mothers and babies exposed to the virus at NICHD; vector control, contraceptive access and counseling, diagnostic testing, public education, and birth defects surveillance at the CDC; and much more. ACOG urges you to prioritize protecting women of reproductive age, pregnant women, and infants from this deadly virus in fiscal year 2019.

Diagnosing and Treating Maternal Depression (HHS):

About 1 in 7 women experience maternal depression, and ACOG recommends that all women be screened. Yet women face barriers to accessing treatment. ACOG commends Congress for fully funding Sec. 10005 of Public Law 114–255 in the Consolidated Appropriations Act of 2018 to establish a program at HHS to expand depression screening and treatment for pregnant and postpartum women. ACOG urges you to again fully fund the program at \$5 million for fiscal year 2019, as authorized by Sec. 10005 of Public Law 114–255.

Addressing Opioid Use Disorder in Pregnancy at the Substance Abuse and Mental Health Services Administration (SAMHSA):

Opioid use disorder has risen dramatically in recent years. For pregnant and parenting women struggling with a substance use disorder, treatment that supports the family unit maintains maternal sobriety and child well-being. We commend Congress for reauthorizing the Pregnant and Postpartum Women (PPW) program funded through SAMHSA in Sec. 501 of Public Law 114–198, which provided flexibility for innovative pilot programs to address service gaps for pregnant and postpartum women, including access to out-patient treatment, and including a \$10 million increase for the program in the fiscal year 2018 omnibus. ACOG supports, at minimum, \$29.931 million to fund the PPW program for fiscal year 2019 to ensure

funds are available for innovative programs that may better serve women and their families.

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

[This statement was submitted by Rebecca Nathanson, Federal Affairs Manager, American College of Obstetricians and Gynecologists.]

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 2019. ACP is the largest medical specialty organization and the second-largest physician group in the United States. ACP members include 152,000 internal medicine physicians (internists), related subspecialists, and medical students. Internal medicine physicians are specialists who apply scientific knowledge and clinical expertise to the diagnosis, treatment, and compassionate care of adults across the spectrum from health to complex illness. As the Subcommittee begins deliberations on appropriations for fiscal year 2019, ACP is urging funding for the following proven programs to receive appropriations from the Subcommittee:

- Title VII, Section 747, Primary Care Training and Enhancement (PCTE), Health Resources and Services Administration (HRSA), \$71 million;
- National Health Service Corps (NHSC), \$415 million in total program funding;
- Agency for Healthcare Research and Quality (AHRQ), \$454 million;
- Centers for Medicare and Medicaid Services (CMS), Program Operations for Federal Exchanges, \$690 million;
- Expand Comprehensive Drug Addiction and Recovery Act (CARA) appropriations, \$1 billion and continue increased State Targeted Response to the Opioid Crisis (Opioid STR) grant program funding, \$1.5 billion;
- Centers for Disease Control and Prevention (CDC), Injury Prevention and Control, Research on Prevention of Firearms-related Injuries and Deaths, \$50 million;
- National Institutes of Health (NIH), \$39.3 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 14,800 to 49,300 primary care physicians by 2030. (IHS Inc., prepared for the Association of American Medical Colleges. 2018 Update, The Complexities of Physician Supply and Demand: Projections from 2016 to 2030. March, 2018. Accessed at: https://aamc-black.global.ssl.fastly.net/production/media/file_public/85/d7/85d7b689-f417-4ef0-97fb-ecc129836829/aamc_2018_workforce_projections_update_april_11_2018.pdf). Without critical funding for vital workforce programs, this physician shortage will only grow worse. The health professions' education programs, authorized under Title VII of the Public Health Service Act and administered through HRSA, support the training and education of healthcare providers to enhance the supply, diversity, and distribution of the healthcare workforce, filling the gaps in the supply of health professionals not met by traditional market forces, and are critical in helping institutions and programs respond to the current and emerging challenges of ensuring that all Americans have access to appropriate and timely health services. Within the Title VII program, we urge the Subcommittee to fund the Section 747 PCTE program at \$71 million, in order to maintain and expand the pipeline for individuals training in primary care. While the College appreciates the \$10 million increase to the program in fiscal year 2018, ACP urges more funding because the Section 747 PCTE program is the only source of Federal training dollars available for general internal medicine, general pediatrics, and family medicine. For example, general internists, who have long been at the frontline of patient care, have benefitted from PCTE training models emphasizing interdisciplinary training that have helped prepare them to work with other health professionals, such as physician assistants, patient educators, and psychologists.

The College urges at least \$415 million in total program funding for the NHSC. For the first time in many years, the NHSC received discretionary funding—\$105 million—in the fiscal year 2018 Omnibus Appropriations Act to expand and improve access to quality opioid and substance use disorder treatment in underserved areas in addition to \$310 million in mandatory funds for fiscal year 2018. The NHSC awards scholarships and loan repayment to healthcare professionals to help expand the country's primary care workforce and meet the healthcare needs of underserved

communities across the country. With a field strength of over 10,000 primary care clinicians, NHSC members are providing culturally competent care to over 10.7 million patients at over 16,000 NHSC-approved healthcare sites in urban, rural, and frontier areas. These funds would help maintain NHSC's field strength helping to address the health professionals' workforce shortage and growing maldistribution. The College was pleased that the NHSC received \$105 million in discretionary funding for fiscal year 2018 and urges that the NHSC should receive at least the fiscal year 2018 program level of funding for fiscal year 2019.

AHRQ is the leading public health service agency focused on healthcare quality. AHRQ's research provides the evidence-based information needed by consumers, clinicians, health plans, purchasers, and policymakers to make informed healthcare decisions. The College is dedicated to ensuring AHRQ's vital role in improving the quality of our Nation's health and recommends a budget of \$454 million, restoring the agency to its fiscal year 2010 enacted level adjusted for inflation. This amount will allow AHRQ to help providers help patients by making evidence-informed decisions, fund research that serves as the evidence engine for much of the private sector's work to keep patients safe, make the healthcare marketplace more efficient by providing quality measures to health professionals, and, ultimately, help transform health and healthcare.

ACP supports at least \$690 million in discretionary funding for Federal exchanges within CMS' Program Operations, which has been funded at \$2.52 billion the last several fiscal years. This funding would allow the Federal Government to continue to administer 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. If the Subcommittee decides to deny 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.

ACP supports expanded appropriations for the CARA of 2016's grant programs for fiscal year 2019 and continuing the Opioid STR grant program's increase for fiscal year 2019. The College greatly appreciates CARA grant programs funded at the level of \$360 million for fiscal year 2018 and the tripling of Opioid STR grants program to \$1.5 billion provided under the fiscal year 2018 omnibus. For fiscal year 2019, the College urges the Subcommittee to increase CARA funding to \$1 billion to help expand proven programs such as evidence-based medication-assisted treatment and first-responder training and access to naloxone for overdose reversal, as included in the CARA 2.0 Act of 2018. ACP also strongly supports the continued increase of Opioid STR grant funding level at \$1.5 billion for fiscal year 2019.

As data-driven decision makers, ACP advocates for robust research about the causes and consequences of firearm violence and unintentional injuries and for strategies to reduce firearm-related injuries. The CDC should receive adequate funding to study the effect of firearm violence and unintentional firearm-related injury on public health and safety. The College supports \$50 million for the CDC's Injury and Prevention Control to fund research on prevention of firearms-related injuries and deaths and support 10 to 20 multi-year studies and help rebuild lost research capacity in this area.

Lastly, the College strongly supports \$39.3 billion for NIH in fiscal year 2019 so that the Nation's medical research agency continues making important discoveries that treat and cure disease to improve health and save lives and maintain the United States' standing as the world leader in medical and biomedical research.

The College greatly appreciates the support of the Subcommittee on these issues and looks forward to working with Congress on the fiscal year 2019 appropriations process.

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

PREPARED STATEMENT OF THE AMERICAN COLLEGE OF PREVENTIVE MEDICINE

The American College of Preventive Medicine (ACPM) urges the Senate Labor, Health and Human Services, Education, and Related Agencies Appropriations Subcommittee to support training for preventive medicine physicians and other public health professionals by providing \$11.136 million in fiscal year 2019 to the Health Resources and Services Administration (HRSA) for preventive medicine residency training under the public health and preventive medicine line item in Title VII of the Public Health Service Act. ACPM also supports the recommendation of the Health Professions and Nursing Education Coalition of \$690 million in fiscal year

2019 to support all health professions and nursing education and training programs authorized under Titles VII and VIII of the Public Health Service Act.

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

Organizations across the spectrum have recognized the growing demand for preventive medicine professionals. The Institute of Medicine released a report in 2007 calling for an expansion of preventive medicine training programs by an "additional 400 residents per year," and the Accreditation Council on Graduate Medical Education (ACGME) recommends increased funding for preventive medicine residency training programs. Additionally, the Association of American Medical Colleges released statements in 2011 that stressed the importance of incorporating behavioral and social sciences in medical education as well as announcing changes to the Medical College Admission Test that would test applicants on their knowledge in these areas. Such measures strongly indicate increasing recognition of the need to take a broader view of health that goes beyond just clinical care—a view that is a unique focus and strength of preventive medicine residency training.

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

According to HRSA, and health workforce experts, there are personnel shortages in many public health occupations, including epidemiologists, biostatisticians, and environmental health workers among others. According to the 2016 Physician Specialty Data Book released by the Association of American Medical Colleges, there was a 3.4 percent decrease of active preventive medicine physicians between 2010 and 2015, with no corresponding increase in the number of first year preventive medicine residents. This represents a worsening trend in the number of preventive medicine physicians in the field that is not due to a lack of interest or need, but is due to a lack of funding. Nearly 70 percent of preventive medicine physicians are over age 55, and the funding gaps mean that there are not enough entering the field to make up for the current and expected future shortage. ACPM is deeply concerned about the shortage of preventive medicine-trained physicians and the ominous trend of even fewer training opportunities. This deficiency in physicians trained to carry out core public health activities will lead to major gaps in the expertise needed to deliver clinical prevention and community public health services. The impact on the health of those populations served by HRSA is likely to be profound.

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

Currently, residency programs scramble to patch together funding packages for their residents. Support for faculty and tuition has been almost non-existent. Directors of residency programs note that they receive many inquiries about and applications for training in preventive medicine; however, training slots often are not available for those highly qualified physicians who are not directly sponsored by an outside agency or who do not have specific interests in areas for which limited stipends are available (such as research in cancer prevention).

HRSA-as authorized in Title VII of the Public Health Service Act-is a critical funding source for several preventive medicine residency programs, as it represents the largest Federal funding source for these programs.

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

- Thirty-five percent of HRSA-supported preventive medicine graduates practice in medically underserved communities, a rate of almost 3.5 times the average for all health professionals. These physicians are meeting a critical need in these underserved communities.
- Nearly one in five preventive medicine residents funded through HRSA programs are under-represented minorities, which is almost twice the average of minority representation among all health professionals.
- Fourteen percent of all preventive medicine residents are under-represented minorities, the largest proportion of any medical specialty.

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

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

Many of the leaders of our Nation's local and State health departments are trained in preventive medicine. Their unique combination of expertise in both medical knowledge and public health makes them ideal choices to head the fight against chronic disease as well as other threats to our Nation's health, such as the opioid epidemic. Their contributions are invaluable. Investing in the residency programs that provide physicians with the training and skills to take on these leadership positions is an essential part of keeping Americans healthy and productive. As such, the American College of Preventive Medicine urges the Labor, Health and Human Services, Education, and Related Agencies Appropriations Subcommittee to reaffirm its support for training preventive medicine physicians and other public health professionals by providing \$11.136 million in fiscal year 2019 to HRSA for preventive medicine residency training under the public health and preventive medicine line item in Title VII of the Public Health Service Act.

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

PREPARED STATEMENT OF THE AMERICAN COUNCIL ON EDUCATION

Chairman Blunt, Ranking Member Murray, and members of the subcommittee, thank you for the opportunity to testify about the importance of funding for the Federal student aid and postsecondary education programs at the U.S. Department of Education. The American Council on Education (ACE) represents nearly 1,800 2-year and 4-year colleges and universities, as well as higher education organizations.

We would like to first thank the subcommittee for your leadership and champion-ship of Federal student aid programs in the fiscal year 2018 appropriations bills. The increased funding will expand access and encourage completion for our students. We are especially grateful for the \$175 increase to the maximum Pell Grant, which will help over seven million low-income families access postsecondary education. Today, I urge you to continue to support and protect the Pell Grant (adminis-tered by the U.S. Department of Education) by increasing the maximum award enough to at least keep pace with inflation, continuing to fund year-round Pell, and

opposing any cuts to the program. This includes cuts to the so called “Pell surplus,” which remains an important guarantee of Pell investments in the future.

As you now turn your attention fully to fiscal year 2019 appropriations, we ask that you carry this commitment forward. While we recognize that the allocation for the fiscal year 2019 Labor-HHS-Education and Related Agencies appropriations bill will be level with fiscal year 2018, we urge you to continue to keep student aid funding a priority. The requests identified below are intended to ensure that programs reach a level of funding consistent with what appropriators have provided in the past. The benefits of restoring funding in this manner are clear and direct. Enabling students to pursue postsecondary education has significant benefits for individuals and for our country as a whole. A better-educated workforce means a stronger economy with lower unemployment, greater earnings, higher tax revenues, and less need for social services. A real effort to build our economy requires a vigorous postsecondary education component.

To that end, we support increasing the Pell Grant maximum to \$6,230 in fiscal year 2019. Pell Grants are the foundation of Federal student aid and the Congressional Budget Office (CBO) estimates over 7.5 million students will use Pell Grants in the coming academic year to finance their education. With the expiration of the automatic inflation adjustment for the Pell Grant maximum, we encourage you to continue to provide sufficient discretionary funding to ensure the equivalent is provided for the neediest students. An increase in the maximum grant to \$6,230 would reflect an adjustment to the fiscal year 2018 Pell Max of \$6,095 at CBO’s current projected Consumer Price Index (CPI) for 2018, ensuring that available aid keeps pace with inflation.

In addition, we strongly encourage the subcommittees to avoid rescinding appropriations from the Pell Grant program. In the last decade, benefits and eligibility for Pell Grants were repeatedly cut in response to funding shortfalls, pushing hundreds of thousands of students out of the program. Using Pell Grant surplus dollars to fund other programs in the Labor-HHS-Education bill puts the future stability of the program in jeopardy.

Like the Pell grant, the campus-based aid programs are critical components of Federal student aid. These are the original risk-sharing programs and require institutions to match Federal funding to participate. The two main campus-based programs are the Supplemental Educational Opportunity Grants (SEOG) and Federal Work-Study (FWS). SEOG provides targeted, need-based grant aid of up to \$4,000 per student to 1.6 million students. Participating colleges match Federal dollars to make more than \$1 billion in grant aid available. Over 99 percent of all SEOG recipients are Pell Grant recipients, and SEOG recipients have higher need on average than students receiving only Pell Grants. The FWS program provides Federal and institutional funding to support part-time employment for more than 700,000 students to help them pay their college costs. Studies show that students who work on campus have higher graduation rates.

Over the last decade, both of these programs have seen level or reduced funding year after year, eroding their ability to serve low- and middle-income students. In order to restore the purchasing power of these programs, Congress should fund them at their pre-sequester levels, adjusted for inflation. For SEOG, that would be \$1.028 billion and for FWS it would be \$1.434 billion. We understand that meeting these requests would require a substantial increase on top of the significant increases already provided in the fiscal year 2018 omnibus, and may not be possible in 1 year due to the smaller overall increase in non-defense discretionary funding available in fiscal year 2019. We ask that you consider the importance of restoring full funding for these programs and work towards that as you finalize fiscal year 2019 appropriations.

In fiscal year 2019, we believe the Federal TRIO programs should be increased to \$1.07 billion. This funding amount would restore services for the more than 30,000 students who have lost access to the TRIO programs over the last decade. TRIO serves students from middle school through college, including military veterans and students with disabilities, helping them get into college and complete their programs. Additionally, GEAR UP should be funded at \$375 million in fiscal year 2019. This increase would bring approximately 70,000 new students into the program and increase the overall number of students served to 770,000. GEAR UP has a proven track record of success in preparing students to enter and succeed in college.

We believe Graduate Assistance in Areas of National Need (GAANN) should be funded at \$48 million, the pre-sequester high-water mark for funding graduate education in the humanities, adjusted for inflation. GAANN grants offer support to top students studying in fields directly related to American competitiveness.

The Leveraging Educational Assistance Partnership (LEAP) grants should be funded at \$65 million. While LEAP has not been funded since fiscal year 2011, it has not been repealed, and provides a strong Federal-State partnership for States to increase their efforts to support need-based financial aid.

Thank you for considering our requests and allowing us to submit testimony to the subcommittee. Without the strong partnership between the Federal Government, States, institutions, and families, millions of students would not be able to go to college. We call on Congress to continue its bipartisan support of Federal student aid programs—which combine grants, work-study, and loan programs—to enable low- and middle- income students to succeed.

[This statement was submitted by Ted Mitchell, President, American Council on Education.]

PREPARED STATEMENT OF THE AMERICAN DENTAL ASSOCIATION

On behalf of the American Dental Association (ADA) and our 161,000 members, thank you, Mr. Chairman and Subcommittee members, for the opportunity to submit testimony in support of Federal programs that work to expand access to oral healthcare. The American Dental Association is requesting for fiscal year 2019, \$20 million for the Center for Disease Control's (CDC) Division of Oral Health and \$24 million for pediatric and general dental residencies in the Health Resources and Services Administration (HRSA).

The ADA thanks the Committee for its commitment to oral health over the years; however, oral health challenges persist. Dental caries, tooth decay, remains the most common chronic disease of children aged 6 to 11 years and adolescents aged 12 to 18 years:

- About 1 in 5 (20 percent) children aged 5 to 11 years have at least one untreated decayed tooth.
- 1 in 7 (13 percent) adolescents aged 12 to 18 years have at least one untreated decayed tooth.
- Children aged 5 to 18 years from low-income families are twice as likely (25 percent) to have cavities, compared with children from higher-income households (9 percent).¹

CDC's and HRSA's investment in programs including: community water fluoridation, school-based programs and oral health residency training, have helped to significantly reduce the incidence of oral disease among children and build a well-qualified dental workforce.

FLUORIDATION

Because of Congress' outstanding efforts to address oral health prevention, community water fluoridation is one of the most cost-effective tools to reduce tooth decay. Studies prove water fluoridation reduces tooth decay by more than 25 percent in children and adults.² The cost of a lifetime of water fluoridation for one person is less than the cost of one filling; however, the real cost benefit of fluoridation is the savings that can be realized by the healthcare system by preventing tooth decay rather than treating it. CDC launched a pilot initiative in 2017 to help local water systems install or replace water fluoridation equipment leading many communities to improved dental health, but more communities are in need. In pilot year 2018, 21 applications were received from 12 States requesting \$600,000 total from \$370,000 available funds. Of those applicants, only 17 organizations in 10 States received awards, but most applicants did not receive full funding. Additional funding would help States develop a robust fluoridation system to benefit more communities.

SCHOOL SEALANT PROGRAMS

School-based sealant programs increase access to care, help reduce caries and lower treatment costs in vulnerable children especially those who are less likely to access dental care. Each tooth sealed saves more than \$11 in dental treatment

¹ADA Health Policy Institute. Untreated Caries Rates Falling Among Low-Income Children. http://www.ada.org/-/media/ADA/Science%20and%20Research/HPI/Files/HPIgraphic_0617_2.pdf?la=en.

²Center for Disease Control and Prevention. Community Water Fluoridation. <https://www.cdc.gov/fluoridation/index.html>.

costs.³ Applying sealants in schools to the nearly 7 million low-income children who don't have them could prevent more than 3 million cavities and save up to \$300 million in dental treatment costs.⁴ CDC currently funds 18 States to support school-based sealant programs. Additional funding included in our \$20 million funding request would help expand preventive care to more States with communities that have limited access to dental services.

ORAL HEALTH TRAINING

Title VII is the only Federal program focused on improving the supply, distribution, and diversity of the dental profession workforce. By providing advanced training opportunities to oral health professionals, the program plays a critical role in helping the workforce adapt to meet the Nation's changing healthcare needs. We are pleased that Congress understands the importance of this program and the impact that it has on medically underserved communities. Since 2000, approximately \$100 million has supported over 60 pediatric dentistry programs, including 10 new programs.⁵ Continuing to increase the number of pediatric dentists is vital for treating underserved populations. Pediatric dentists treat a higher percentage of Medicaid and CHIP patients in their practices than any other type of dentist. Nearly 70 percent of pediatric dentists treat children enrolled in Medicaid, CHIP or both, which represent on average 25 percent of their patients. In communities where pediatric dentists are not available, dentists who have completed a general dental residency fill the gap. Their residency includes advanced training in pediatric care.

The Administration's fiscal year 2019 budget request asserts that Title VII/oral health residency programs have not demonstrated a significant impact on the effectiveness of the oral health workforce. However, the fiscal year 2018 HRSA budget justification indicates that in 2015–2016, oral health training programs helped train 3,835 dental and dental hygiene students in pre-doctoral training, 435 primary care dental residents and fellows, and 946 dental faculty members in faculty development.⁶ We believe that these numbers support our request of \$24 million for pediatric and general dentistry residencies. These programs are paramount in training future generations of dentists to meet the needs of a diverse population.

Behind every successful residency program, is a strong faculty. We thank Congress for funding the dental faculty loan repayment program. A critical factor in recruiting and retaining dental school faculty is helping them reduce their student loan debt. Almost 85 percent of dental students graduate with student loan debt which averaged \$289,331 in 2017. Academic positions pay only one-third of what graduates can earn upon entering private practice. According to the *Journal of Dental Education*, there are approximately 342 dental faculty vacancies, of which 271 are full-time and 78 percent are clinical.⁷

Finally, the ADA believes that in order for HRSA to maintain its dental residencies, faculty loan and prevention programs, there needs to be a leading voice on oral health. In 2012, the Chief Dental Officer (CDO) position was downgraded to a senior dental advisor and moved several layers below HRSA leadership and decision makers. This occurred despite the Administration's commitment in 2010 to establish the Oral Health Initiative, which highlighted several HRSA initiatives to improve access to oral healthcare, especially for needy populations. We thank the Committee for its strong support directing HRSA to reinstate the CDO. However, while the title was restored last year, the function of the position remains unchanged. The CDO is expected to serve as the agency representative on oral health issues to international, national, State, and/or local government agencies, universities, oral health stakeholder organizations, etc. We urge the Committee to direct HRSA to fully restore this position with the appropriate duties of a chief dental officer.

Mr. Chairman, thank you for the opportunity to share with you and the Subcommittee the importance of access to dental care and the programs needed to help

³ Community Preventive Services Task Force. Preventing Dental Caries: School-based Dental Sealant Delivery Programs. Atlanta, GA: US Department of Health and Human Services, Community Preventive Services Task Force; 2016. <https://www.thecommunityguide.org/findings/dental-caries-cavities-school-based-dental-sealant-delivery-programs>.

⁴ Centers for Disease Control and Prevention. Dental Sealants Prevent Cavities—Vital Signs website. <https://www.cdc.gov/vitalsigns/pdf/2016-10-vitalsigns.pdf> [PDF—2.37 MB].

⁵ http://www.aapd.org/assets/1/7/Fact_Sheet_1-HRSA.pdf.

⁶ <https://www.hrsa.gov/sites/default/files/hrsa/about/budget/budget-justification-2018.pdf>.

⁷ Dental Schools Vacant Budgeted Faculty Positions, Academic Year 2015–2016. Washington, DC. *Journal of Dental Education*; 2017; 81 (8) 1033–1043. <http://www.jdentaled.org/content/81/8/1033>.

meet the Nation's changing oral healthcare needs. The ADA looks forward to working with the Subcommittee in maintaining oral health as a priority in healthcare.

PREPARED STATEMENT OF THE AMERICAN DENTAL EDUCATION ASSOCIATION

The American Dental Education Association (ADEA) represents all 66 U.S. dental schools, more than 1,000 allied and advanced dental education programs, 66 corporations and more than 20,000 individuals. ADEA submits this testimony on the HHS budget for the record and for your consideration as you begin prioritizing fiscal year 2019 appropriation requests.

ADEA member institutions' clinics and extramural dental school facilities provide dental care to more than 3 million patients annually. America's dental schools are one of the Nation's largest dental care safety nets in the United States, providing more than \$74 million in uncompensated oral healthcare annually to the uninsured and under-insured.

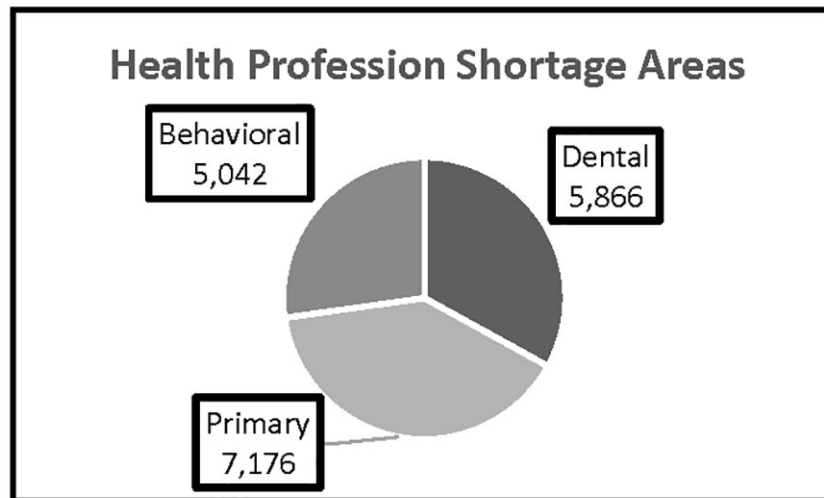
America's academic dental institutions educate and train future dental care providers and dental and craniofacial researchers. As one of the largest safety net providers in the United States, for these services U.S. dental schools provide significant care to both the uninsured and underserved populations. Research continues to demonstrate the indivisible link between good oral health and overall health. Therefore, adequate funding must be provided to programs that facilitate access to dental care and allow for cutting-edge dental and craniofacial research.

ADEA urges you to protect funding for Title VII Oral Health Training programs at HRSA and the National Institute of Dental and Craniofacial Research (NIDCR) at the National Institute of Health (NIH). Title VII facilitates dental care access for millions of Americans and NIDCR fosters globally-recognized dental and craniofacial research.

As you deliberate funding for fiscal year 2019, ADEA respectfully urges your support for the following funding requests:

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

The dental programs in Title VII provide critical training in general, pediatric and public health dentistry and dental hygiene. Support for these programs will help ensure an adequately prepared dental workforce. The funding supports predoctoral dental education and advanced dental education in pediatrics, general and public health dentistry. The investment made by Title VII not only educates dentists, dental hygienists and dental therapists, but it also expands access to care for underserved persons in community-based settings located in Health Profession Shortage Areas (HPSA). Following are specific programs under Title VII that ADEA particularly valuable to protecting oral health in the U.S.



Section 748 addresses the dental school faculty shortage with the dental faculty loan repayment program and faculty development courses for those who teach pediatric, general or public health dentistry and dental hygiene. Currently, more than 200 open, budgeted faculty positions exist in dental schools. These two programs assist schools with recruiting and retaining faculty. Additionally, ADEA is increasingly concerned that with projected restrained funding, the dental research community will not be able to grow and the pipeline of new researchers into academic dental institutions will not meet future need.

Title VII Diversity and Student Aid programs play a critical role in diversifying the health professions student body and, thereby, the healthcare workforce. For the last several years, these programs have not received adequate funding to sustain the progress necessary to meet the healthcare needs, including dental care, an increasingly diverse U.S. population.

The Health Careers Opportunity Program (HCOP) provides a vital source of support for dental professionals serving underserved and disadvantaged patients by providing a professional opportunity pipeline for individuals from these populations. This unique workforce program encourages young people from diverse and disadvantaged backgrounds to explore careers in healthcare generally and dentistry specifically. ADEA requests that this program continue to be funded.

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

\$452 Million: National Institute of Dental and Craniofacial Research (NIDCR)

Research serves as the foundation of the profession of dentistry. Discoveries stemming from dental research have reduced the burden of oral diseases, led to better dental health for millions of Americans and uncovered important links between oral and systemic health. ADEA and dental school researchers across the Nation are grateful for the increase NIDCR received in fiscal year 2018; however, we note that according to the Bureau of Labor Statistics, medical inflation has risen 24 percent since 2010 and the NIDCR budget has increased 8 percent, so our research dollars are not going as far.

The requested increase for fiscal year 2019 will not bring us to parity with inflation but will bring us closer and provide the stable and consistent growth that Drs. Collins and Somerman seek for research. Through NIDCR grants, dental researchers in academic dental institutions have enhanced the quality of the Nation's dental and overall health. Dental researchers are now poised to make dramatic breakthroughs, such as restoring natural form and function to the mouth and face as a result of disease, accident, or injury, and diagnosing systemic disease (such as HIV

and certain types of cancer) from saliva instead of blood and urine samples. These future breakthroughs and countless others, which bolster America's role as a global scientific leader, require adequate funding.

\$20 Million: Centers for Disease Control and Prevention (CDC) Division of Oral Health

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

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

Patients with compromised immune systems are more prone to oral infections such as periodontal disease and caries (tooth decay). The DRP is a cost-effective Federal/institutional partnership that provides partial reimbursement to academic dental institutions for costs incurred from providing dental care to people living with HIV/AIDS. In addition, the program provides educational and training opportunities to dental students, residents and allied dental students. However, DRP reimbursement only averages 26 percent of the dental schools' unreimbursed costs, an unsustainable phenomenon. Adequate funding of the Ryan White Part F programs will help ensure that people living with HIV/AIDS receive necessary dental care.

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

PREPARED STATEMENT OF THE AMERICAN DIABETES ASSOCIATION

For fiscal year 2019, the American Diabetes Association (ADA) urges the Subcommittee to increase its investment in diabetes research and prioritize funding for diabetes prevention to help stop the diabetes epidemic in our country. This is best accomplished by the Subcommittee providing funding levels of \$2.165 billion for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH), \$185 million for the Division of Diabetes Translation (DDT) at Centers for Disease Control and Prevention (CDC), and \$29 million for the National Diabetes Prevention Program (National DPP) at CDC.

Over 30 million Americans live with diabetes and an additional 84 million Americans have prediabetes. As a practicing endocrinologist focusing on diabetes since 1977, I have witnessed remarkable progress in the last 41 years. Thanks to the medical discoveries and advancements at the NIH and translational research from CDC, endocrinologists like me no longer preside over the decline of our patients, but help them manage their disease-saving lives, saving eyes, saving feet, and saving kidneys. Gone are the days where we had only urine tests and beef and pork insulin obtained in slaughterhouses for treatment. Today, I can work with my patients to manage their diabetes so they avoid complications and lead normal lives.

In addition to serving as an endocrinologist, I have been the principal investigator on a number of NIH-funded studies. These studies have led to better lives for people with diabetes, but NIDDK does not have the funding to award grants for every promising research opportunity. My patients live longer, healthier lives because of studies like the landmark Diabetes Control and Complications Trial (DCCT) and the many NIDDK-sponsored studies that result from continued review of the data generated by the follow-up EDIC study. It is because of the Federal investment in research that diabetes treatment has advanced so far in the decades of my practice.

The human cost of diabetes is significant. The lifetime risk for developing diagnosed diabetes among U.S. adults is 40 percent. Today alone, 4,110 Americans will be diagnosed with diabetes, diabetes will cause 295 Americans to undergo an amputation, and 137 will enter end-stage kidney disease treatment.

In addition to the horrendous physical toll, diabetes is economically devastating to our country and individuals with the disease. Released in March 2018, "Economic Costs of Diabetes in the U.S. in 2017," found the total annual cost of diagnosed dia-

betes in our country has skyrocketed by an astonishing 26 percent over 5 years, to \$327 billion-\$237 billion in direct medical costs and an additional \$90 billion in reduced productivity. This is unsustainable for our Nation, especially when one in three Medicare dollars is already spent caring for people with diabetes. We also know that people with diagnosed diabetes have healthcare costs 2.3 times higher than those without diabetes. Despite the escalating physical and economic cost of diabetes to our Nation and families, the Federal investment in diabetes research and prevention programs at the NIH and CDC still falls short of the need. The state of our Nation's diabetes epidemic justifies increased Federal funding in fiscal year 2019.

BACKGROUND

Diabetes is a chronic disease impairing the body's ability to utilize food. The hormone insulin, which is made in the pancreas, is needed for the body to convert food into energy. In people with diabetes, either the pancreas does not create insulin (type 1 diabetes), or it does not create enough insulin and/or cells are resistant to insulin (type 2 diabetes). Diabetes results in too much glucose in the blood stream. Blood glucose levels that are too high or too low (because of medication to treat diabetes) can be life threatening in the short term and cause long term complications like kidney failure, blindness, and non-traumatic lower limb amputations. Diabetes is also a leading cause of heart disease and stroke. Additionally, up to 9.2 percent of pregnancies are affected by gestational diabetes, a form of glucose intolerance diagnosed during pregnancy that places both mother and baby at risk for complications and for type 2 diabetes later in life. Individuals with prediabetes have higher than normal blood glucose levels and are at risk for developing type 2 diabetes, but they can lower that risk with lifestyle interventions. Diabetes does not have a cure, and management is necessary every single day. In my experience, working as part of a team where the patient is the center and nurses, diabetes educators, endocrinologists, dietitians, and sometimes mental health professionals work together to manage care-results in the best outcome for diabetes patients.

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

The ADA requests funding of \$2.165 billion for NIDDK in fiscal year 2019 to support new and existing research opportunities. NIDDK is responsible for major research breakthroughs that have revolutionized how diabetes is treated and managed in individuals with the disease. People with diabetes can now use a variety of insulin formulations and regimens far superior to those used in the past, which has significantly reduced the risk for serious complications of diabetes. NIDDK research has led to the development of continuous glucose monitors and insulin pumps, which are considered life-changing management tools by patients.

As exciting as these advances are, there is even more promising research that needs to be funded. Diabetes researchers across the country are working on exciting proposals that can lead to our ultimate goal—a cure for this devastating disease. With fiscal year 2019 funding of \$2.165 billion, the NIDDK would be able to fund additional investigator-initiated research grants to meet critical needs in areas such as:

- Improving understanding of gestational diabetes, including optimal gestational age to identify gestational diabetes, best method to identify gestational diabetes, best treatment for gestational diabetes, and later impact of gestational diabetes on the health of mother and child,
- Expanding NIDDK's comparative effectiveness clinical trial testing different medications to determine the best treatments for type 2 diabetes,
- Improving the treatment of diabetic foot ulcers to reduce amputations,
- Understanding the relationship between diabetes and neuro-cognitive conditions like dementia and Alzheimer's disease, and
- Discovering how drugs to treat diabetes may help those facing heart disease and cancer.

THE DIVISION OF DIABETES TRANSLATION AT CDC

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

The ADA urges Congress to provide \$185 million in fiscal year 2019. With these resources, the DDT will be able to continue diabetes prevention activities at the State and local levels. Funding will support these efforts through the State and Local Public Health Actions to Prevent Obesity, Diabetes, and Heart Disease grants, with a focus on improving prevention at the community and health system levels in populations with highest risk for diabetes. It will support basic and enhanced diabetes prevention efforts under the State Public Health Actions grant program for cross-cutting approaches to prevent and control diabetes, heart disease, and stroke. It will also enable the DDT to expand its translational research activities to improve diabetes prevention and continue its valuable diabetes surveillance work.

THE NATIONAL DIABETES PREVENTION PROGRAM AT CDC

I am alarmed 84 million Americans have prediabetes and are on the cusp of developing type 2 diabetes. I practice in an ethnically diverse area of New York City, and our population has a very high rate of prediabetes. Programs such as the National DPP can make a significant dent in the incidence diabetes in this high-risk population. Nine of ten individuals with prediabetes do not know they have it, and 15–30 percent of individuals with prediabetes develop type 2 diabetes within 5 years. Managed by the CDC, the National DPP is a public-private partnership of community organizations, private insurers, employers, healthcare organizations, faith-based organizations, and government agencies focused on type 2 diabetes prevention.

The National DPP grew out of a successful NIDDK clinical study showing weight loss of 5 to 7 percent of body weight, achieved by reducing calories and increasing physical activity to at least 150 minutes per week, reduced risk of developing type 2 diabetes by 58 percent in people with prediabetes and by 71 percent for those over 60 years old. Additional translational research was then done, showing the program also works in the less-costly community setting-at a cost of about \$425 per participant.

The National DPP supports a national network of local sites where trained staff provides those at high risk for diabetes with cost-effective, group-based lifestyle intervention programs. There are four key components to the National DPP:

1. Community-based diabetes prevention sites where those at high risk for diabetes attend the intervention program.
2. A national recognition program, coordinated by CDC, to establish evidence-based standards for participating intervention sites and provide the quality monitoring to ensure success.
3. Public and healthcare provider education efforts giving trustworthy information on the availability of high quality diabetes prevention programs in communities so people understand what they need to do when they are diagnosed with prediabetes.
4. Informed referral networks so healthcare providers can refer patients with prediabetes to the local intervention sites.

In 2016, the CMS Office of the Actuary found that seniors participating in a National DPP program have Medicare costs that are \$2,650 lower than non-participants over a 15-month period. Through a demonstration project administered by the YMCA, we know that this program both improves health and lowers healthcare costs, positively impacting our Nation's economy. Because of the tremendous cost-savings, of April 1, 2018, the National DPP is covered as a Medicare benefit.

The ADA urges Congress to provide \$29 million for the National DPP in fiscal year 2019 to continue its nationwide expansion. This level of funding for the National DPP will allow CDC to increase the number of sites that offer this effective program, continue to manage its recognition program to ensure sites follow the evidence-based curriculum and achieve the same high level of results, and support programs as they get setup to be Medicare suppliers.

CONCLUSION

When I started my practice, a large part of my job was witnessing the disaster as patients who had diabetes for 20 years came in and it was too late to help them. Luckily, we have moved to helping patients manage their diabetes to prevent problems and complications, helping them live long and healthy lives. We can and must continue to make progress on the diabetes front; we cannot wait. I urge the Subcommittee to make decisions for fiscal year 2019 appropriations that reflect the necessity of reversing the human and economic burden of this horrendous disease. I look forward to working with you and the ADA to stop diabetes.

[This statement was submitted by Daniel Lorber, MD, FACP, CDE, Chair, National Advocacy Committee, American Diabetes Association.]

PREPARED STATEMENT OF THE AMERICAN EDUCATIONAL RESEARCH ASSOCIATION

Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee; thank you for the opportunity to submit written testimony on behalf of the American Educational Research Association. AERA recommends that the Institute of Education Sciences (IES) within the Department of Education receive \$670 million in fiscal year 2019. This recommendation is also consistent with the request from the Friends of IES coalition, in which we are a leading member. AERA also recommends \$1.531 billion in fiscal year 2019 for the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD).

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

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

We see numerous examples of bipartisan support for scientific research and to evidence-based decisionmaking. With the passage of the Every Student Succeeds Act, the introduction of College Transparency Act, as well as the broad support for the Evidence-Based Policymaking Commission Act, Congress is directing Federal agencies to inform their policy and practice decisions with evidence. Unfortunately, these improvements to the data and research infrastructure require additional funding necessitating action by your committee.

Now is a critical time to invest in education research, data, and statistics to produce essential knowledge about education and learning across all levels of education. It is both efficient and cost-effective to drive policies, programs, and practices based on scientific evidence and to continue to assess performance based on rigorous research.

Since IES was created in 2002, it has made visible scientifically-based contributions to the progress of education. Take, for example, IES supported-research at the Community College Research Center (CCRC) that led to significant changes in the remedial education program in the North Carolina Community College System. In a partnership between the system and CCRC, there was a shift from remedial education toward an accelerated structure of developmental education that increased student retention and degree completion. At the same time, the money saved from restructuring remedial education was reinvested into STEM and high-demand technical education. Despite the potential of research to inform key policy decisions, we have much left to do to provide high-quality education to all of our students. In addition to old questions that remain only partially answered—such as how to best prepare teachers—we have barely begun to understand the opportunities newly possible by advances in technology.

As States are moving forward implementing their Every Student Succeeds Act (ESSA) State plans, they are increasingly depending on their Statewide Longitudinal Data Systems (SLDS). Initially developed to help States measure accountability to their students, 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. In 2015, only 16 of 43 applications received grants. Those States that have benefitted from SLDS grants have clear success to show from the Federal investment. The House Education and Workforce Committee has heard from State leaders in Georgia and Mississippi about their use of SLDS to improve student outcomes in their States. I also want to bring to your attention the numerous ways that Congress has signaled support for the use of education data in decisionmaking. The most recent bipartisan, bicameral draft of the IES reauthorization includes the continuation of SLDS. Eliminating funding for SLDS would undermine the generation of essential knowledge and stand in stark contrast to the broad bipartisan support to increase the use of data to inform policy decisions. Furthermore, cuts to SLDS hurt States working to build data capacity at the same time that ESSA is requiring States to make evi-

dence-based decisions. Rather than eliminating the SLDS program, AERA encourages this committee to expand upon this very successful program. Additionally, AERA opposes the proposal to eliminate the Regional Educational Laboratories in the fiscal year 2019 budget.

As you consider funding for IES in fiscal year 2019, I urge you to consider the importance of having a recently confirmed permanent director, a position that has been acting since August of 2014. Technology and the tools to harness data into knowledge are advancing at light speed. Our country needs IES leadership to have the funding and flexibility to support the innovative and ground breaking research that will enable our educators to best prepare our learners for these rapidly changing times.

In addition to IES, AERA recommends \$1.531 billion in fiscal year 2019 for the Eunice Kennedy Shriver NICHD, consistent with the Friends of NICHD request. Funding for NICHD supports research at the intersection of health and education, including the genetic and behavioral risks for child obesity, the use of opioids by mothers and potential impact on infant and child brain development, and interventions for students with learning disabilities who struggle with reading. This investment in NICHD will allow the institute to align resources as part of its ongoing strategic planning process, continue research to both increase understanding of the impact of opioid use across the educational lifespan and to reduce risk for addiction, and to bolster the professional development of early career researchers.

Thank you for the opportunity to submit written testimony in support of \$670 million for IES and \$1.531 billion for NICHD in fiscal year 2019. 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 GERIATRICS SOCIETY

The American Geriatrics Society (AGS) greatly appreciates the opportunity to submit this testimony. The AGS is a non-profit organization of nearly 6,000 geriatrics healthcare professionals dedicated to improving the health, independence, and quality of life of all older Americans. As the Subcommittee works on its fiscal year 2019 Labor-HHS Appropriations Bill, we ask that you prioritize funding for the geriatrics education and training programs under Title VII and Title VIII of the Public Health Service (PHS) Act, and for aging research within the National Institutes of Health (NIH)/National Institute on Aging (NIA).

We are deeply disappointed with proposed cuts to geriatrics training outlined by President Trump in his budget plan for fiscal year 2019, and are concerned about what these cuts will mean for the care and health of older adults. Specifically, the President's budget calls for the health professions programs within HRSA to receive a \$451 million cut which would likely zero out funding for the Geriatrics Workforce Enhancement Program (GWEP).

We urge you to reject this proposal, and ask that the Subcommittee consider the following funding levels for these programs in fiscal year 2019:

- \$51 million for the Geriatrics Workforce Enhancement Program (PHS Act Title VII, Sections 750 and 753(a) and PHS Act Title VIII, Section 865)
- An increase of \$500 million over the enacted fiscal year 2018 level for aging research across the NIH, in addition to the funding allocated for Alzheimer's disease and related dementias

Sustained and enhanced Federal investments in these initiatives are essential to delivering high quality, better coordinated, and more cost effective care to 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 will more than double between 2014 and 2060 to 98.2 million or 23.5 percent of the population; and those 85 and older will increase threefold to 19.7 million.¹ 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.

¹ Colby SL, Ortman JM. Projections of the Size and Composition of the U.S. Population: 2014 to 2060, Current Population Reports, P25-1143, U.S. Census Bureau, Washington, DC, 2014.

PROGRAMS TO TRAIN GERIATRICS HEALTHCARE PROFESSIONALS

Geriatrics Workforce Enhancement Program (\$51 million)

Our Nation is facing a critical shortage of geriatrics faculty and healthcare professionals across disciplines. This trend must be reversed if we are to provide our seniors with the quality care they need and deserve. Care provided by geriatrics healthcare professionals, who are trained to care for the most complex and frail individuals, has been shown to reduce common and costly conditions—such as falls, polypharmacy, and delirium—that are often preventable with appropriate care.

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. GWEP seeks to improve high-quality, interprofessional geriatrics education and training to the health professions workforce, including geriatrics specialists, as well as increase geriatrics competencies of primary care providers and other health professionals to improve care in medically underserved areas. It supports the development of a healthcare workforce that improves health outcomes for older adults by integrating geriatrics with primary care, maximizing patient and family engagement and transforming the healthcare system.

In July 2015, HRSA announced 44 three-year grant funded programs located in 29 States that consolidated the Title VIII Comprehensive Geriatric Education Program and the Title VII Geriatric Academic Career Award, Geriatric Education Centers, and Geriatric Training for Physicians, Dentists and Behavioral and Mental Health Providers programs into the GWEP.

This consolidation—a change made by HRSA in December 2014—provides greater flexibility to grant awardees by allowing applicants to develop programs that are responsive to the specific interprofessional geriatrics and training needs of their communities. While the AGS has been encouraged by elements of this new approach, we remain concerned that there is no longer a sufficient focus on the training and education of health professionals who wish to pursue academic careers in geriatrics or gerontology. The Geriatric Academic Career Award (GACA) program is the only Federal program that is intended to increase the number of faculty with geriatrics expertise in a variety of disciplines. In the past, the number of GACA awardees has ranged from 52 to 88 in a given grant cycle; in the most recent round of GWEP grants, it appears that only a small number of the grantees have dedicated resources to train faculty in geriatrics and gerontology.

At a time when our Nation is facing a severe shortage of both geriatrics healthcare providers and academics with the expertise to train these providers, the AGS believes the number of educational and training opportunities in geriatrics and gerontology should be expanded, not reduced.

To address this issue, we ask the subcommittee to provide a fiscal year 2019 appropriation of \$51 million for the GWEP. This small increase would restore GACAs and expand GWEP programs to close current geographic and demographic gaps in geriatrics workforce training.

RESEARCH FUNDING INITIATIVES

National Institutes of Health (additional \$500 million over fiscal year 2018)

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 a minimum increase of \$500 million over the enacted fiscal year 2018 level in the fiscal year 2019 budget for biomedical, behavioral, and social sciences aging research efforts across the NIH. The AGS also supports an additional \$425 million specific to research on Alzheimer’s disease and related dementias (ADRD), resulting in an NIH-wide dementia research budget of at least \$2.253 billion in fiscal year 2019.

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 with ADRD is estimated to reach 13.8 million—more than double the number in 2018—and is projected to cost more than \$1 trillion (in 2018 dollars).² Further, chronic diseases related to aging, such as diabetes, heart disease, and cancer continue to afflict 80 percent of people age 65 and older and ac-

² Alzheimer’s Association. 2018 Alzheimer’s Disease Facts and Figures. *Alzheimer’s Dement* 2018;14(3):367–429.

count for more than 75 percent of Medicare and other Federal health expenditures.³ 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 the Ad Hoc Group on Medical Research recommendation to appropriate at least \$39.3 billion in fiscal year 2019 for the NIH, including funds provided through the 21st Century Cures Act for targeted initiatives. We believe that a meaningful increase in NIH-wide funding, in combination with aging and ADRD specific increases, will be essential to sustain the research needed to make progress in addressing chronic disease, ADRD, and other diseases 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 thank the Subcommittee for the opportunity to submit this testimony.

PREPARED STATEMENT OF THE AMERICAN HEART ASSOCIATION

On behalf of 40 million volunteers and supporters, the American Heart Association praises Congress for boosting funding for the National Institutes of Health (NIH) and for Centers for Disease Control and Prevention (CDC) heart disease and stroke prevention programs. We salute Congress for its sustained focus on the link between disease burden and funding levels. The association firmly thinks that evidence-based disease burden measures should guide and inform Congress when allocating research and prevention funding and setting priorities for fiscal year 2019.

The association released a study that projects steep increases in prevalence, medical costs, and subsequent burden of cardiovascular disease (CVD) on Americans through 2035. It is located at: www.heart.org/burden. We remain confident that it will be a useful tool to appropriately align funding and resources to help cut the huge toll CVD inflicts on our Nation's health and economy.

As our Nation's No. 1 killer and most costly disease, CVD, including heart disease and stroke, tops the disease burden list. In 2015, stroke and heart failure remained the most costly chronic conditions in the Medicare fee-for-service program. Today, more than 92 million U.S. adults suffer from some form of CVD. Moreover, recent projections show that by the year 2035, 45 percent of U.S. adults will live with CVD at an annual cost of more than \$1 trillion.

However, heart disease and stroke research and prevention remain disproportionately underfunded compared to the devastating burden and suffering CVD inflicts. And despite a \$30-to-\$1 return on CVD investment, NIH continues to invest only 4 percent of its budget on heart research, just 1 percent on stroke research, and a scant 2 percent on other CVD research. AHA challenges Congress to correct this glaring disparity, starting with the fiscal year 2019 appropriations process.

The American Heart Association urges Congress to boost, safeguard, and sustain NIH and CDC funding and resources. We are committed to building healthier lives free of cardiovascular diseases and stroke. Leveraging disease burden measures is key to accomplishing our mission.

FUNDING RECOMMENDATIONS: INVESTING IN THE HEALTH OF OUR NATION

Despite the renewed danger CVD presents to our Nation's long-term health and economic stability, research that could ultimately develop a cure goes unfunded. Insufficient and erratic funding remain our most difficult obstacles. But, our budget recommendations outlined below are fiscally responsible and focus on the huge burden CVD inflicts on all Americans.

Capitalize on Investment for the National Institutes of Health (NIH)

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

³National Council on Aging. Chronic Disease Self-Management Facts. <https://www.ncoa.org/news/resources-for-reporters/get-the-facts/chronic-disease-facts/>. Accessed April 18, 2018.

In addition to enriching health, NIH generates a strong return on investment. In 2017, NIH supported more than 404,000 U.S. jobs and nearly \$70 billion in economic activity. Every \$1 in NIH funding created \$2 in economic activity in 2007. NIH research investments have led to 210 new medicines winning FDA approval over 6 years. Yet, due to insufficient funding since 2003, NIH lost over 19 percent of its purchasing power since 2003, adjusted for inflation, as other countries have boosted scientific investments, some by double digits. Moreover, NHLBI extramural heart research dropped 17 percent in constant dollars since 2002. This could deter early U.S. career scientists from following careers in research unless Congress acts now.

American Heart Association Advocates: We urge Congress to appropriate a \$2 billion increase for NIH each year over the next several years to give the agency stable, predictable and sustained funding boost to continue to restore its purchasing power and enhance heart and stroke research.

Enhance Funding for NIH Heart and Stroke Research: Investments in Cures, High ROI

Robust NIH research funding is critical to reducing CVD death rates. Now, researchers are closer to breakthroughs that could revolutionize treatments and bring us closer to cures. In addition to saving lives, NIH research can generate considerable cost savings. For example, investments in the NIH Women's Health Initiative postmenopausal estrogen plus progestin trial produced an economic return of \$140 for every \$1 invested, leading to 76,000 fewer cases of CVD. The first NIH tPA drug trial led to a 10-year net \$6.47 billion cut in stroke care costs.

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

NHLBI research has caused declines in CVD death rates. But, present funding is not commensurate with CVD burden, nor does it let scientists build on investments that have led to key advances. For example, a clinical trial showed a systolic blood pressure of 120 mm Hg in adults over age 50 cut heart attack, heart failure, and stroke 25 percent and death 27 percent, compared to the standard treatment target of 140 mm Hg. Adoption of these targets could save an estimated 100,000 lives and were used as the basis for new treatment guidelines. Medical engineers created a cardio patch from human stem cells for use after a heart attack to replace damaged muscle.

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

Stroke continues to inflict a massive burden on our Nation's long-term health and economic stability. An estimated 795,000 Americans will suffer a stroke this year, and more than 140,000 will die. Many of the 7 million survivors face grave physical, mental, and emotional distress. Stroke costs an estimated \$40 billion in medical expenses and lost productivity annually. And a recent study projects that stroke's medical direct costs will triple between 2015 and 2035.

NINDS investment in stroke must be drastically augmented to capitalize on stroke research progress, including the DEFUSE3 trial that proves brain imaging can identify patients who will benefit from clot removal up to 16 hours post stroke; and studies showing that a specific molecule plays a major function in brain repair after stroke. Increased stroke funding could enhance the NIH Stroke Clinical Trials Network, including early stroke recovery; prevent vascular cognitive damage; expedite comparative effectiveness research trials; develop imaging biomarkers; refine clot-busting treatments; achieve strong brain protection; and advance the use of neural interface devices. Additional funding is necessary to further the BRAIN Initiative.

American Heart Association Advocates: We recommend that NHLBI be funded at \$3.6 billion and NINDS at \$2.3 billion.

Increase Funding for the Centers for Disease Control and Prevention (CDC)

CVD is mainly preventable, yet effective evidence-based prevention initiatives are not fully executed due to limited resources. In addition to supporting surveillance and implementation research, the Division for Heart Disease and Stroke Prevention manages the Paul Coverdell National Acute Stroke Program. DHDSPP, with the Centers for Medicare and Medicaid Services, directs Million Hearts™ 2022 to prevent heart attacks and strokes. DHDSPP administers WISEWOMAN, to help uninsured and under-insured, low-income women ages 40 to 64 cut heart disease and stroke risk by screenings and community resources staging healthy behavior.

American Heart Association Advocates: We join the CDC Coalition in asking for \$8.445 billion for CDC. The association requests \$160 million for the DHDSPP to support, strengthen and expand heart disease and stroke prevention efforts in State,

local, and Tribal public health departments, and enhance surveillance and implementation research. We ask \$37 million to expand WISEWOMAN. And we request \$5 million for Million Hearts™ 2022 to continue implementation of ABCS, develop innovative scalable ways for communities and the healthcare sector to execute evidence-based prevention in the highest burden areas and to expand focus on physical activity, cardiac rehabilitation, and people age 35–64 whose event rates are on the rise.

CONCLUSION

Recent projections show cardiovascular disease, including stroke, will continue to impose the highest disease burden on Americans. Our budgetary recommendations for NIH and CDC will save lives and cut healthcare costs. We urge Congress to enact our recommendations that are a wise investment for the long-term health and economic stability of our Nation. Thank you.

[This statement was submitted by John Warner, M.D., President, American Heart Association.]

PREPARED STATEMENT OF THE AMERICAN INDIAN HIGHER EDUCATION CONSORTIUM

This statement includes the fiscal year 2019 funding requests of the Nations' 38 American Indian Tribal Colleges and Universities (TCUs), with justifications for these modest funding recommendations. The following is a list of recommendations including Department, program, and amount sought, per the subcommittee instructions. Detailed information and justifications are contained in this statement.

Department of Education

Office of Postsecondary Education

- HEA Title III—Part A (Sec. 316): \$35,000,000 (discretionary)
- HEA Title III—Part F (Sec. 371): \$30,000,000 (mandatory)
- Pell Grants: Increase to \$6,230
- Federal TRIO Program: \$1.07 billion
- Perkins Career and Technical Education Programs (Sec. 117): \$10,000,000

Department of Health and Human Services

- Administration for Children and Families/Office of Head Start (TCU-Head Start Partnership Program, sec. 648(g) of the Head Start Act (42 U.S.C. 9843g)): \$8,000,000 in existing funds
- Substance Abuse and Mental Health Services Administration, SAMHSA (TCU Centers of Excellence): \$10,000,000

Institute of Museum and Library Services

- The Institute of Museum and Library Services (IMLS): Reject the President's proposal to eliminate IMLS funding.

Tribal Colleges and Universities: A Sound Investment for Students & the Federal Government

Aaron Sansosie of Flatrock, AZ, is a U.S. Army veteran, father of four, and Navajo Technical University (NTU) student. He is one of thousands of American Indian and Alaska Native (AI/AN) students gaining valuable education and technical skills to enter the workforce at Tribal Colleges. Aaron is enrolled in NTU's Carpentry certificate program and Building Information Modeling Applied Science associate's degree program. To achieve his goals, Aaron has been taking 17–19 credits each semester, which keeps his days busy. While the schedule may seem grueling for any student, it is important to note that Aaron does this all while sleeping out of his truck. "The cost of living here is pretty high, especially in the dorms and having three meals a day. Sometimes Pell won't cover it all, which leaves me in debt. Even with my veteran benefits, which help me out a lot, [I need to save]," explained Aaron, whose desire to help his family and community is powerful.

Stories like Aaron's can be found across Indian Country as TCUs attempt to stretch Federal dollars to meet the unique needs of AI/AN students. In fact, a 2015 economic impact study on the TCUs, conducted by Economic Modeling Specialists International (EMSI), revealed that for every Federal dollar invested in the TCUs, the taxpayers receive a cumulative value of \$2.40. The average annual rate of return is 6.2 percent, a solid rate of return that compares favorably with other long-term investments. On an individual basis, TCU students see an annual return of investment of 16.6 percent, and the vast majority of TCU-trained workers remain in Indian Country and contribute to the local economy. TCUs benefit taxpayers

through increased tax receipts and reduced demand for Federal social services—a win all-round.

Ramifications of the Administration's Proposed Funding Cuts

Imposing cuts to already modest programs that fund institutions that provide access and strong support to achieve postsecondary degrees and certificates to some of the Nation's most underserved populations is neither acceptable nor appropriate. Cuts in any amount from even one TCU program would threaten accreditation status and most definitely would result in cuts to faculty and staff—who are already stretched thin (some teaching five courses/semester)—as well as vital programs and services that students rely on to complete degree and certificate programs needed to succeed in their chosen career paths. Programs such as the TCUs' HEA Title III (Strengthening Institutions) provide critical funds for faculty; student support programs designed to improve academic success to bolster their success; preservation of native language; improvements, renovations, and basic upkeep of campus buildings and infrastructure; enterprise management systems; and other items that are critical to the success of a college in offering students a quality education experience. We strongly urge the Subcommittee to reject the Administration's proposed cuts to higher education programs and instead take a measured look at what is working and continue to build the investment in the TCUs and the students and communities that they serve.

Specific programmatic requests administered within the departments and agencies funded under the Labor-HHS, Education appropriations bill, are as follows:

U.S. DEPARTMENT OF EDUCATION

I. Higher Education Act Programs

—*Strengthening Institutions Title III-A&F Sec. 316.*—TCUs urge the Subcommittee to fund the discretionary and mandatory funding for HEA Title III-A&F, Sec. 316 at \$65,000,000 in fiscal year 2019. Titles III and V of the Higher Education Act support institutions that enroll large proportions of financially disadvantaged students. The TCUs, which truly are developing institutions, are funded under Title III-A Sec. 316 and provide quality higher education opportunities to some of the most rural, impoverished, and historically underserved people in the country. In fact, more than 50 percent of our students are first generation; 85 percent participate in Federal financial aid; average family income is less than \$21,000; and local unemployment rates often exceed 50 percent. The goal of HEA-Titles III/V programs is “to improve the academic quality, institutional management and fiscal stability of eligible institutions... to increase their self-sufficiency and strengthen their capacity to make a substantial contribution to the higher education resources of the Nation.” The TCU Title III-A program is specifically designed to address the critical, unmet needs of AI/AN students and their communities, and to effectively prepare them to succeed in a globally competitive workforce. Yet, in fiscal year 2011 this program was cut by over 11 percent and then received subsequent cuts, including sequestration, until last year. Despite increases in fiscal year 2018, TCUs still have not recovered from the earlier cuts to this vitally important program. It is also important to note the size of the TCU program, as compared to other Titles III/V programs, such as the HBCU and HSI programs. When greatly appreciated increases are proposed, but which use a common percentage to allocate the increases, TCUs are at a disadvantage because of our program's size. For example, in fiscal year 2017, when funding was increased for all Titles III/V programs, the TCU program was the only program that actually lost ground, and we ended the year funded at a level lower than the level in either the House or Senate bill.

—*Pell Grants (increase maximum Pell to \$6,230).*—The importance of Pell Grants to TCU students cannot be overstated. Eighty-five percent of TCU students receive Pell Grants, primarily because their income levels are so low and they have fewer sources of financial aid than students at State-funded and other institutions. At TCUs, Pell Grants are doing exactly what they were intended to do: they serve the needs of the lowest income students by helping them gain access to quality postsecondary education, an essential step toward becoming active, productive members of the workforce. AIHEC supports the request of the Student Aid Alliance to increase to the maximum Pell Grant to \$6,230.

—*TRIO (increase to \$1.07 billion).*—Retention and support services are vital to achieving success with traditionally underserved students who have few, if any, higher education role models. TRIO programs were created out of a recognition that college access is not enough to ensure advancement and that multiple fac-

tors work to prevent successful completion by many low-income and first-generation students and students with disabilities. In the final fiscal year 2018 consolidated appropriations bill, TRIO received a much-needed \$60 million increase. AIHEC supports the request of the Student Aid Alliance to increase funding for the Federal TRIO program to \$1.07 billion. It is critical that Congress sustain and increase support for TRIO programs so that low-income and minority students have the support they need to access and complete postsecondary education programs.

II. Carl D. Perkins Career and Technical Education Programs

—*Tribally Controlled Postsecondary Career and Technical Institutions.*—AIHEC requests \$10,000,000 to fund grants under Sec. 117 of the Perkins Act. Section 117 of the Carl D. Perkins Career and Technical Education Act provides a competitively awarded grant opportunity for tribally chartered career and technical institutions which provide vitally needed 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.

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES PROGRAMS

I. Administration for Children and Families—Office of Head Start

—*Tribal Colleges and Universities Head Start Partnership Program (42 U.S.C. 9843g).*—AIHEC requests that \$8,000,000 be designated for the TCU-Head Start Partnership program. 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 (Region 11), and only 70 percent of workers in Region 11 met the associate-level requirements, or were enrolled in associate programs, compared to 90 percent nationally. This disparity in preparation and teaching should alarm the Subcommittee. It requires our immediate attention: AI/AN children deserve, and clearly need, qualified teachers. TCUs are the most cost effective way for filling this inexcusable gap. From 2000 to 2007, the U.S. Department of Health and Human Services provided modest funding for the TCU-Head Start Program, which helped TCUs build capacity in early childhood education by providing scholarships and stipends for Indian Head Start teachers and teacher's 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 Saliish Kootenai College in Pablo, Montana are providing culturally based early childhood education free of charge to local Head Start professionals. Bay Mills Community College provides online education programming for \$50/credit to Head Start staff nationwide. However, many Head Start programs are paying far more for other sources to provide training. With the restoration of this modestly funded program, TCUs can aid in building an early childhood education workforce to better serve the education needs of our AI/AN children. The Head Start program was increased by more than \$610 million last year. Please use some of this funding to reestablish this critically needed program.

II. Substance Abuse and Mental Health Services Administration (SAMHSA)

—*NEW Tribal College and University Centers for Excellence in Behavioral Health/Substance Abuse Prevention (\$10,000,000).*—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 well-skilled and culturally competent AI/AN behavioral health workforce by developing an apprenticeship-based network of TCUs and partners from the health industry and local, Tribal, State, and regional providers. The TCU Centers of Excellence would share best practices in curriculum development, program implementation, and apprenticeships; recruit students to careers in behavioral health fields to address mental and substance use disorders; provide training that can lead to careers in the behavioral health fields; and prepare students for achieving credentials in behavioral health fields. The TCU Centers

of Excellence would emphasize education, awareness, workforce training, and preparation for careers in mental and substance use disorder treatment, prevention and research, including addressing opioid abuse prevention, opioid use disorder treatment, serious mental illness, and suicide prevention.

AI/AN college-aged youth (ages 15–24) are the most at-risk group in the Nation. Suicide, alcohol/substance abuse, domestic violence/abuse, extreme poverty are all too common to TCU students and their families. A seminal behavior health survey of TCU students,¹ revealed that 50 percent of TCU students reported being physically intimidated, assaulted, or bullied/excessively teased by a peer. Nearly 25 percent reported having used opioids, compared to under 9 percent of mainstream college students (2013 national survey—the only comparable data). Of TCU students who had used opioids, 25 percent reported feeling signs of addiction, and nearly 34 percent had taken opioids without a prescription in the last 3 months. AIHEC and partnering entities are on the leading edge nationally in collecting this type of data due to modest grants from the underfunded “Native American Research Centers on Health” program, operated by the National Institutes of Health. TCUs collect this data, because we want to address the problem before it spirals out of control. However, while we advocate annually for sustained community-based intervention in Indian Country and try to do what we can with little or no resources, the problem is nearly beyond our ability to address it. Already, the death rate among AI/ANs from heroin overdose has increased 236 percent between 2010 and 2014. The CDC reported that in 2014, AI/AN opioid related deaths were triple the rate of African-Americans and Hispanic Whites; yet, while States and others receive funding, TCUs—which have proven their fiscal responsibility, ability to effect change, and leadership in emerging areas—must continue to do more with less.

“Administrators at [our college believe] that our decreasing enrollment of degree seeking students is attributed to the increasing number of community members who are addicted to meth, heroin, and prescription drugs,” says Fort Peck Community College (Poplar, MT) president, Haven Gourneau. “[N]o one wants to be an addict, and if asked every addict would willingly take a ‘magic’ pill that would cure them if they could. With that said, we know there is no ‘magic’ pill and so we will continue to see a decline in our community socially and economically unless we can beat these addictions.”

As engaged, place-based institutions, TCUs are committed to addressing the many challenges facing our communities, including the growing opioid epidemic. TCUs are leading the way through student-based participatory research to identify the specific needs of tribal communities (youth and students), so that community-relevant solutions can be identified and culturally adapted, tested, and then shared with others. SAMHSA, which has an ongoing effort with HBCUs, seems an appropriate agency to administer the TCU Centers for Excellence in Behavioral Health/Substance Abuse Prevention.

THE INSTITUTE OF MUSEUM AND LIBRARY SERVICES (IMLS)

AIHEC requests that Congress reject the recommendation to eliminate IMLS funding. IMLS is critically important to sustaining and growing TCU libraries, many of which are also the public library for their communities. Recently, eight TCUs received IMLS enhance grants that were used to address important issues of literacy in the community; digitizing tribal newspapers and cultural enrichment classes/lecture series for access through States’ library systems; increasing community awareness and involvement in library-based activities and programs; and creating classroom curriculum kits addressing AI/AN students. In the North Slope Region of Alaska alone, seven public libraries, operated through Ilisagvik College in Barrow, would be forced to close, leaving the most isolated Americans without access to library or reading services. In conjunction with the TCUs, IMLS is instrumental in preserving tribal culture. The elimination of IMLS would be devastating to generations past, present, and future.

We respectfully request that the Members of the Subcommittee continue to recognize the significant contribution of the Tribal Colleges and Universities to their students, their communities, and the Nation as a whole by continuing and expanding the vital Federal investment in our institutions. Thank you.

¹TCU–CCC Baseline Survey Conducted in 22 TCUs, March 2015–Feb 2016. Preliminary Data. This research is supported by grants from the NIAAA, 1R01AA022068 and the NIMHD, 5P60-MD006909 through the National Institutes of Health.

PREPARED STATEMENT OF THE AMERICAN LIBRARY ASSOCIATION

The American Library Association (ALA) is the oldest and largest library association in the world, with more than 58,000 librarians and 120,000 academic, public, school, government, and special libraries in every State and Congressional district. Libraries are visited over 2.7 billion times every year and are entities that produce dramatic impacts for businesses and millions of Americans every day in communities large and small throughout the Nation. ALA urges the Subcommittee to include in its fiscal year 2019 appropriations bill at least \$189.3 million for programs under the Library Services and Technology Act (LSTA), and at least \$27 million for the Innovative Approaches to Literacy (IAL) program under the Department of Education.

On behalf of ALA, I want to thank the Subcommittee for the opportunity to provide comments in support of two important, tested, cost-effective and successful programs.

Libraries serve a vital and unique role in communities across the country by providing a growing range of services, including many on-line services making today's technology-focused libraries 24-hour enterprises offering much more than they did 20 years ago.

With funding from the \$189.3 million LSTA, 120,000 public, academic, government and other libraries advance Employment, Entrepreneurship, Education, Empowerment and Engagement (The E's of Libraries®) in communities across the country.

Employment

- 73 percent of public libraries assist patrons with job applications and interview skills.
- LSTA funds training for school and public librarians to prepare students for today's competitive job market.

Entrepreneurship

- Nearly 100 percent of public libraries offer economic/workforce services; about half of those provide entrepreneurship and small business development services.
- LSTA funds allow entrepreneurs in rural communities to receive business development assistance from a skilled business & technology outreach librarian.

Education

- 98 percent of public libraries provide formal or informal technology training.
- LSTA funds support teen maker labs teaching teens 3D file creation and printing, coding and circuitry in emerging technologies.

Empowerment

- Nearly 100 percent of public libraries offer no-fee public access to Wi-Fi and computers.
- LSTA funds provide online exam preparation tools at libraries that would otherwise be cost prohibitive, enabling patrons to improve career prospects and education.

Engagement

- 97 percent of public libraries help people apply for government services online.
- LSTA funds enable veterans to claim well-earned benefits to further their education, get medical treatment, start a business, and transition to civilian life.

The bulk of LSTA funds are distributed to each State through the Institute of Museum and Library Services (IMLS) according to a population-based grant formula. Each State must provide a 34 percent match and determines at the State level how to meet local needs and best allocate its LSTA grant awards. Libraries have used LSTA funding for a broad range of diverse and innovative programs that profoundly touch and better the lives of tens of millions of Americans in every State in the Nation, including particularly service to the disabled, veterans, and job seekers. LSTA is truly a local decisionmaking success story and a shining example of how a small Federal investment can be efficiently and reliably leveraged into dramatic State and local social and economic results. Here are just a few current examples made possible by LSTA:

- The Pierce County Library (WA) utilized an LSTA grant to support Open Lab, a program preparing soldiers transitioning to civilian life by improving their technology skills and helping them find new careers in the digital world. More than 1,400 people enrolled in the program and over 500 earned a Microsoft Technology Associate Certification.

- The St. Louis County (MO) Library District is using its LSTA grant to address a need for a healthier community. The grant is supporting a project to improve health literacy, promote healthy eating, helping patrons learn nutritious cooking skills, and creating classes on exercise, understanding health restrictions, and aging wisely.
- The Wilcox County (AL) Library received an LSTA grant to support a pilot program that helps residents learn the skills to run small home-based or online businesses. The pilot proved so successful that the library was forced to find space for larger classes.

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

Accordingly, ALA asks that the Subcommittee provide at least \$189.3 million for LSTA in fiscal year 2019 to ensure that Americans of all ages continue to have access to the life-sustaining, -affirming and—expanding resources at their local library. ALA respectfully submits that there can be few, if any, more democratic, cost-effective and impactful uses of Federal dollars than LSTA in the entirety of the Federal budget.

In addition to supporting LSTA, ALA also asks that you maintain fiscal year 2018's modest, but critical, Federal investment of \$27 million in the Innovative Approaches to Literacy (IAL) program, which was authorized under Every Student Succeeds Act last year. IAL provides competitive awards to school libraries and national not-for-profit organizations (including partnerships that reach families outside of local educational agencies) to put books into the hands of children and their families in high-need communities.

Providing books and literacy support for children is crucial to their—and the Nation's—economic futures. Studies have shown that developing early childhood reading proficiency is directly correlated to success in K–12 and college education and in careers. IAL also supports parental engagement in their children's reading life and focuses on promoting student literacy from birth through high school. IAL grants have been awarded during the life of the program to almost every State in the Nation. Schools across the country have received grants, including the Northwest Artic Borough (AK) School District, Dillon School District Four (SC), and Karnes City (TX) Independent School District as well as many others. We urge the Subcommittee to foster this work by continuing to invest at least \$27 million in IAL.

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

PREPARED STATEMENT OF THE AMERICAN LIVER FOUNDATION

SUMMARY OF FISCAL YEAR 2019 RECOMMENDATIONS

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- Please provide the National Institutes of Health (NIH) with a funding increase of at least \$2 billion for fiscal year 2019 to bring total funding up to a minimum of \$39.1 billion.
 - Please continue to support and encourage liver-related medical research and public health activities with key committee recommendations.
 - Please provide the Health Resources and Services Administration (HRSA) with a funding level of at least \$8.5 billion for fiscal year 2019 and ensure adequate support for organ donation activities.
 - Please provide the Centers for Disease Control and Prevention (CDC) with a meaningful funding increase for fiscal year 2019 and facilitate important activities, including a liver cancer awareness campaign.
 - Please provide dedicated resources to address the intersection of the opioid epidemic and the spike in infectious diseases, thus ensuring impacted communities have access to testing and linkages to care for affected individuals.
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Thank you for the opportunity to submit testimony on behalf of the American Liver Foundation (ALF). Chairmen Blunt and Shelby, Ranking Member Murray, Vice Chair Leahy, and distinguished members of the Subcommittee, the community would like to take this opportunity to extend its thanks for the significant investment in NIH and CDC secured through fiscal year 2018. The notable fiscal year

2018 funding increases will have a significant impact on medical research and public health activities. Thank you again.

HISTORY

ALF was created in 1976 by the American Association for the Study of Liver Disease (AASLD). This organization of scientists and healthcare professionals was concerned with the rising incidence of liver disease and the lack of awareness among both the general public and the medical community. The mission, the programs and the services provided by American Liver Foundation complement the great work of AASLD. American Liver Foundation makes a measurable difference in the fight against liver disease by providing financial support for medical research, education for medical professionals, and advocacy and information for patients and their families, and by creating public awareness campaigns about liver wellness and disease prevention.

FACTS

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

THE OPIOID EPIDEMIC

CDC has dubbed opioids and the infectious diseases that arrive in the wake of the opioid crisis a “dual epidemic”. Due to the rise in rates of injection drug use, CDC has identified a 400 percent increase in rates of hepatitis C among 20–29 year olds and a 300 percent increase among 30–39 year olds. The lack of an effective response for affected communities will prevent the eradication of hepatitis and lead to rising healthcare costs. Compounding the current problem is the reality that hepatitis symptoms do not emerge for years and many are unaware of their health status. However, new research suggests that when individuals receive testing and proper health services, the awareness of hepatitis or HIV infection often leads to a reduction in opioid abuse. Please provide meaningful funding to address opioid related infectious diseases.

LIVER CANCER AWARENESS PROGRAM

CDC hosts many important programs for cancer as well as chronic disease, but none focused on preventing liver cancer. While liver cancer is a leading killer, it is also preventable and more easily managed if diagnosed early. However, risk factors are not well known and there is an overall lack of public and professional awareness. CDC should have resources and encouragement to partner with stakeholder organizations and engage in a comprehensive, collaborative effort to improve public health with a liver cancer awareness campaign.

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.

LIVER RESEARCH

The National Commission on Digestive Diseases previously worked to establish a long-range digestive disease research plan that NIH and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) has worked to implement. This plan along with additional resources has led to meaningful growth in the liver, liver diseases, and liver cancer research portfolios.

CAROLYN'S STORY

My name is Carolyn Evans. In 1992, I was diagnosed with a rare liver disease, Primary Biliary Cholangitis. To this day, no one knows what causes PBC, nor do they have a cure other than an eventual transplant. Research has developed medication that helps slow the progression of the disease in many, not all, patients. As a young mom with two children, this was devastating news. PBC's outward symptoms include extreme fatigue and unbelievable itching, but otherwise, it is a silent killer. "But you look fine" are comments I heard daily. Internally, my liver was killing itself. I became very ill on the inside, still "looking fine", and 14 years later was told I needed a liver transplant. Living in the NY/NJ area, I was told that I would die from PBC before a traditional liver donation would be possible and to receive a transplant I needed a living donor liver transplant. I was fortunate to receive my living donor liver transplant at Mt. Sinai Hospital in NYC in 2006.

Funding for testing and treating liver patients with curable diseases serves many and ultimately helps other patients. The risk of liver cancer for that individual is greatly reduced once cured. Once treated, those patients come off the transplant list, thus freeing up all donated livers for patients, like me, whose only end treatment for their disease is a transplant. Continued research is critical in order to find new treatments and cures for all liver diseases, including PBC. In addition to the health and quality of life of the patient, there are many additional issues that arise when living with liver disease; lifetime medication costs and medical coverage for those facing transplant, and continued lifetime treatment. After transplant, the risk to other organs becomes a bigger concern and regular monitoring is required. I will continue to advocate for others with liver disease in the hope that one day science will find a way to treat and cure all those dealing with the challenges, fears, and threat of death that I faced over 26 years ago.

[This statement was submitted by Tom Nealon, CEO, American Liver Foundation.]

PREPARED STATEMENT OF THE AMERICAN PHYSIOLOGICAL SOCIETY

The American Physiological Society (APS) thanks the subcommittee for its ongoing support of the National Institutes of Health (NIH). The \$3 billion funding boost you provided in fiscal year 2018, following on the \$2 billion increases you provided in fiscal year 2016 and 2017, have put the NIH on a path toward sustainable budget growth. These much-needed increases will help NIH address critical health problems and emerging challenges through cutting-edge research. The APS urges you to sustain this vital effort by providing the NIH budget with at least \$39.3 billion in fiscal year 2019.

Breakthroughs in basic and translational research are the foundation for new drugs and therapies that help patients, fuel our economy, and provide jobs. Federal investment in research is essential because the NIH is the primary funding source for discovery research through its competitive grants program. We look to the private sector to develop new treatments, but the private sector relies upon this federally-funded research to identify where to find the next break-through. This system of public-private partnership has been critical to U.S. leadership in the biomedical sciences. A recent article in the Proceedings of the National Academy of Sciences showed that all of the 210 new molecular entities approved by the Food and Drug Administration between 2010 and 2016 were associated with NIH-supported research. Importantly, 84 of those new drugs were first-in-class, meaning they work through a novel mechanism of action or target.¹

Federal research dollars also have a significant impact at the local level: Approximately 83 percent of the NIH budget is awarded to some 30,000 researchers who work in institutions throughout the country. They in turn use these grant funds to train students, pay research and administrative staff, purchase supplies and equipment, and cover other costs associated with their research. According to an updated

¹<http://www.pnas.org/content/early/2018/02/06/1715368115>.

2018 report, NIH research funding in fiscal year 2017 supported more than 400,000 jobs nationwide, generating nearly \$69 billion in total economic activity nationwide.²

The increases Congress has provided NIH over the last 3 years are helping to correct the devastating effects of sequestration and several years of budgets that declined in real terms due to inflation. To keep the agency on the right path forward, we urge you to continue providing meaningful and predictable annual budget increases that will keep up with the rate of inflation and take full advantage of the incredible opportunities for discovery that are before us.

As specified in the 21st Century Cures Act, NIH continues to pursue a number of important initiatives including the Cancer Moonshot, the All of Us program (formerly the precision medicine initiative), and the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative. These programs focus resources on specific areas of scientific opportunity that are ripe for innovation, but it is important to bear in mind that these projects build upon decades of basic research. If we are to advance our knowledge and lay the groundwork for similar opportunities for innovation in the future, NIH must continue to invest in creative investigator-initiated research.

Over the past several decades, NIH has used a merit-based peer review system to identify and fund the best research proposals. To date, NIH has supported the work of 153 Nobel Laureates, including the 2017 winners of the Chemistry and Physiology or Medicine prizes. Thanks to NIH research, Americans can expect to live longer and healthier lives. NIH also plays an important role in training the next generation of scientists, supporting trainees through individual fellowships and institutional grants as they complete their graduate degrees and seek the post-doctoral training necessary to pursue successful independent research careers.

Today significant challenges loom before us: The opioid epidemic has become a national public health crisis. An aging population will bring an increase in diseases that contribute to death and disability such as heart disease, diabetes, kidney disease, arthritis, and cancer. New and emerging infectious diseases will require us to be able to make a nimble investment of resources. If we are to continue to advance new and innovative ways to address these and other challenges on the horizon-including developing the workforce necessary to do so-the NIH will need stable and predictable funding increases in future years.

The APS joins the Federation of American Societies for Experimental Biology (FASEB) in urging that NIH be provided with no less than \$39.3 billion in fiscal year 2019. This represents a \$2 billion increase over fiscal year 2018 in addition to 21st Century Cures funding.

The American Physiological Society is a professional society dedicated to fostering research and education as well as the dissemination of scientific knowledge concerning how the organs and systems of the body work. The Society was founded in 1887 and now has more than 11,000 member physiologists. APS members conduct NIH-supported research at colleges, universities, medical schools, and other public and private research institutions across the U.S.

[This statement was submitted by Jeff Sands, MD, President, American Physiological Society.]

PREPARED STATEMENT OF THE AMERICAN PSYCHOLOGICAL ASSOCIATION

The APA is the largest scientific and professional organization representing psychology in the U.S.: its membership includes over 116,000 researchers, educators, clinicians, consultants and students. Many programs in the Labor-HHS-Education bill impact science, education, and the diverse populations served by clinical psychologists.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Administration for Community Living / Administration on Aging

APA supports \$187.5 million in funding to support the vital role of family caregivers in caring for older adults and the fiscal year 2018 funding levels for the Developmental Disabilities Act, Independent Living, Limb Loss, Traumatic Brain Injury and Paralysis Resource Center programs.

² <http://www.unitedformedicalresearch.com/wp-content/uploads/2018/02/NIHs-Role-in-Sustaining-the-U.S.-Economy-2018-Update-FINAL.pdf>.

Administration on Children and Families

APA supports \$1.7 billion in funding for the Social Services Block Grant for fiscal year 2019, which allows States and territories to provide vital social services including protective services, special services to people with disabilities, adoption services, and employment services. In addition, to ensure that the most vulnerable families have opportunities to thrive in their schools and communities, APA recommends \$100 million for Title I and \$80 million for Title II of the Child Abuse Prevention and Treatment Act (CAPTA).

Centers for Disease Control and Prevention (CDC)

The Committee is urged to provide \$8.445 billion for the Centers for Disease Control and Prevention's programs for fiscal year 2019, including \$50 million in funding for public health research into firearm morbidity and mortality prevention. We also urge you to protect CDC's National Center for Health Statistics' budget from further cuts and provide the agency with \$175 million in budget authority in fiscal year 2019, \$15 million more than fiscal year 2018.

APA strongly supports funding of \$327 million for the Title X Family Planning Program. Title X is the sole source of Federal funding for family planning for underserved populations, and provides vital access to birth control, cancer screenings, and testing for sexually transmitted infections for those who would otherwise not have access to these services.

APA requests \$660 million for the Maternal and Child Health Block Grant and recommends continued funding of \$5 million for the Maternal and Child Health Bureau to support depression screening and treatment for pregnant women.

National Institutes of Health

APA supports funding of at least \$39.3 billion in fiscal year 2019 for the NIH, including funds provided through the 21st Century Cures Act for targeted initiatives. This funding level would continue a trajectory of steady and predictable annual increases, allowing for meaningful growth above inflation in the base budget that would expand NIH's capacity to support promising science in all disciplines—and would ensure that the Innovation Account supplements the agency's base budget, as intended.

Research to Combat Opioid Abuse.—APA strongly encourages NIH to more fully examine the obstacles and opportunities to combat the opioid epidemic affecting pregnant women and children. The consequences of untreated illicit substance use by pregnant women and children are unique in their potential to impact the next generation. These consequences include premature birth, low birth weight, being small for gestational age; and in the longer term, behavioral and cognitive effects such as attention deficit disorders, language development, and emotional reactivity.

APA lauds the recently announced NIH HEAL (Help End Addiction Long-term) Initiative which will advance research in critically important programmatic areas including expanding therapeutic options for treating addiction, increasing access to non-pharmacologic treatments for chronic pain, an expanded focus on neonatal abstinence syndrome, and integrating substance use treatment within primary care and criminal justice settings. Missing from the rollout of the HEAL Initiative was any reference to the highly successful community prevention research portfolio managed by the National Institute on Drug Abuse (NIDA), which has demonstrated decreases in prescription drug misuse in rigorously designed randomized controlled trials. APA recommends that NIH include primary prevention research as the HEAL Initiative moves forward.

Loan Repayment Program for Pain and Addiction Research.—APA recommends that NIH immediately expand its Loan Repayment Program beyond the five currently eligible extramural programmatic areas to include mission-oriented pain and addiction research. Although some pain and addiction research could be effectively subsumed under the category of “clinical research,” APA believes the opioid crisis requires that NIH place added emphases on the training of scientists in these inextricably linked research domains as well as emphasize the primacy of non-human animal pain and addiction research. It was the HIV/AIDS epidemic that led Congress to address that critical area of need by authorizing the first LRP focused on AIDS Research in 1988. Congress expanded the scope of eligibility for the program with the NIH reauthorization in 2000 to include Clinical Research, Pediatric Research, Health Disparities Research, Contraception and Infertility Research, and Clinical Research for Individuals from Disadvantaged Backgrounds but to our knowledge, has not revisited those categories since.

NIMH behavioral research—APA appreciates the research supported by NIMH to address the causes, prevention, underlying mechanisms, and treatment of mental disorders, including current work in areas such as early detection of psychosis and

suicide prevention. Much of NIMH's focus and investment in the last decade has been on understanding the biological mechanisms underlying mental disorders, with funding directed particularly to research in neuroscience and genomics. Although biological approaches to understanding and treating mental disorders are indispensable, we believe that research addressing the behavioral and social levels of analysis, including work that does not directly examine neural or genomic phenomena, are also necessary and can provide unique insights for furthering our understanding of the causes and mechanism of mental disorders, and developing improved methods for preventing and treating them. APA encourages the Committee to join us in urging NIMH to broaden the portfolio of research it supports.

Clinical Trials Definition.—APA's basic scientists are understandably concerned that NIH's recently adopted definition of clinical trials now includes almost all basic research involving humans and burdensome new requirements for scientists whose research has not been considered "clinical" until now. We support NIH's goal to register all human research and report all results, but the definitional change does not further the stated aims of quantifying all NIH-supported research. We thank the Committee for its support on this issue, and, with our scientific association allies, hope to continue to engage with NIH to resolve the continuing difficulties caused by the definitional change.

Substance Abuse and Mental Health Services Administration

SAMHSA provides critical resources to reduce the impact of substance use disorders and mental illness on America's communities, including responding to the opioid crisis. APA supports \$5.666 billion in funding for the agency that includes support for the following programs. APA urges increased funding of the Minority Fellowship Program to reach \$20 million by 2020. Ethnic minorities represent 30 percent of the U.S. population, but only 23 percent of recent doctorates in psychology, social work and nursing. APA recommends \$72 million for Project AWARE (Advancing Wellness and Resilience in Education) and level funding for the National Child Traumatic Stress Network, to ensure access for children to high quality and evidence-based mental and behavioral health services.

APA strongly supports the Garrett Lee Smith Memorial Act (GLSMA) programs, which help meet the mental and behavioral health needs of youth and young adults by increasing access to prevention, education, and outreach services to reduce suicide risk in States, tribes, and institutions of higher education. APA encourages Congress to maintain current funding levels for these programs in fiscal year 2019, including \$35.4 million for the State and Tribal Youth Suicide Prevention Program, \$7 million for the Campus Mental and Behavioral Health Program, and \$6 million for the Suicide Prevention Resource Center.

Health Resources and Services Administration (HRSA)

There is overwhelming evidence that our Nation's mental and behavioral health workforce must be expanded to respond adequately to the opioid epidemic, as well as the healthcare needs of our increasingly diverse and aging population. Psychologists, as researchers and practitioners, are integral to a healthcare system in which more than half of U.S. mortality is linked to behavior, and in which mental and behavioral disorders are a significant public health concern.

APA supports robust investments in the Bureau of Health Workforce, which supports critical mental health workforce training programs. APA strongly encourages the Committee to maintain \$36 million for HRSA's Mental and Behavioral Health Account in fiscal year 2019, with at least \$15 million for the interprofessional Graduate Psychology Education Program to increase the number of health service psychologists trained to provide integrated services to high-need, underserved populations in rural and urban communities. In addressing the opioid epidemic, APA urges the Committee to recognize the growing need for highly trained mental and behavioral health professionals to deliver evidence-based behavioral interventions for pain management. In addition, APA recommends the Committee provide \$75 million for Behavioral Health Workforce Education and Training Program, and \$41 million for the Geriatric Workforce Enhancement Program.

DEPARTMENT OF EDUCATION

APA supports an increase in funding for Federal grant programs that support graduate study, including the Graduate Assistance in Areas of National Need (GAANN) Program, where psychology is recognized as a national need area. In addition, we urge you to support the Institute of Education Sciences (IES), with \$670 million for fiscal year 2019. This level of funding is essential to maintain and build upon the research and data infrastructure that State and local education leaders depend on to make effective and efficient decisions.

Sincere thanks to the Labor-HHS-Education Subcommittee for accepting public witness testimony for the record.

PREPARED STATEMENT OF THE AMERICAN PUBLIC HEALTH ASSOCIATION

APHA is a diverse community of public health professionals who champion the health of all people and communities. We are pleased to submit our request to fund the Centers for Disease Control and Prevention at \$8.445 billion and the Health Resources and Services Administration at \$8.56 billion in fiscal year 2019. We strongly urge you to reject the many proposed cuts to important CDC and HRSA programs contained in the president's fiscal year 2019 budget proposal.

Centers for Disease Control and Prevention: We believe Congress should support CDC as an agency and urge a funding level of \$8.445 billion in fiscal year 2019. We are grateful for the important increases provided for CDC programs in the fiscal year 2018 omnibus bill and urge Congress to build upon these investments to strengthen all of CDC's programs. We continue to oppose any effort to repeal or cut the Prevention and Public Health Fund which currently makes up approximately 10 percent of CDC's budget. Congress must ensure that the CDC's budget remains whole in the face of these efforts that threaten many CDC programs.

CDC provides the foundation for our State and local public health departments, supporting a trained workforce, laboratory capacity and public health education communications systems. It is notable that more than 70 percent of CDC's budget supports public health and prevention activities by State and local health organizations and agencies, national public health partners and academic institutions.

CDC serves as the lead agency for bioterrorism and other public health emergency preparedness and response programs and must receive sustained support for its preparedness programs. Given the challenges of terrorism and disaster preparedness we urge you to provide adequate funding for the Public Health Emergency Preparedness grants which provide valuable resources to State and local health departments to protect communities in the face of public health emergencies.

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 Zika virus to playing a lead role in the control of Ebola in West Africa and detecting and responding to cases in the U.S., to monitoring and investigating disease outbreaks 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. States, communities and the international community rely on CDC for accurate information and direction in a crisis or outbreak.

Programs under the National Center for Chronic Disease Prevention and Health Promotion address heart disease, stroke, cancer, diabetes and arthritis that are the leading causes of death and disability in the U.S. These diseases, many of which are preventable, are also among the most costly to our health system. The center 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.

The National Center for Environmental Health works to control asthma, protect from threats associated with natural disasters and climate change, reduce, monitor and track exposure to lead and other environmental health hazards and ensure access to safe and clean water. We urge you to support adequate funding for all NCEH programs.

In 2016, opioids killed more than 42,000 individuals nationwide. CDC provides States with resources for opioid overdose prevention programs and to ensure that health providers to have the information they need to improve opioid prescribing and prevent addiction and abuse. The National Center for Injury Prevention and Control must be adequately funded to prevent injuries and help save lives. This includes providing CDC with \$50 million in fiscal year 2019 for gun violence prevention research. Each year, 38,000 Americans lose their lives due to gun violence. The Dickey amendment has stymied our progress on gun violence prevention research for the past 20 years and Congress must correct this by removing this language and providing CDC with this critical investment to begin this long overdue gun violence prevention research.

The development of antimicrobial resistance is occurring at an alarming rate, far outpacing the research and development of new antibiotics. Congress should con-

tinue support for CDC's Antibiotic Resistance Initiative and efforts to bolster prevention and control activities, enhanced data collection and surveillance and antimicrobial stewardship.

Health Resources and Services Administration: HRSA operates programs in every State and U.S. territory and has a strong history in improving the health of Americans through the delivery of quality health services and supporting a well-prepared workforce, serving people who are medically underserved or face barriers to needed care.

We are grateful for the increases provided for HRSA programs in the fiscal year 2018 omnibus and we urge Congress to continue their support for these important programs in fiscal year 2019. We recommend providing \$8.56 billion for HRSA's total discretionary budget authority in fiscal year 2019 in order to keep pace with our growing, aging and diversifying population, constantly evolving healthcare system, and the persistent and changing health demands of our Nation. Furthermore, the U.S. is facing a severe shortage of health professionals, which disproportionately affects rural and underserved communities. HRSA grantees are well positioned to address these issues and have a successful history of doing so, but additional funding is required to build upon these successes and pave the way for new achievements by supporting critical HRSA programs, including:

- Primary Health Care* that supports more than 10,400 health center sites in every State and U.S. territory, improving access to care for more than 27 million patients in underserved communities. HRSA-funded community health centers provide comprehensive, cost-effective care by reducing barriers such as cost, lack of insurance, distance, and language for their patients.
- Health Workforce* supports the education, training, scholarship and loan repayment for health professionals across the entire training continuum. These are the only Federal programs focused on addressing Health Professional Shortage Areas, and improving the distribution and diversity of the workforce. The programs are responsive to the changing delivery systems, models of care and healthcare needs, and encourage collaboration between disciplines to provide effective and efficient coordinated care.
- Maternal and Child Health* including Title V Maternal and Child Health Block Grant, Healthy Start and others support initiatives designed to promote optimal health, reduce disparities, combat infant mortality, prevent chronic conditions and improve access to quality healthcare, including children with special healthcare needs such as autism and developmental disabilities.
- HIV/AIDS* programs provide assistance to States and communities most severely affected by HIV/AIDS, delivering comprehensive care, prescription drug assistance and support services for more than 550,000 people impacted by HIV/AIDS. Additionally, the programs provide education and training for health professionals treating people with HIV/AIDS and work toward addressing the disproportionate impact of HIV/AIDS on racial and ethnic minorities. HRSA's Ryan White HIV/AIDS Program effectively engage clients in comprehensive care and treatment, including increasing access to HIV medication, which has resulted in 85 percent of clients achieving viral suppression, compared to just 49 percent of all people living with HIV nationwide.
- Family Planning* Title X services ensure access to a broad range of reproductive, sexual and related preventive healthcare for more than 4 million women, men and adolescents, with priority given to low-income individuals. This program promotes healthy families, helps improve maternal and child health outcomes, reduces unintended pregnancy rates, limits transmission of sexually transmitted infections and increases early detection of breast and cervical cancer.
- Rural Health* improves access to care for people living in rural areas that experience a persistent shortage of healthcare services. These programs are designed to support community-based disease prevention and health promotion projects, help rural hospitals and clinics implement new technologies and strategies and build health system capacity in rural and frontier areas.

In closing, we emphasize that the public health system requires stronger financial investments at every stage. This funding makes up less than 1 percent of Federal spending. Cuts to public health and prevention programs will not balance our budget and will only lead to increased costs to our healthcare system. Prevention opportunities, screening programs, lifestyle and behavior changes and other population-based interventions are effective, and a stronger investment in these programs will enable us to meet the mounting health challenges we currently face and to become a healthier Nation.

Thank you for considering our views on fiscal year 2019 funding for these critical Federal public health agencies and programs.

[This statement was submitted by Georges C. Benjamin, MD, Executive Director, American Public Health Association.]

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

Chairman Roy Blunt, Ranking Member Patty Murray, and Members of the Subcommittee, the American Red Cross and the United Nations Foundation appreciate the opportunity to submit testimony in support of measles and rubella control activities of the U.S. Centers for Disease Control and Prevention (CDC). The American Red Cross and the United Nations Foundation recognize the leadership that Congress has shown in funding CDC for these essential and life-saving activities. We request this subcommittee support CDC's global measles control activities for fiscal year 2019 at \$50 million.

THE MEASLES & RUBELLA INITIATIVE

In 2001, CDC—along with the American Red Cross, the United Nations Foundation, the World Health Organization (WHO), and UNICEF—founded the Measles Initiative, a partnership committed to reducing measles deaths globally. In 2012, the Initiative expanded to include rubella control and adopted a new name, the Measles & Rubella Initiative. In 2013, all WHO regions established measles elimination goals by 2020. The Measles & Rubella Initiative is committed to reaching these goals by providing technical and financial support to governments and communities worldwide.

The Measles & Rubella Initiative has achieved outstanding results by supporting the vaccination of more than two billion children since 2001 and saving the lives of more than 20 million children. In part due to the Measles & Rubella Initiative, global measles mortality dropped 84 percent, from an estimated 651,600 deaths in 2000 to an estimated 90,000 in 2016 (the latest year for which data is available). During this same period, measles deaths in Africa fell by 89 percent. However, in 2016 approximately 246 children died every day from a virus that can be prevented by a safe, effective and inexpensive vaccine. Measles is among the most contagious diseases ever known, and a top killer of children in low-income countries where children have little or no access to medical treatment and are often malnourished.

Measles spreads much more quickly than the flu or the Ebola virus. A single person infected with measles can infect up to 18 other unvaccinated people, compared with three for Ebola. The 2014–2015 Ebola outbreak in Guinea, Sierra Leone and Liberia killed a total of 11,310 people. By comparison 2014, measles killed more than 100,000 people worldwide. Measles can also cause severe complications such as pneumonia and encephalitis. In addition, each year more than 100,000 children are born with congenital rubella syndrome (CRS). CRS can cause severe birth defects, including blindness, deafness, heart defects and mental retardation. CRS is very costly to treat, yet very inexpensive to prevent. In lower income countries, it costs less than \$2 to vaccinate a child against both measles and rubella.

Working closely with host governments, the Measles & Rubella Initiative has been the main international supporter of mass measles immunization campaigns since 2001. The Initiative mobilized more than \$1.2 billion and provided technical support in 88 developing countries on vaccination campaigns, surveillance and improving routine immunization services. From 2000 to 2016, an estimated 20.4 million measles deaths were averted as a result of these accelerated measles control activities, making measles mortality reduction one of the most cost-effective public health interventions. Between 2000–2016, measles vaccines were the single greatest contribution to reducing preventable child deaths. Thanks to the efforts of CDC along with global partners, measles declined from the fifth leading cause of death in 2000 to the twelfth in 2016.

The majority of measles vaccination campaigns have been able to reach more than 90 percent of their target populations. Countries recognize the opportunity that measles vaccination campaigns provide in accessing mothers and young children and integrating the campaigns with other life-saving health interventions has become the norm. In addition to measles vaccine, other health interventions are often distributed during campaigns. These include: administering vitamin A, which is crucial for preventing blindness in under nourished children; de-worming medicine to reduce malnutrition; and distributing insecticide treated bed nets to help prevent malaria and screening for malnutrition. Doses of oral polio vaccines are also frequently dispensed during measles campaigns in polio-endemic and high-risk countries. The delivery of polio vaccines in conjunction with measles vaccines in these campaigns strengthens the reach of elimination and eradication efforts of both dis-

eases. The provision of multiple child health interventions during a single campaign is far less expensive than delivering the interventions separately. This strategy increases the potential positive impact on children's health from a single campaign while serving to increase vaccination coverage rates.

In addition to the lifesaving benefits of measles vaccines, immunization makes sound economic sense. A recent study by Johns Hopkins University revealed the economic benefits of increased investment in global vaccination programs. The study compared the costs for vaccinating against 10 disease antigens in 94 low- and middle-income countries during the period 2011–2020 versus the costs for estimated treatments of unimmunized individuals during the same period. Their findings show, on average, every \$1 invested in these 10 immunizations produces \$44 in savings in healthcare costs, lost wages, and economic productivity. The return on investment for measles immunization was particularly high, at \$58 saved for every \$1 invested.

In 2016, the Measles and Rubella Initiative requested an independent evaluation of progress towards the Global Measles and Rubella Strategic Plan, 2012–2020. This evaluation found that the technical strategies are sound and elimination is feasible as evidenced by the certification of the elimination of measles in the Americas during 2016. The Americas eliminated rubella in 2015. The review recommended that to achieve the elimination goals and avoid a resurgence of measles, the following actions are required:

- Sustaining the gains in reduced measles deaths, especially in Africa, by strengthening disease surveillance and immunization programs to ensure rapid disease detection and more than 90 percent of infants are vaccinated against measles through routine health services as well as conducting timely, high quality mass immunization campaigns. Routine immunization is the foundation to achieving and sustaining high levels of immunity to measles and rubella in the community.
- Accelerating the introduction of a second dose of measles-containing vaccine and a dose of rubella vaccine into the routine immunization program of eligible countries with support from Gavi, the Vaccine Alliance.
- Fully implementing activities, both through campaigns and strengthening routine measles vaccination coverage, particularly in Democratic Republic of Congo, Ethiopia, India, Indonesia, Nigeria, and Pakistan which together account for the majority of measles cases and 75 percent of measles deaths.
- Securing sufficient funding for measles and rubella-control activities both globally and nationally. Between 2018–2020 the Measles & Rubella Initiative is facing a funding shortfall of U.S. \$108 million. The decrease in donor funds available at a global level to support measles and rubella elimination activities makes increased political commitment and country ownership of the activities critical for achieving and sustaining the goal of reducing measles mortality by 95 percent. Implementation of timely measles and rubella campaigns is increasingly dependent upon countries funding these activities locally, which can be challenging under such downward financial pressure. For 9 months of 2016, labs in Africa did not have funds to buy diagnostic kits to confirm measles cases. Without these kits, it was impossible to distinguish measles from other causes of fever and rash such as dengue and parvovirus B19. Responding to a dengue outbreak with measles vaccine risks lives, wastes resources and diminishes confidence in the effectiveness of the vaccine.

If these challenges are not addressed, the remarkable gains made since 2000 will be lost and a major resurgence in measles death and disability will occur. Measles is one of the most contagious diseases known to humans and, due to our highly interconnected world, measles can be spread globally including to countries that have already eliminated the disease. The threat of importation of measles was one of the reasons that the Global Health Security Agenda has selected measles as an important indicator of whether a country's routine immunization system is vaccinating all children. Additionally, the ability of a country to rapidly detect and respond to measles cases is a marker of the quality of a routine immunization system to identify and respond to disease outbreaks more generally.

Controlling measles and rubella cases in other countries also protects adults and children in the U.S. In the United States, measles control measures have been strengthened, and endemic transmission of measles cases has been eliminated since 2000 and rubella in 2002. However, importations of measles cases into this country continue to occur each year. Since 2000, the annual number of people reported to have measles ranged from a low of 37 in 2004 to a high of 667 people across 27 States in 2014; the greatest number of cases reported in the U.S. since measles was declared eliminated in 2000. Additionally, on July 2, 2015, the Washington State

Department of Health confirmed a measles-related death—the first death in 12 years in the U.S. Last year, 123 people in 15 States were reported to have measles.

Responding to a measles outbreak can cost State and local health departments \$100,000 per case to halt disease spread. One in four cases of measles requires hospitalization, costing up to \$15,000 per patient. For people experiencing complications such as encephalitis, occurring in one in 1,000 cases, the diagnosis and treatments can cost patients more than \$100,000. In the U.S., caring for a person with congenital rubella syndrome can cost close to \$1 million over the patient's lifetime.

Eliminating measles and rubella is the right thing to do for children to meet their full potential. The \$58 to \$1 return on investment, coupled with the benefit of protecting American children against importation of measles into the U.S., demonstrates that investments in CDC's measles and rubella elimination program is an excellent use of taxpayer dollars. We should be united in our commitment to end these dangerous diseases because until we achieve this goal, we are all at risk. By supporting the work of the CDC, we can save lives and prevent the needless suffering measles and rubella cause.

THE ROLE OF CDC IN GLOBAL MEASLES MORTALITY REDUCTION

Since fiscal year 2001, Congress has provided funding to protect children and their families from the threat of measles and rubella in developing countries. This support has assisted 88 countries around the world and has contributed to saving the lives of 20.4 million children over the past 16 years. For this support, we extend our deep appreciation to Congress. This support permitted the provision of technical support to Ministries of Health that specifically included:

- Planning, monitoring, and evaluating large-scale measles vaccination campaigns;
- Conducting epidemiological investigations and laboratory surveillance of measles outbreaks;
- CDC's Global Measles Reference Laboratory to serve as the leading worldwide reference laboratory for measles and rubella. The reference laboratory provides specimen confirmation and testing as well as training for country and regional labs; and
- Conducting operations research to guide cost-effective and high-quality measles control programs.

In addition, CDC epidemiologists and public health specialists have worked closely with WHO, UNICEF, the United Nations Foundation, and the American Red Cross to strengthen measles and rubella control programs at global and regional levels and will continue to work with these and other partners in implementing and strengthening rubella control programs. There is no doubt that CDC's financial and technical support—made possible by the funds appropriated by Congress—were essential in helping achieve the sharp reduction in measles deaths in just 15 years.

The American Red Cross and the United Nations Foundation would like to acknowledge the leadership and work provided by CDC and recognize that CDC brings much more to the table than just financial resources. The Measles & Rubella Initiative is fortunate to have a partner that provides critical personnel and technical support for vaccination campaigns and in response to disease outbreaks. CDC personnel have routinely demonstrated their ability to effectively coordinate and plan with international organizations and provide solutions to complex problems that help critical work get done faster and more efficiently.

Since fiscal year 2010, the CDC's measles and rubella elimination program has been funded at approximately \$50 million. In fiscal year 2019, the American Red Cross and the United Nations Foundation respectfully request the continuation of level funding of \$50 million. This investment will allow CDC to maintain measles and rubella control and elimination activities, safeguard the progress made over the last decade and protect Americans by preventing measles cases and deaths in the United States.

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 Jono Anzalone, Vice President, International Services, American National Red Cross and Kathy Calvin, President, Chief Executive Officer, United Nations Foundation.]

PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR BIOCHEMISTRY AND MOLECULAR BIOLOGY

America is the global leader for biomedical research and innovation, and that leadership mantle is made possible by the robust investments in the National Institutes of Health that begin here, with the bipartisan support of the members of this subcommittee. Under the leadership of Chairman Blunt and Ranking Member Murray, the NIH has seen its budget begin to grow again, following a decade of stagnant investments, at a time when Federal investments in research—especially basic research—are critically important. For this reason, we ask the subcommittee to continue its commitment to the biomedical research community, and fund the NIH at a level 3.5 percent above the fiscal year 2018 level for fiscal year 2019. Specifically, this increase should support investigator initiated research (R-01 grants), in an attempt to improve historical low funding success rates at many of the institutes that make up the NIH. We thank you for your commitment, and look forward to working with you and the rest of the committee as partners into the future.

ASBMB is a nonprofit scientific and educational organization that was established in 1906 by 28 biochemists and has since grown to an organization with more than 12,000 members worldwide. Most members conduct research and teach at colleges and universities, government laboratories, at nonprofit research institutions and in industry. The Society's student members attend undergraduate and graduate institutions. We are proud to include 97 Nobel Prize winners among our members since 1922. The increased longevity and improved quality of life enjoyed by Americans over the past century can be attributed in large part to innovations resulting from discoveries and breakthroughs in biomedical research—most of which stem from biochemistry and molecular biology. Beyond health improvements, the biomedical research enterprise has been a key segment of economic growth and job creation in the 21st century.

Let me highlight a few key contributions made in the fields represented by ASBMB that have made this possible. One area of biochemistry is metabolism, i.e. the conversion of nutrients in food into other molecules that are essential for normal, healthy biological function. For example, the conversion of fats into cholesterol is important for health, but excess cholesterol increases the risk of cardiovascular disease. NIH funded research on this biochemical pathway provided the knowledge required for the development of a number of drugs that reduce cholesterol, which have contributed greatly to the reduction in death due to cardiovascular disease.

Molecular biology, which emerged as a marriage of biochemistry and genetics, is the foundation for much of modern biomedical science including genomics and other cutting edge technologies being used today. Discoveries in molecular biology, supported by funding from the NIH, led to the development of biotechnology as an entirely new industry. Biotechnology allows the production of complex biological molecules such as human insulin and antibodies such as the breast cancer drug, Herceptin. The lives of individuals with diabetes, cancer, and many other disorders have been greatly improved because these molecules are now produced in pure form and in sufficient quantity for use as drugs. Furthermore, the United States has been the leader in this important new industry largely because the key, foundational discoveries were made here.

The power of these approaches, both as research tools and as drivers for industry, had become strikingly clear toward the end of the last century. Congress wisely supported substantial increases in the appropriation for the NIH between 1998 and 2003. Those funds made it possible to increase the capability of the biomedical research enterprise in the United States. Established scientists were able to take their research in new directions and many talented young scientists launched productive careers. Sequencing of the human genome was completed and many important and unanticipated discoveries were made. Many of these exposed levels of complexity in biological systems that had not been anticipated. For example, RNA, a close cousin of DNA, was found to play new roles in regulating biological systems in important, but subtle, ways. The human body was found to include more microbial cells than human cells. NIH funded Research has shown that these microbes contribute to both health and disease in newly discovered and unexpected ways.

Despite this impressive progress, there is still much to learn about human biology to enable the successful translation of what we do know into improvements in human health. NIH funded research has successfully reduced the mortality and morbidity of once acute and lethal conditions. This research continues to reduce the burden of heart disease, cancer, stroke (the three leading causes of death in the United States), as well as other diseases such as AIDS, Alzheimer's and diabetes. Robust and sustainable future funding for NIH will support continued biomedical research that saves lives, improves human health and provides the basic knowledge

needed by private industry to develop the drugs and therapies we rely upon today and will continue to rely on in years to come.

When setting budgetary priorities, it is important to remember that technological innovation will be a key component for our future economic security and international competitiveness. More than 80 percent of the investment this Congress makes in the NIH leaves the Bethesda campus and funds academic researchers across the country. Each NIH grant—on average—supports approximately seven high-tech, high-paying jobs. These are precisely the type of jobs each member of this committee would want to have in their own district. These are also the kind of jobs that contribute to a 21st century, technology and information based economy. Additionally, analysis of the economic impact of your NIH investments indicates that for every \$1 invested in the NIH, the economy derives a \$2 return. Finally, investment in research will continue to modernize our Nation's research laboratories and facilities, spur innovation, provide an immediate boost in employment for our Nation's workforce, and train the next generation of scientists.

The ASBMB understands the Nation is facing difficult budgetary decisions, with Federal spending reaching nearly unsustainable levels. Some programs will need to be cut, while some, such as biomedical research, cannot sustain continued, "stop-start" funding. Given this context, our membership appreciates that the Congress recognizes the importance of NIH support, if the US is to contribute to biomedical discovery at the cutting edge.

Today, the U.S. stands proud as the world's leader in biomedical research, but this will not continue to be true if we do not do all we can in support of the NIH. The American biomedical research enterprise plays a critical role in creating high-tech, high-paying jobs, helping to keep America a global leader in innovation and discovery, but it cannot do so without a reliable and robust Federal investment.

[This statement was submitted by Benjamin Corb, Director of Public Affairs, American Society for Biochemistry and Molecular Biology.]

PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR ENGINEERING EDUCATION

SUMMARY

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 the fiscal year (FY) 2018 omnibus and asks you to robustly fund student aid, teacher preparation, and STEM programs in fiscal year 2019. Additionally, ASEE requests Federal funding to support initiatives aimed to increase the access and success of historically underrepresented populations in engineering and other STEM fields. The strong support of the National Institutes of Health (NIH) in fiscal year 2018 was greatly appreciated and ASEE advocates for the continued support of NIH.

WRITTEN TESTIMONY

The American Society for Engineering Education (ASEE) is dedicated to advancing engineering and engineering technology education and research, 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. The U.S. engineering workforce numbered 1.7 million people in 2015,¹ the most jobs of any STEM discipline, and the demand for engineering professionals continues to grow. As the pre-eminent authority on the education of engineering professionals, ASEE works to develop the future engineering and engineering technology workforce, expand technological literacy, and convene academic and corporate stakeholders to advance innovation and sound policy.

Student Aid

Student aid programs like Pell Grants, Federal Work-Study (FWS), TRIO, and others make higher education accessible for millions of students. ASEE joins the higher education community in requesting funding to support a maximum Pell Award of \$6,230. Pell Grants provide need-based aid to students with demonstrated financial need. These awards are vital in helping students access the life-altering

¹National Science Board. 2018. Science and Engineering Indicators 2018. NSB-2018-1. Alexandria, VA: National Science Foundation.

impacts that higher education provides. ASEE requests funding for FWS at \$1.206 billion and \$896 million for Supplemental Educational Opportunity Grant (SEOG). These programs are need-based, and often this aid is the difference between a student completing and securing a degree and dropping out. ASEE firmly believes in ensuring access to engineering and engineering technology education for all students, not just those who can afford it. It is important that student aid options, particularly for graduate students, are maintained. Engineering education provides a proven pathway to the middle class, especially for students from low-income backgrounds. It is critical that this pathway continues to be accessible to students in need.

Teacher Preparation

The need for strong 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. 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. A lack of focus on engineering in K12 teacher preparation and professional development is exacerbated by the low levels of funding these programs have received. Programs like UTeach, a STEM teacher preparation program that expands access to STEM education and improves STEM learning outcomes by supporting a national network of universities and STEM educators are vital to increasing the number of high-quality teachers. 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 funding increases many STEM programs received in fiscal year 2018. ASEE supports funding for Title IV of ESEA at its authorized amount of \$1.6 billion, which will allow states and school districts additional resources to pursue STEM programs. The need to expand the inclusion of historically underrepresented populations in STEM is also a priority for ASEE. 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, particularly the engineers, technologists, and computer scientists, is the driving force behind innovation 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.

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 fiscal year 2018. 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 Subcommittee to provide NIH with \$39.3 billion in fiscal year 2019 so that NIBIB can continue to support critical biomedical engineering research and training.

CONCLUSION

Engineering and engineering technology education and research investments are vital in supporting communities, providing opportunities, and spurring our economy. We ask that you robustly support these critical programs. Thank you for the opportunity to submit this testimony.

[This statement was submitted by Bevelee Watford, Ph.D., P.E., 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) appreciates the opportunity to submit this statement in support of making medical research, public health, and public health emergency preparedness national priorities as you begin consideration of spending for fiscal year 2019.

ASM is the largest single life science society, composed of more than 50,000 scientists and health professionals. Our mission is to promote and advance the microbial sciences, including programs and initiatives funded by the Federal Government departments and agencies, by virtue of the pervasive role of microorganisms in health and society. The Department of Health and Human Services (HHS) is home to a number of very important initiatives of interest to ASM members.

This year marks the 100th anniversary of the Great Influenza pandemic, which killed almost 40 million people, reminding us that we must remain prepared for rapid research and development of therapeutics, vaccines and medical diagnostics in the face of emerging infectious disease epidemics. Research is integral to this preparedness as is our investment to rapidly respond to declared and potential public health emergencies.

Among the most consequential issues facing world is antimicrobial resistance. ASM urges the Subcommittee to recommit in fiscal year 2019 to funding research and programs to address this growing threat. According to the Centers for Disease Control and Prevention (CDC), each year in the United States, at least two million people become infected with bacteria that are resistant to antibiotics and at least 23,000 people die each year as a direct result of these infections. Furthermore, these infections result in an additional \$20 billion per year of excess costs to our healthcare system. Dedicated funding for antibiotic resistance through the National Institutes of Health (NIH), the CDC, and the Agency for Healthcare Quality and Research should continue, as well as increased funding for the HHS public health emergency preparedness programs that allow for the development and rapid deployment of medical countermeasures, including those to combat antibiotic resistant bacteria that could be used in a biological attack.

Medical Research Funding

The ASM appreciates the Subcommittee's leadership in securing a \$3 billion increase for the NIH in the fiscal year 2018 Omnibus Appropriations bill, which brought its funding level to \$37.084 billion. We also appreciate the funding increase for research on antibiotic resistance and the development of a universal influenza vaccine through the National Institute of Allergy and Infectious Diseases (NIAID). We encourage the Subcommittee to continue prioritizing medical research by increasing the NIH's budget in fiscal year 2019 by \$2 billion, including an additional \$215 million in 21st Century Cures Act funding.

Central to advancing research to defend against infectious disease is a better understanding of the human microbiome. This April the Interagency Strategic Plan for Microbiome Research (SPMR) was released by the Microbiome Interagency Working Group, an interagency working group under the Life Sciences Subcommittee of the National Science and Technology Council Committee on Science. This plan includes five strategic research areas, including human health and safety, to support the plan's three research objectives (Support Interdisciplinary Research; Develop Platform Technologies; and Expand the Microbiome Workforce).

Microbial communities live in and on all surfaces of the human body, and play a vital role in human health and development. Indeed, the functions of many organ systems and body regions depend on microorganisms: gastrointestinal tract, respiratory tract, oral, urogenital, brain, skin, cardiovascular system, blood, immune system. Expanding our knowledge of the microbiome through NIH-funded research can help us understand the diseases associated with these organ systems and body regions.

As highlighted in the SPMR, important microbiome discoveries must be used to better understand human health and transformed into strategies for microbiome-based therapeutic intervention and treatments for disease. Microbiome research is also integral to developing new antimicrobials and understanding the role of specific foods on the microbiome and the intersection between nutrition and obesity, heart disease and cancer. We urge the Subcommittee to provide a sizable increase to the NIH to further important cross-cutting microbiome research.

Public Health and Preparedness Against Public Health Emergencies

Another ASM priority area is public health emergency preparedness. This May, the Health, Education, Labor and Pensions Committee approved the Pandemic and All-Hazards Preparedness Advancing Innovation Act—legislation strongly supported by the ASM. Reauthorization of the Pandemic and All-Hazards Preparedness Act must be met with a corresponding commitment of Federal resources. The ASM calls upon Congress to fund at authorized levels, beginning with fiscal year 2019, the programs supported by the legislation, including the: Public Health Emergency Preparedness Program at the CDC; Hospital Preparedness Program; Strategic National Stockpile; Biomedical Advanced Research Development Authority; and the Bioshield Special Reserve Fund.

Increases to the Strategic National Stockpile and the CDC's Public Health Emergency Preparedness Program will not be possible without a strong investment in the CDC. The ASM requests a funding level of \$8.445 billion for the CDC in fiscal year 2019 and asks the Subcommittee to prioritize funding within that budget for global health. In this era of mass global travel, the United States must make a strong commitment to health security both at home and abroad to secure its borders against public health threats.

The Ebola and Zika pandemics did not originate within our borders, but traveled here quickly. There is no question that there will be another threat. The only questions are when and where in the world it will originate. Protecting Americans requires stopping these public health threats at their points of origin, which requires a strong, effective, and strategically placed U.S. global presence, but this entails continued and effective investments in both the domestic and global capacity to prevent, detect, and respond to biological threats.

The United States must also continue its investments in emerging and zoonotic infectious diseases, including vector borne diseases. Threats include the emergence of West Nile, Chikungunya, and Zika viruses, as well as the continued geographic expansion of dengue and yellow fever viruses and Lyme disease. In fact, the CDC recently reported that vector borne diseases are a large and growing public health problem in the United States.

Conclusion

The ASM again commends the Subcommittee for the increases in funding for the NIH, CDC, Assistant Secretary for Preparedness and Response, and Public Health and Social Services Emergency Fund in fiscal year 2018 and asks that you reject cuts to these agencies and divisions as called for in the President's budget request. We appreciate the increased Labor-HHS-Education spending allocation for fiscal year 2019, but we are concerned that an allocation of \$179.288 billion may not allow for the increases that are needed to advance medical research, public health and public health emergency preparedness in a way that is necessary.

Thank you for the opportunity to submit this testimony for the record. Should you have any questions, please contact Camille Bonta, ASM policy advisor.

PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR NUTRITION

Dear Chairman Blunt and Ranking Member Murray:

Thank you for the opportunity to provide testimony regarding fiscal year 2019 appropriations. The American Society for Nutrition (ASN) respectfully requests at least \$39.3 billion dollars for the National Institutes of Health (NIH) and \$175 million dollars for the Centers for Disease Control and Prevention/National Center for Health Statistics (CDC/NCHS) in fiscal year 2019. ASN is dedicated to bringing together the world's top researchers to advance our knowledge and application of nutrition, and has more than 6,500 members working throughout academia, clinical practice, government, and industry.

NATIONAL INSTITUTES OF HEALTH

The NIH is the Nation's premier sponsor of biomedical research and is the agency responsible for conducting and supporting 86 percent of federally-funded basic and

clinical nutrition research. Although nutrition and obesity research make up less than 8 percent of the NIH budget, some of the most promising nutrition-related research discoveries have been made possible by NIH support. NIH nutrition-related discoveries have impacted the way clinicians prevent and treat heart disease, cancer, diabetes and other chronic diseases. For example, from 2001 to 2011, the U.S. death rate from heart disease has fallen by about 39 percent and from stroke by about 35 percent.¹ However, the burden and risk factors remain high. With additional support for NIH, additional breakthroughs and discoveries to improve the health of all Americans will be made possible.

Investment in biomedical research generates new knowledge, improved health, and leads to innovation and long-term economic growth. From fiscal year 2003 to 2015, the NIH lost 22 percent of its capacity to fund research due to budget cuts, sequestration, and inflationary losses. Such economic stagnation is disruptive to training, careers, long-range projects and ultimately to progress. Since fiscal year 2016, Congress has begun to restore the NIH budget but there is much work to be done; in real dollars, the NIH budget is still 16 percent below the fiscal year 2003 level. ASN recommends at least \$39.3 billion dollars for NIH in fiscal year 2019 to support NIH nutrition-related research that will lead to important disease prevention and cures. A budget of \$39.3 billion will allow NIH to support at least 400 additional early career and early established investigators 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, and to improve the health of all Americans.

CENTERS FOR DISEASE CONTROL AND PREVENTION NATIONAL CENTER FOR HEALTH
STATISTICS

The National Center for Health Statistics (NCHS), housed within the Centers for Disease Control and Prevention (CDC), is the Nation's principal health statistics agency. ASN recommends a fiscal year 2019 funding level of \$175 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. A decade of flat-funding has taken a significant toll on NCHS's ability to keep pace.

The NCHS provides critical data on all aspects of our healthcare system, and it is responsible for monitoring the Nation's health and nutrition status through surveys such as the National Health and Nutrition Examination Survey (NHANES), that serve as a gold standard for data collection around the world. Nutrition and health data, largely collected through NHANES, are essential for tracking the nutrition, health and well-being of the American population, and are especially important for observing nutritional and health trends in our Nation's children.

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, which are consumed in inadequate amounts by many subsets of our population. Data such as these are critical to guide policy development in health and nutrition, including food safety, food labeling, food assistance, military rations and dietary guidance. For example, NHANES data are used to determine funding levels for programs such as the Supplemental Nutrition Assistance Program (SNAP) and the Women, Infants, and Children (WIC) clinics, which provide nourishment to low-income women and children.

Thank you for the opportunity to submit testimony regarding fiscal year 2019 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,

¹ https://www.heart.org/idc/groups/ahamah-public/@wcm/@sop/@smd/documents/downloadable/ucm_470704.pdf.

at 9211 Corporate Boulevard, Suite 300, Rockville, Maryland 20850 or jcourtney@nutrition.org, if ASN may provide further assistance.

Sincerely,

[This statement was submitted by Mary Ann Johnson, Ph.D., President, American Society for Nutrition.]

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF CLINICAL ONCOLOGY

The American Society of Clinical Oncology (ASCO), the world's leading professional organization representing nearly 45,000 physicians and other professionals who treat people with cancer, thanks this Subcommittee for its long-standing commitment to support federally funded research at the NIH and the NCI. ASCO applauds your leadership in securing a \$3 billion increase for the NIH in fiscal year 2018. This strong recommitment to scientific discovery will help the research community regain momentum and sustain our Nation's position as the world leader in biomedical research. We are in an exciting and promising era of medical research; new discoveries are leading to major improvements in the way we care for patients with cancer. Continued progress in preventing and treating cancer depends on consistent and reliable funding for research that provides the insight needed for better treatments and quality of life for all Americans. For fiscal year 2019, ASCO calls for continued support for biomedical support by requesting an increase of at least \$2 billion, plus the \$215 million authorized under as part of the 21st Century Cures Act to maintain the momentum gained over the past 3 years. ASCO appreciates this opportunity to provide the following recommendations for fiscal year fiscal year 2019:

—National Institutes of Health (NIH): \$39.3 billion

—National Cancer Institute (NCI): \$6.375 billion

Clinical cancer research in the United States is made possible through funding from both the public and private sectors. Federal funding is indispensable to the high-risk, pioneering research that has contributed to the rapidly expanding population of cancer survivors. In many cases, these are studies commercial entities typically do not pursue, including research on cancer prevention, screening, treatment comparisons, and therapies that combine multiple therapies.

Funding from the NIH supported more than 25 percent of the top advances highlighted in ASCO's 2018 Clinical Cancer Advances report, the Society's 13th annual report on progress against cancer, and its corresponding supplement, which focused specifically on the importance of Federal funding. Some of the most notable federally funded advances highlighted in the 2018 report are:

—Prolonged cancer survival using new approaches:

—A new treatment regimen by combining a targeted therapy with traditional chemotherapy, which helps women with recurrent ovarian cancer live longer.

—A web-based tool for symptom management that helps patients with advanced cancer live longer.

—Modified times for hormone therapy to reduce risk of breast cancer recurrence.

—Mitigating adverse effects of chemotherapy with less treatment:

—Shortening duration of adjuvant chemotherapy for stage III colorectal cancer proved to be safe and reduced adverse effects.

—Less extensive surgery lowers the risk of lymphedema in patients with melanoma without compromising survival.

—Lowering the radiation dose for oropharyngeal cancer reduces health complications without compromising survival.

—Effective strategies to help patients with advanced cancer understand and cope with their prognosis.

—For cancer-related fatigue, exercise and psychological support are more effective than medication.

—New insights on the adverse effects of certain prostate cancer and lung cancer treatments help inform treatment and survivorship discussions.

Sustained and steady funding of the NIH and NCI is critical to maintaining the pace of scientific discovery and continued progress against cancer, such as the advances outlined above. We appreciate that over the last few years Congress has prioritized Federal funding for biomedical research, increasing the NIH budget by \$3 billion in fiscal year 2018, the largest increase for the NIH in 15 years. Despite Congress' efforts, however, the budget of the NCI, when adjusted for biomedical inflation, remains below pre-recession levels. Funding for our Nation's biomedical research infrastructure needs to catch up to what is needed today and needs sustained increases to meet the possibility of today's science. Failure to continue the historic investment in research places health outcomes, scientific leadership, and economic growth at risk.

The bipartisan, 2-year budget agreement passed earlier this year allows Congress to build on its recent investments in biomedical research. ASCO's fiscal year 2019 request for the NIH calls on Congress to increase funding for the NIH by at least \$2 billion, in addition to funding the full \$215 million authorized in the 21st Century Cures Act, bringing the fiscal year 2019 total for the NIH to \$39.3 billion. This investment would ensure that the US continues lead the world in biomedical research and discovery and help deliver the next generation of cancer cures to patients.

ECONOMIC IMPACT: THE NIH IS A GOOD INVESTMENT

Almost 1.7 million Americans will be diagnosed with cancer this year and more than 609,000 Americans will die as a result. The cancer burden will cost the US economy an estimated \$216 billion in direct treatment costs and lost productivity. Annual cancer incidence rates are also projected to increase by 31 percent over the next decade, growing to 2.1 million people diagnosed in 2025.¹

NIH-supported screening and prevention programs have been cost effective. In addition to helping reduce the economic burden and human toll of cancer, the NIH provides a good return on Federal investment by spurring economic progress throughout the country. The NIH supports more than 400,000 jobs and contributes approximately \$69 billion annually in economic activity. All fifty States and the District of Columbia have institutions that receive NIH research funding, and the average State can attribute over 4,000 jobs to NIH activity. In fact, every dollar of NIH funding generates over \$2.20 in local economic growth.²

SUPPORTING PILLARS OF CARE: CLINICAL TRIALS AND TRANSLATIONAL RESEARCH

NIH-funded translational research and clinical trials have significantly improved the standard of care in many diseases. Federal funding and targeted programs extend cutting edge science to communities and diverse participants across the United States. Clinical trials and translational research provide cost-effective treatment options for many common cancers. They yield insight critical to the development of targeted therapies, which identify patients most likely to benefit and help patients who will not benefit avoid the cost and pain of treatment unlikely to help them. This is where science becomes practice-changing for patients in America.

ASCO has developed the Targeted Agent and Profiling Utilization Registry (TAPUR(tm)) Study, which provides access to certain targeted therapies for patients who are age twelve and older and who have been identified as candidates for benefiting from those treatments. The TAPUR Study evaluates use of these molecularly targeted anti-cancer drugs and collects data on clinical outcomes. As of April 2018 there are more than 840 participants enrolled in the TAPUR Study at more than 113 sites in twenty States.

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). ASCO is very concerned that Federal funding is not at a level that allows NCI to sustain this important network of community practices that engage in clinical research and provide an important source of patients willing to participate. An increase in NCI's budget would enable the Institute to maintain or increase the number of accruals to trials and cover the cost of conducting the research.

CAPTURING OPPORTUNITY: THE CANCER MOONSHOT INITIATIVE

ASCO thanks appropriators for inclusion of funding for the Beau Biden Cancer Moonshot Initiative in the fiscal year 2018. The NCI is working to achieve the stated goal of the Moonshot, which aims to achieve 10 years of cancer research progress in 5. The Moonshot task force report and Blue Ribbon panel recommendations contained bold ideas about how to achieve this goal. Specifically, the Cancer Moonshot Initiative is currently working towards modernizing clinical trials, building on advances in precision oncology, and developing effective immunotherapies for a broader array of cancers. Adequate funding is needed to make progress in each of these areas over the coming years. However, funding for this Initiative should supplement rather than supplant predictable increases in the underlying NCI budget.

¹American Cancer Society; Cancer Facts & Figures 2018; <https://www.cancer.org/research/cancer-facts-statistics/all-cancer-facts-figures/cancer-facts-figures-2018.html>.

²United for Medical Research; NIH's Role in Sustaining the U.S. Economy 2018 Update; http://www.unitedformedicalresearch.com/advocacy_reports/nihs-role-in-sustaining-the-u-s-economy-2018-update/.

BRINGING RESEARCH TO THE PATIENT: NIH FUNDING SPURS DEVELOPMENT OF NEW TREATMENTS

Modern cancer research delivers new treatments to patients faster than ever, thanks to the National Cancer Act of 1971 and continuing innovation in research and regulatory infrastructure. In just 1 year's time (from November 2016 through October 2017), the FDA has approved 31 therapies for more than sixteen different types of cancer, and included the first adoptive cell immunotherapy, also known as CAR-T cell therapy, which utilizes the patient's own immune cells to fight cancer. Today, there are 15.5 million cancer survivors in America, more than five times the number of survivors alive in 1971. None of this could be accomplished without the research engine spurred by the NCI.

ASCO again thanks the Subcommittee for its continued support of cancer patients in the US through funding for the NIH and NCI. We look forward to working with all members of the subcommittee on a fiscal year 2019 budget that continues to advance US cancer research. Please contact Kristin Palmer at Kristin.Palmer@asco.org with any questions.

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[This statement was submitted by Bruce E. Johnson, MD, FASCO, President, American Society of Clinical Oncology.]

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF GENE & CELL THERAPY

Dear Chairman Blunt, Ranking Member Murray, and Subcommittee Members:

Thank you for the opportunity to provide this testimony on behalf of the American Society of Gene & Cell Therapy (ASGCT). ASGCT is a membership organization consisting of scientists, physicians, and other professionals involved in the gene and cell therapy fields in settings such as universities, hospitals, government agencies, foundations, and biotechnology and pharmaceutical companies.

The Society respectfully requests robust fiscal year 2019 appropriations to the National Institutes of Health to fund additional gene and cell therapy research. Funding further gene and cell therapy research has the potential to accelerate the discovery and clinical application of more safe, effective, innovative genetic and cellular therapies to alleviate and ease human disease, which is a core component of the mission of ASGCT.

SIGNIFICANCE OF NIH RESEARCH FUNDING FOR GENE AND CELL THERAPY

NIH funding is crucial to support basic research on biological targets as well as applied research on new molecular entities, which both contribute to new therapeutic approvals.¹ NIH funding contributed to published research associated with every one of the 210 new drugs approved by the Food and Drug Administration from 2010–2016.¹ The development of new therapeutics therefore relies upon this investment, which could expedite the progression of the gene and cell therapies in the pipeline to treat multiple diseases.

The gene and cell therapy fields have reached a turning point over the past year that illustrates the contribution of NIH funding to the development of life-altering treatments. For example, the December 2017 FDA approval of voretigene neparvovec (Luxturna) began with the discovery of the RPE65 gene at the National Eye Institute.² This intramural NIH funding provided necessary baseline information for further research that led to the development of the gene therapy to treat the mutations in both copies of that gene, which cause a rare inherited retinal disorder that nearly always progresses to complete blindness. In Phase III clinical trials for this gene therapy, 93 percent of all treated participants saw a gain of functional vision, as assessed by a mobility test, over the follow-up period of at least 1 year from administration of Luxturna to each eye.³ Some patients reported put-

¹ Cleary, E.G., Beierlein, J.M., Khanuja, N.S., McNamee, L.M., Ledley, F.D. (2018). Contribution of NIH funding to new drug approvals. In Snyder, S. H. (Ed.) Proceedings of the National Academy of Sciences, 201715368, doi: 10.1073/pnas.1715368115.

² Shaberman, B. A. (2017). Retinal research nonprofit paves the way for commercializing gene therapies. *Human Gene Therapy* 28(12), 1118–1121.

³ Spark Therapeutics, Inc. (November 10, 2017). Three-year follow-up phase 3 data provide additional information on efficacy, durability and safety of investigational LUXTURNA™ (voretigene neparvovec) in patients with biallelic RPE65-mediated inherited retinal disease

Continued

ting away their navigational canes and seeing facial expressions for the first time following treatment.²

Similarly, two CAR (chimeric antigen receptor) T-cell therapies were approved over the past year for certain forms of leukemia and lymphoma. CAR T-cell therapy is a genetically-modified cell therapy in which a gene is added to a patient's T cells (a type of immune cell) in a laboratory, which enables these cells to recognize and attack cancer cells when multiplied and infused back into the patient.⁴ This advance was made possible with robust Federal investment in cancer research.⁵ The first clinical trial of CAR T-cell therapy in children with acute lymphoblastic leukemia (ALL) was funded in part by grants from the National Cancer Institute (NCI) of the NIH, and researchers at the NCI were the first to report on the potential of CAR T-cell therapy for multiple myeloma.⁵ These discoveries are the result of decades of prior research on immunology and cancer biology, much of which was supported by Federal funding.⁵

CAR T-cell therapies are now providing hope of effective treatment for patients with certain types of ALL and lymphoma that are resistant to other treatment or have had two or more relapses. For example, tisagenlecleucel (Kymriah) is providing an overall survival rate of 76 percent 1 year after treatment for children and young adults with certain forms of relapsed or refractory ALL.⁶ Long-term survival of these patients without this treatment—with standard chemotherapy and stem cell transplantation—is approximately 5 percent.⁷

In addition to its direct contributions to gene therapy-related research, NIH-funded basic research is estimated to provide a positive return to public investment of 43 percent.⁵ Studies show that NIH investments in biomedical research stimulate increased private investment, with every dollar of increase in public clinical research stimulating \$2.35 of industry investment at 3 years.⁵ This economic stimulation is even higher for gene-related research, with a Federal investment of \$3.8 billion in the Human Genome Project from 1988 to 2003 helping to drive \$796 billion in economic output, which is a return of \$141 for every \$1 invested.⁸

Need for Additional Gene and Cell Therapy Research

The approvals in 2017 of a gene therapy and two gene-modified cell therapies exemplify the vast medical progress that NIH research has contributed to in these areas. However, considerable additional scientific study will be necessary for gene and cell therapies to reach their potential to transform the lives of patients with multiple additional diseases. Many of the diseases for which gene therapy offers great promise are rare inherited disorders. Of the 7,000 rare diseases that exist, 95 percent have no current treatment.⁹

Continued strong funding for multiple institutes and centers of the NIH can support gene and cell therapy research to address this immense unmet need and the resulting human and economic costs of diseases such as sickle cell disease, hemophilia, and muscular dystrophy that collectively impact the lives of 10 percent of the U.S. population.⁸ Children with some hereditary diseases cannot walk, or even breathe or swallow on their own. Tragically, many of these children die young or become severely disabled by adolescence. For diseases with longer life expectancy, such as sickle cell disease and hemophilia, patients face a lifetime of intensive and expensive medical care. For example, the average lifetime cost of treating hemophilia for a lifetime is approximately \$12 million.¹⁰ To develop potentially durable, often one-time gene therapy treatments for these diseases will require significant

[Press release]. Retrieved from <http://ir.sparktx.com/news-releases/news-release-details/three-year-follow-phase-3-data-provide-additional-information>.

⁴NCI Dictionary of Cancer Terms. Retrieved from www.cancer.gov/publications/dictionaries/cancer-terms/def/car-t-cell-therapy.

⁵Heymach, J., Krilov, L., Alberg, A., Baxer, N., Chang, S. M., Corcoran, R., . . . Burstein, H. Clinical Cancer Advances 2018: Annual Report on Progress Against Cancer From the American Society of Clinical Oncology. *Journal of Clinical Oncology* 2018 36(10), 1020–1044.

⁶Maude, S., Laetsch, T., Buechner, J., Rives, S., Boyer, M., Bittencourt, H., . . . Baruchel, A. (2018). Tisagenlecleucel in children and young adults with B-cell lymphoblastic leukemia. *N Engl J Med* 378, 439–448.

⁷Queudeville, M., Handgretinger, R., Ebinger, M. (2017). Immunotargeting relapsed or refractory precursor B-cell acute lymphoblastic leukemia—role of blinatumomab. *Onco Targets Ther* 10, 3567–3578

⁸Accelerating Biomedical Research Act, H.R. 5455, 115th Cong. (2018).

⁹Institute of Medicine (US) Committee on Accelerating Rare Diseases Research and Orphan Product Development; Field, M.J., & Boat, T.F., editors. *Rare Diseases and Orphan Products: Accelerating Research and Development*. Washington (DC): National Academies Press (US); 2010. Available from www.ncbi.nlm.nih.gov/books/NBK56189. doi: 10.17226/12953.

¹⁰Chen, S.L. (2016). Economic costs of hemophilia and the impact of prophylactic treatment on patient management. *Am J Manag Care* 22(5 Suppl), S126–S133.

research funding to ease or potentially end the human suffering, and in some cases the high current medical costs, that they currently incur.

Since gene and cell therapies are types of regenerative medicine, ASGCT is grateful for the funding authorized by the 21st Century Cures Act for the Regenerative Medicine Innovation Project (RMIP). The Society requests that the \$10 million authorized by the Cures Act for fiscal year 2019 is appropriated specifically for this initiative, in addition to generous general NIH appropriations. Appropriations of a total of \$12 million in fiscal year 2017 and fiscal year 2018 for RMIP are greatly appreciated. Initial fiscal year 2017 funds supported eight research project awards. The Society also appreciates the \$2.2 billion increase from fiscal year 2018 that the Senate Appropriations Committee has adopted in 302(b) allocations to the Labor, Health and Human Services, Education, and Related Agencies Department, compared to the flat appropriations level adopted by the House of Representatives. ASGCT encourages retention of at least this level of appropriations to enable sufficient NIH funding for fiscal year 2019.

While NIH funding increases have been generous over the past 3 years, the need remains to maintain global leadership in medical innovation, and to compensate for NIH funding not keeping pace with biomedical research inflation between 2003 and 2015.⁸ This era resulted in the grant application success rate diminishing to below historic averages. From 1980 to 2003, the grant application success rate ranged between 25 and 35 percent. By 2016, the grant application success rate had fallen to 19.1 percent.⁸ Increases in funding to the NIH in general, and to the gene and cell therapy fields in particular, need to continue to support the potential progress in the development of these transformative treatments.

In conclusion, because NIH funding can contribute to the development of new gene and cell therapies to treat diseases with great unmet medical need, ASGCT encourages the Senate Committee on Appropriations, Subcommittee on Labor, Health and Human Services, Education, and Related Agencies to provide robust appropriations in its fiscal year 2019 funding to the many institutes and centers of the NIH that engage in gene and cell therapy related research. The Society also advocates for separate, specific appropriations to fund the Regenerative Medicine Innovation Project. We appreciate your consideration of these comments.

Sincerely,

[This statement was submitted by Michele P. Calos, PhD, President and Timothy D. Hunt, JD, Government Relations Committee Chairman, American Society of Gene & Cell Therapy.]

PREPARED STATEMENT OF 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. These diseases encompass malignant disorders such as leukemia, lymphoma, and myeloma; life-threatening conditions, including thrombosis and bleeding disorders; and congenital diseases such as sickle cell anemia, thalassemia, and hemophilia. In addition, hematologists have been pioneers in the fields of bone marrow transplantation, stem cell biology and regenerative medicine, gene- and immunotherapy, and the development of many drugs for the prevention and treatment of heart attacks and strokes.

FISCAL YEAR 2019 REQUEST: NIH FUNDING

ASH thanks Congress for the robust bipartisan support that has resulted in several consecutive years of welcome and much needed funding increases for the National Institutes of Health (NIH), including the \$3 billion increase that Congress provided in the fiscal year 2018 Consolidated Appropriations Act. For fiscal year 2019, ASH strongly supports the Ad Hoc Group for Medical Research recommendation that NIH receive at least \$39.3 billion, including funds provided to the agency through the 21st Century Cures Act's Innovation Account for targeted initiatives. This funding level, supported by more than 200 other stakeholder organizations, would continue the momentum of recent years by enabling meaningful base budget growth above inflation to expand NIH's capacity to support promising science in all disciplines, including hematology, and also would ensure that the Innovation Account supplements the agency's base budget, as intended, through dedicated funding for specific programs. Securing a reliable, robust budget trajectory for NIH will be key in positioning the agency to capitalize on the full range of research in the biomedical, behavioral, social, and population-based sciences. Given the abundance of scientific opportunity, this recommendation represents a minimum investment to

sustain progress that only would be amplified through an even more robust commitment.

Over the past 60 years, American biomedical research has led the world in probing the nature of human disease. This 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 NIH. Funding for hematology research has been an important component of this investment in the Nation's health. The study of blood and its disorders is a trans-NIH issue involving 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), and the National Institute on Aging (NIA).

With the advances gained through an increasingly sophisticated understanding of how the blood system functions, hematologists have changed the face of medicine through their dedication to improving the lives of patients. As a result, children are routinely cured of acute lymphoblastic leukemia (ALL); more than 90 percent of patients with acute promyelocytic leukemia (APL) are cured with a drug derived from vitamin A; older patients suffering from previously lethal chronic myeloid leukemia (CML) are now effectively treated with well-tolerated pills; and patients with multiple myeloma are treated with new classes of drugs, including three therapies approved in 2016).

Hematology advances also help patients with other types of cancers, heart disease, and stroke. Even modest investments in hematology research have yielded large dividends for other disciplines. Basic research on blood has aided physicians who treat patients with heart disease, strokes, end-stage renal disease, cancer, and AIDS. Blood thinners effectively treat or prevent blood clots, pulmonary embolism, and strokes. Death rates from heart attacks are reduced by new forms of anticoagulation drugs.

The field of hematology has experienced a recent surge in progress thanks to novel technologies, mechanistic insights, and cutting-edge therapeutic strategies that have driven significant and meaningful advances in the quality of care. Insights into new genetic and biologic markers can be used to understand what causes a disease, the risk factors that predispose to disease, and how patients will respond to a particular treatment. These foundational insights are reframing modern research with the continued goal of improving outcomes and discovering cures for the most challenging hematologic diseases.

The approval of chimeric antigen receptor T-cell (CAR-T) therapy by the Food and Drug Administration in August 2017 marked an important shift in the blood cancer treatment paradigm. CAR-T therapy is an innovative new treatment for certain patients with leukemia and lymphoma. We now have proof that it is possible to eradicate cancer by harnessing the power of a patient's own immune system. This is a potentially curative therapy in patients who have typically exhausted all other treatment options, including chemotherapy, radiation, or stem cell transplant, and represents the latest milestone in the shift away from chemotherapy toward precision medicine. The FDA's approval of this groundbreaking therapy was the result of over a decade of hematology research, including research funded by the NIH.

However, while the importance of CAR-T cannot be overstated, this approval only pertains to a small population of patients. More research is needed to make this therapy more effective for a broader population, to reduce the severe side effects that patients experience during treatment, and ultimately to find a broader application beyond blood cancers. Continued research will also lead to improved manufacturing of large numbers of cells, which is necessary to make this therapy accessible to more patients.

ASH has created several videos highlighting the progress made, and the future promise, in areas such as immunotherapy, precision medicine, and genomic profiling.

FISCAL YEAR 2019 REQUEST: CENTERS FOR DISEASE CONTROL AND PREVENTION

The Society also recognizes the important role of the Centers for Disease Control and Prevention (CDC) in preventing and controlling clotting, bleeding, and other hematologic disorders.

Sickle cell disease (SCD) is an inherited, lifelong disorder affecting nearly 100,000 Americans. Individuals with the disease produce abnormal hemoglobin which results in their red blood cells becoming rigid and sickle-shaped and causing them to get stuck in blood vessels and block blood and oxygen flow to the body. SCD complications include severe pain, stroke, acute chest syndrome (a condition that lowers the level of oxygen in the blood), 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.

Surveillance is necessary to improve understanding of the health outcomes and healthcare system utilization patterns, increase evidence for public health programs and to establish cost-effective practices to improve and extend the lives of people with SCD. With funding from the CDC Foundation, CDC has established a population-based surveillance system to collect and analyze longitudinal data about people living in the U.S. with SCD. Data is being collected from multiple sources (newborn screening programs and Medicaid) in order to create individual healthcare utilization profiles. However, due to limited funding, implementation of the program has occurred only in two States—California and Georgia (approximately 10 percent of the U.S. SCD population).

CDC's SCD Surveillance Program should be maintained and expanded to include additional States with the goal of covering the majority of the US SCD population over the next 5 years. For fiscal year 2019, the Society urges the Subcommittee to provide dedicated funding for SCD surveillance, outreach, and education programs to the CDC's Blood Disorders Division within the National Center on Birth Defects and Developmental Disabilities. Funding is needed for coordination and implementation of a training curriculum in the States with large SCD populations. CDC should develop a comprehensive, national public health awareness campaign for people with SCD and sickle cell trait (SCT, when a person carries a single gene for sickle cell disease and can pass this gene along to their children), their families, and the general public along with an educational campaign for the medical professionals who provide healthcare for people living with SCD or SCT. The goals of this effort would be to improve overall awareness of SCD and SCT and knowledge about health outcomes and to provide educational tools for healthcare professionals to help them understand the effects of medical interventions and inform best practices for SCD.

Additionally, ASH is supportive of the Public Health and Prevention Fund which has supported many critical projects at CDC, including investments in health-care associated infections. Currently the fund comprises approximately 12 percent of CDC's budget. ASH is concerned about the repeated efforts to eliminate this fund because of the budgetary pressure this would place on other programs within the Subcommittee's jurisdiction.

Finally, ASH supports the request recently made by 81 national medical, public health, and research organizations to provide funding for the CDC to conduct public health research into firearm morbidity and mortality prevention. 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. Robust research on motor vehicle crashes and subsequent legislation has helped save hundreds of thousands of lives through public health interventions including seat belts and other safety features. The same approach can help reduce gun violence in our communities, including ensuring CDC is able to adequately fund and perform research into this public health priority.

Thank you again for the opportunity to submit testimony. Please contact Tracy Roades, ASH Legislative Advocacy Manager, at troades@hematology.org, if you have any questions or need further information concerning hematology research or ASH's fiscal year 2019 requests.

PREPARED STATEMENT OF AMERICAN SOCIETY OF NEPHROLOGY AND AMERICAN
SOCIETY OF PEDIATRIC NEPHROLOGY

On behalf of the more than 40 million children, adolescents, and adults living with kidney diseases in the United States, the American Society of Nephrology and the American Society of Pediatric Nephrology requests a \$2.2 billion increase for the National Institutes of Health (NIH) over enacted fiscal year 2018 levels in the Labor, Health and Human Services, and Education appropriations bill, including a robust funding increase for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) that is at least proportional. In addition, we urge you to consider a Special Statutory Funding Program for Kidney Research at \$150 million per year over 10 years.

A January 2017 Government Accountability Office (GAO) report highlighted the pressing need for investment in kidney research; at the time the report was prepared, the GAO found that the annual cost for care of the approximately 650,000 patients in the Medicare End-Stage Renal Disease (ESRD) program exceeds the budget allocation for the entire NIH (\$32.8 billion vs. \$31.1 billion). Though the NIH received a substantial increase in fiscal year 2017 with a total allocation of \$37 billion, the number of individuals covered in the Medicare ESRD program and total cost of care has also risen substantially to 700,000 individuals and \$34 billion in 2015, the most recent year with available data. Despite this investment in the Medicare ESRD program, only approximately 1 percent of the annual total cost of care for kidney failure is allocated to kidney research at the NIH. Greater investment in kidney research should be an urgent priority to deliver better outcomes for patients and bring greater value to the Medicare program.

As the GAO highlighted, Congress made a commitment to treat all Americans with kidney failure through the Medicare End-Stage Renal Disease (ESRD) Program—the only health condition for which Medicare automatically provides coverage regardless of age. This unique commitment underscores the imperative for Congress to foster innovation and discovery in kidney care.

Our organizations believe the Special Statutory Funding Program for Type 1 Diabetes Research provides an ideal model to foster breakthroughs in kidney therapies and cures. This Special Diabetes Program has generated remarkable progress for diabetes patients, including the development of the Artificial Pancreas. We urge your support for an additional \$150 million per year over 10 years to establish a similar program NIDDK focused kidney research—a Special Statutory Funding Program for Kidney Research—supplementing regularly appropriated funds that the NIDDK receives.

NIDDK funds the vast majority of Federal research in kidney diseases, and despite the immense gap between the Federal Government's expenditures on kidney care and its investment in kidney research, NIDDK-funded scientists have produced several major breakthroughs in the past several years that require further investment to stimulate therapeutic advancements. For example, geneticists focused on the kidney have made advances in understanding the genes that cause kidney failure, and other kidney scientists have developed an innovative method to determine if new drugs cause kidney injury before giving them to patients in clinical trials.

NIDDK recently launched the Kidney Precision Medicine Project that will pinpoint targets for novel therapies—setting the stage for personalized medicine in kidney care. The groundbreaking APOL1 Long-term Kidney Transplantation Outcomes Research Network (APOLLO) study will convene a multidisciplinary group of investigators to follow a longitudinal cohort of kidney donors and recipients to determine the impact of APOL1 genetic variants on transplantation. The APOL1 gene, common in individuals of West-African descent, has been linked with kidney diseases in several studies and may help to better explain and treat the high incidence of kidney diseases among African Americans. Additional, sustained funding is needed to accelerate these and other novel opportunities to improve the care of patients with kidney disease and bring better value to the Medicare ESRD program.

Thank you again for your leadership, and for your consideration of our request. Should you have any questions or wish to discuss NIDDK or kidney research in more detail, please contact Erika Miller with the American Society of Pediatric Nephrology at emiller@dc-crd.com or Rachel Meyer with the American Society of Nephrology at rmeyer@asn-online.org.

ABOUT THE AMERICAN SOCIETY OF NEPHROLOGY

The American Society of Nephrology is a 501(c)(3) non-profit, tax-exempt organization that leads the fight against kidney disease by educating the society's nearly 18,000 nephrologists, scientists, and other healthcare professionals, advancing research and innovation, communicating new knowledge, and advocating for the highest quality care for patients. For more information, visit www.asn-online.org.

ABOUT THE AMERICAN SOCIETY OF PEDIATRIC NEPHROLOGY

Founded in 1969, the American Society of Pediatric Nephrology is a professional society composed of pediatric nephrologists whose goal is to promote optimal care for children with kidney disease and to disseminate advances in the clinical practice and basic science of pediatric nephrology. ASPN currently has over 600 members, making it the primary representative of the Pediatric Nephrology community in North America.

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF NEPHROLOGY

On behalf of the more than 40 million Americans living with kidney diseases, the American Society of Nephrology (ASN) respectfully requests \$25 million, to be matched dollar for dollar by ASN, be included for “KidneyX”—a public-private partnership to accelerate innovation in the diagnosis, prevention, and treatment of kidney diseases—in the fiscal year 2019 Labor, Health and Human Services, Education and Related Agencies Appropriations bill.¹ ASN has already received a \$25 million commitment for KidneyX from the private sector.

A cross-Health and Human Services (HHS) initiative, KidneyX will be a series of prize competitions run by the Office of the Secretary of HHS under the authority established by the Stevenson-Wydler Technology Innovation Act of 1980 (15 U.S.C. § 3719) and reasserted by the America COMPETES Reauthorization Act of 2010 and the “Eureka Prize Competitions” section of the 21st Century Cures Act of 2016.

More than 40 million people in the United States are living with kidney diseases, and nearly 700,000 have kidney failure, for which there is no cure.² Dialysis, the most common therapy for kidney failure, is often burdensome for patients—93 percent of working-age adults receiving dialysis are classified as disabled.³ Dialysis is not a cure—more than half of people with kidney failure die within 5 years of starting dialysis.⁴ Despite the significant burden of kidney diseases, there has been a dearth of innovation in this space compared to other areas of medicine. Our healthcare system has fostered a sense of complacency with current therapies and technologies, and the bundled payment system for dialysis is a deterrent for innovators and investors to enter the kidney care space.

Treating and managing kidney diseases and kidney failure is costly to the Federal Government. As the Government Accountability Office (GAO) highlighted in 2016, Medicare spent \$33.9 billion to manage kidney failure through Medicare’s End Stage Renal Disease (ESRD) program—more than 7 percent its spending in 2015.⁵

The GAO’s findings highlight the need for KidneyX, a public-private partnership to seed, incent, and accelerate breakthroughs to promising new products for people with kidney diseases. KidneyX was designed to reduce barriers to innovation in the prevention, diagnosis, and treatment of kidney diseases, and catalyze private sector involvement.

KidneyX stimulates the commercialization of new therapies while catalyzing investment by the private market in three specific ways that are not currently addressed by market forces or Federal efforts:

- De-risks the commercialization process by fostering coordination among the National Institutes of Health, the Food and Drug Administration, and the Centers for Medicare & Medicaid Services to provide a clear, predictable path towards commercialization
- Provides non-dilutive funding to seed, incent, and accelerate breakthroughs to promising innovators, selected through a competitive process
- Offers participating innovators access to investors and business experts and repositions the kidney space as an attractive and untapped market

The first round of funding focuses on developing and commercializing next-generation renal replacement therapies, but the portfolio will expand to include diagnostics, other devices, medications, and patient-centered tools that effectively and efficiently manage kidney diseases.

KidneyX is sustainable: revenue generated from breakthrough commercialized developments will be cycled back to support KidneyX, funding future therapies without the need for additional public investment beyond the first 5 years. Similar public-private accelerators, like the Combating Antibiotic Resistant Bacteria Biopharmaceutical Accelerator (CARB-X), have shown great success in catalyzing private sector investment to transform stagnant fields.

KidneyX is a patient-centered solution driven by an invested community. As a true public-private partnership, the private sector is committed to providing matching funds to achieve the total \$250 million required for the first 5 years. To date,

¹National Institutes of Health: Kidney Disease Research Funding and Priority Setting, GAO-17-121 (Dec. 2016).

²National Institutes of Health: Kidney Disease Research Funding and Priority Setting, GAO-17-121 (Dec. 2016).

³Erickson, K F, Zhao, B, Ho, V, Winkelmayr, W C: Employment among Patients Starting Dialysis in the United States. *Clin J AM Soc Nephrol* 13, 2018.

⁴United States Renal Data System. 2017 USRDS annual data report: Epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2017.

⁵National Institutes of Health: Kidney Disease Research Funding and Priority Setting, GAO-17-121 (Dec. 2016).

\$25 million has been committed to KidneyX from the private sector. KidneyX will issue its first round of prize funding using private contributions in 2018.

We respectfully request that the Labor-HHS Subcommittee begin a 5-year commitment by appropriating \$25 million in new funds in fiscal year 2019 for KidneyX, catalyzing private sector investment in kidney health. 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 40 million U.S. citizens are living with kidney diseases, and for nearly 700,000 of those individuals, the diseases progress to kidney failure, requiring access to dialysis or kidney transplantation to live. The Committee notes that kidney failure alone accounted for more than 7 percent of Medicare spending (approximately \$34 billion) in fiscal year 2015.

Given the high cost of kidney disease in terms of health consequences and Federal spending, the Committee recommends that of the total allotted to HHS in fiscal year 2019, that \$25,000,000 be made available to KidneyX—the first of a like 5-year commitment of \$125 million to support KidneyX. The Committee has included funding to support this recommendation. This funding will accelerate the development and adoption of novel technologies that improve the diagnosis and treatment of patients with kidney diseases, through a variety of fund awards, technical assistance, and other support resources and services.

We note that the President's fiscal year 2019 budget request included an allocation of \$50 million for prize competitions under the authority of section 105 of the America COMPETES Reauthorization Act of 2010. This allocation was instructed to focus on the types of innovation highlighted in section 200 "Eureka Prize Competitions" of the 21st Century Cures Act, including:

- "innovations funded through prize competitions on advancing biomedical science or improving health outcomes,"
- "for which public and private investment in research is disproportionately small relative to Federal Government expenditures on prevention and treatment activities with respect to such diseases and conditions, such that Federal expenditures on health programs would be reduced," and
- "that are serious and represent a significant disease burden in the United States."

KidneyX, operated through a series of prize competitions and focused on advancing biomedical science and improving health outcomes, falls squarely in line with section 200 of the 21st Century Cures Act.

Thank you for your consideration of this important request. Should you have questions or need additional information, do not hesitate to contact Rachel Meyer, Director of Policy and Government Affairs of the American Society of Nephrology, at rmeyer@asn-online.org.

ABOUT THE AMERICAN SOCIETY OF NEPHROLOGY

The American Society of Nephrology is a 501(c)(3) non-profit, tax-exempt organization that leads the fight against kidney disease by educating the society's more than 18,000 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.

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF TROPICAL MEDICINE AND HYGIENE

The American Society of Tropical Medicine and Hygiene (ASTMH)—the largest international scientific organization of experts dedicated to reducing the worldwide burden of tropical infectious diseases and improving global health—appreciates the opportunity to submit testimony to the Senate Labor, Health and Human Services, Education, and Related Agencies (LHHS) Appropriations Subcommittee on fiscal year 2019 funding for the National Institutes of Health (NIH) and Centers for Disease Control and Prevention (CDC) programs addressing tropical infectious diseases and global health.

Tropical infectious diseases are by no means a new threat and they continue to pose significant challenges to the U.S. in our ongoing efforts abroad to improve public health and strengthen our relationships to the benefit of maintaining our Nation's security. While we understand the fiscal constraints we face and are sensitive to the job Congress must do, it is critical that the U.S. maintain robust funding in global health research and development (R&D) and that we not continue the current 'funding by crisis' cycle. The best examples of why this is needed can be seen in our

recent response to the Zika and Ebola outbreaks. Responding to the Zika outbreak required billions of dollars of global investment that is still needed to support the development of a vaccine, coordinate mosquito control in at-risk areas, and monitor the spread of the disease.

The vast majority of infectious diseases do not emerge in the U.S., instead they thrive elsewhere often long before a catalytic event occurs that rapidly mobilizes the threat bringing it to the U.S. It is our lack of urgency and response to address these threats while they exist as remote tropical diseases that allows their spread and increases our domestic vulnerabilities. It is not a question of whether a new infectious disease outbreak will occur, it is a matter of when and what it will be. For this reason, Congress needs to support sustainable investments in U.S. global health R&D to increase our knowledge, understanding, and tools to confront infectious disease.

We were alarmed by the deep cuts proposed in the President's fiscal year 2019 budget, particularly for programs that support these efforts within CDC and NIH. We strongly advocate that the Subcommittee fully fund NIH and CDC in the fiscal year 2019 LHHS appropriations bill to protect Americans and ensure continued U.S. investment in global health and tropical medicine research and development.

RETURN ON INVESTMENT OF U.S.-FUNDED RESEARCH

The programs at CDC and NIH are critical to advancing research and development for tropical medicine and global health. Both agencies employ leading experts who are at the forefront of science and provide partnerships that lead the U.S. to development of new tools to combat malaria, tuberculosis (TB), epidemic viruses, neglected tropical diseases (NTDs) and other infectious diseases. In addition to creating lifesaving new drugs and diagnostics to aid some of the poorest, most at-risk people in the world, this research provides jobs for American researchers and shines a light on the U.S. as a leader in health innovation. In 2015, 89 cents of \$1 the U.S. Government invested in global health R&D was invested domestically within the U.S., supporting jobs for American researchers, scientists, and academics.¹

TROPICAL DISEASE

Malaria and Parasitic Disease.—While we have seen tremendous success as a result of U.S. funded efforts to eliminate malaria, the disease remains a significant global health threat. Despite our ability to treat and prevent malaria, it is still one of the leading causes of death and disease worldwide. According to the latest estimates, approximately 3.2 billion people living in 106 countries and territories are at risk for malaria transmission.² Among these, malaria poses the most significant threat to poor women and children, but it is also a major threat to our military and other travelers to the tropics. In 2016, there were about 216 million new cases of malaria and an estimated 445,000 deaths—a small, but not insignificant rise since 2015.³ Therefore, it is critical that the U.S. Government maintain strong investments in malaria efforts to ensure a steady decline in the number of those affected and outbreaks that reach the U.S. In 2015, at least 1 malaria case was reported in each of the 50 States with more than 200 reported in New York City and another almost 60 cases throughout the State of New York. There were over 100 cases in Maryland, Texas and California. Historical data shows that our U.S. investments in eliminating malaria in other countries has a direct correlation with the exposure in the U.S. A steep decline in malaria cases in Mexico since 1985 preceded an almost exact decline in the number of U.S. cases reported from Mexico over the same period of time. As a result of our collaborative efforts to fight malaria, mortality rates have fallen by 62 percent globally since 2002. Still, approximately every two minutes, a child needlessly dies of malaria.

Neglected Tropical Diseases.—NTDs are a group of chronic parasitic and bacterial diseases that represent the most common infections of the world's poorest people. These disease cause disfigurement, debilitation and extreme suffering—reducing cognitive development, stunting growth, and in some cases leading to death. As a result, NTDs severely limit the future earning potential of men, women, and children across the developing world resulting in further economic drain in already strained countries. These infections are considered a primary reason why the “bot-

¹ Global Health Technologies Coalition and Policy Cures Research. (2017). Return on Innovation: Why Global Health R&D is a Smart Investment for the United States. Retrieved from <http://www.ghtcoalition.org/pdf/Return-on-innovation-Why-global-health-R-D-is-a-smart-investment-for-the-United-States.pdf>.

² Centers for Disease Control and Prevention. (2017). Malaria Facts. Retrieved from <https://www.cdc.gov/malaria/about/facts.html>.

³ Centers for Disease Control and Prevention. (2018). Malaria. Retrieved from <https://www.cdc.gov/malaria/index.html>.

tom billion”—the 1.4 billion poorest people living below the poverty line—cannot escape poverty. While there is adequate treatment for some NTDs, there are many without adequate treatment or treatments that are not practical for low-resource settings. Tropical diseases, many of them neglected for decades, impact U.S. citizens working or traveling overseas, as well as our military personnel. Some diseases such as dengue fever, chikungunya, and Zika have even made their way to the U.S. with those like West Nile virus taking root here. Viruses are but a plane ride away from any point in the world, and U.S. citizens are inadequately protected and vulnerable.

NATIONAL INSTITUTES OF HEALTH

Fogarty International Center (FIC).—To protect the health and safety of Americans, the FIC has for three decades managed grant programs that develop scientific expertise in developing countries, ensuring there is local capacity to detect and address pandemics at their point of origin, contain outbreaks and minimize their impact. After all, we are all only as safe as our weakest link. More than 80 percent of FIC’s approximately \$54 million extramural grant making budget goes to U.S. institutions to support scientists’ salaries and other costs. FIC programs fund over 500 projects involving about 100 U.S. universities. 100 percent of FIC grant awards in fiscal year 2016 involved U.S. researchers.⁴

Since 2008, Fogarty, in partnership with the Department of Homeland Security, has coordinated an effort to use mathematical modeling to better predict and prevent the spread of infectious diseases in humans and animals. FIC scientists recently built predictive risk maps to understand and forecast the spread of the Ebola and Zika virus epidemics. With these computational tools and data, policymakers can make informed decisions on how to respond to outbreaks. Fogarty plays a critical role in ensuring U.S. preparedness and our ability to protect our citizens against the next pandemic threat. A FIC trained scientist is leading the Zika vaccine trial in Peru to find a solution that will ultimately help protect Americans from Zika.

ASTMH encourages the subcommittee to continue the important and unique work of FIC to foster a stronger and more effective scientific workforce and health capacity on the ground, and to continue the increasingly influential role of improving the image of the U.S. through science diplomacy in these countries. Investments such as this are critical to protecting Americans from the next disease to cross our borders.

National Institute of Allergy and Infectious Diseases.—NIAID is the lead institute for malaria and NTD research. In the past year, NIAID reported significant progress in addressing malaria, including the recent development of low-cost diagnostic tests that can rapidly detect resistance of malaria to artemisinin, a first-line antimalarial drug. Resistance to artemisinin is a growing danger and one that we must be aggressively addressing. NIAID also helped lead accelerated trials of an Ebola vaccine and is working on important Zika research. Consistent investment is critical to achieve the drugs, diagnostics, and research capacity needed to control malaria, NTDs, Zika and Ebola.

ASTMH encourages the subcommittee to continue its investment in malaria and NTD research, including work in late-stage and translational research for NTDs, and to work with other agencies to foster research and ensure that basic discoveries are translated into much needed solutions.

THE CENTERS FOR DISEASE CONTROL AND PREVENTION

The Global Health Security Agenda.—In partnership with other U.S. Government agencies, nations, international organizations, and public and private stakeholders, CDC announced a Global Health Security Agenda in 2014 to “accelerate progress toward a world safe and secure from infectious disease threats and to promote global health security as an international security priority.” The Agenda focuses on preventing and reducing the likelihood of outbreaks, detecting threats early to save lives, and responding rapidly. The CDC’s Center for Global Health and the National Center for Emerging & Zoonotic Infectious Diseases each play an important role in these efforts and must be supported through robust funding to carry out their duties.

The Center for Global Health:

Malaria and Parasitic Disease.—The CDC remains on the cutting edge of global efforts to reduce the deadly toll of malaria. The agency’s efforts on malaria and

⁴National Institutes of Health. (2018). The John Edward Fogarty International Center: Fogarty at 50. Retrieved from <https://www.fic.nih.gov/News/Publications/Documents/fogarty-international-center-overview.pdf>.

parasitic disease fall into three broad categories: prevention, treatment, and monitoring/evaluation. In addition, the CDC is constantly evaluating programs and interventions to make sure they and the U.S. taxpayer dollars are being used efficiently and effectively.

ASTMH encourages the subcommittee to continue to fund a comprehensive approach to malaria and parasitic disease prevention and treatment efforts through the Malaria and Parasitic Disease program. However, ASTMH continues to be alarmed that the budget request for this program has remained stagnant for at least 10 years. The lack of even modest increases for so long has the result of a cut to the budget as overhead and research costs rise year to year. This strains the ability for the United States to maintain advances made in this area.

Neglected Topical Diseases.—CDC currently receives zero dollars directly for NTD work outside of parasitic diseases. This should be changed to allow for more comprehensive work to be done on NTDs at the agency. CDC has a long history of working on NTDs and has provided much of the science that underlies the global policies and programs in existence today.

ASTMH encourages the subcommittee to provide direct funding to CDC to continue its work on NTDs, including but not limited to parasitic diseases and urge CDC to continue monitoring, evaluating, and providing technical assistance in these areas as an underpinning of efforts to control and eliminate these diseases.

The National Center for Emerging & Zoonotic Infectious Diseases and its Vector Borne Disease Program (NCEZID) funds essential surveillance and monitoring activities that protect the U.S. from deadly infections before they reach our borders and address the problems of tick and flea transmitted infections such as Lyme disease and a dozen other infections, including Zika and Ebola, that can be life-threatening within the U.S. The CDC has previously issued warnings to clinicians across the U.S. to be on the lookout for patients showing symptoms of chikungunya, a debilitating mosquito-borne virus that has recently been found in Americans along the gulf coast.

ASTMH encourages the subcommittee to recognize the critical role that NCEZID and its Vector-Borne Disease Program play in ongoing efforts to prepare for and fight tropical diseases emerging on U.S. soil, such as dengue, Chikungunya and now Zika.

CONCLUSION

Thank you for your attention to these important U.S. and global health matters. Tropical medicine/global health research saves lives and is a smart economic strategy for the U.S. We hope you will provide the requested fiscal year 2019 resources to those programs identified above. ASTMH appreciates the opportunity to share its expertise, and we thank you for your consideration of these requests that will help improve the lives of Americans and the global poor.

[This statement was submitted by Regina Rabinovich, MD, MPH, President, American Society of Tropical Medicine and Hygiene.]

PREPARED STATEMENT OF THE AMERICAN THORACIC SOCIETY

SUMMARY: FUNDING RECOMMENDATIONS

[In millions \$]

| | |
|---|-------------------------|
| National Institutes of Health | At least \$39.3 billion |
| National Heart, Lung & Blood Institute | 3,675 |
| National Institute of Allergy & Infectious Disease | 5,575 |
| National Institute of Environmental Health Sciences | 792.2 |
| Fogarty International Center | 80.2 |
| National Institute of Nursing Research | 159.2 |
| Centers for Disease Control and Prevention | 8,445 |
| National Institute for Occupational Safety & Health | 339.1 |
| Asthma Programs | 30 |
| Div. of Tuberculosis Elimination | 195.7 |
| Office on Smoking and Health | 220 |
| National Sleep Awareness Roundtable (NSART) | 1 |

The American Thoracic Society's (ATS) 16,000 members help prevent and fight respiratory disease through research, education, patient care and advocacy.

LUNG DISEASE IN AMERICA

Respiratory diseases are the third leading cause of death in the U.S., responsible for one of every seven deaths. Diseases affecting the respiratory (breathing) system include chronic obstructive pulmonary disease (COPD), lung cancer, influenza, sleep disordered breathing, pediatric lung disorders, pneumonia, tuberculosis, occupational lung disease, asthma, and critical illnesses such as sepsis.

National Institutes of Health

The NIH is the world's leader in groundbreaking biomedical health research into the prevention, treatment and cure of diseases such as lung cancer, COPD and asthma. The ATS thanks Congress for the \$3 billion funding increase for NIH in fiscal year 2018. In order to continue to accelerate the development of life-saving cures and treatments and innovative prevention interventions, it is essential for Congress to continue providing robust, predictable funding increases across the full spectrum of NIH-supported research. The ATS is concerned that due to past reductions in Federal research funding, there remains a lack of opportunities for young investigators who are the future of scientific innovation. We ask the subcommittee to provide at least \$39.3 billion in funding for the NIH in fiscal year 2019, in addition to funds included in the 21st Century Cures Act for targeted initiatives.

Despite the fact that respiratory disease is the third leading cause of death in the U.S., respiratory research is underfunded. The COPD death rate has doubled within the last 30 years and is still increasing, while the rates for the other top causes of death (heart disease, cancer and stroke) have decreased by over 50 percent. Despite the rising respiratory disease burden, research funding for the disease is disproportionately low relative to funding invested for the other three leading causes of death. In order to stem the devastating effects of respiratory disease, research funding must grow.

COPD

Chronic Obstructive Pulmonary Disease (COPD) is the fourth leading cause of death in the United States and the third leading cause of death worldwide, yet the disease remains relatively unknown to most Americans. CDC estimates that 12 million patients have COPD; an additional 12 million Americans are unaware that they have this life threatening disease. COPD costs the economy almost \$50 billion a year, including \$29 billion in direct health expenditures and \$29 billion in indirect costs such as lost wages.

The COPD National Action Plan, released in 2017, aims to expand surveillance and research on the disease, improve patient care, develop public health interventions and increase public awareness of the disease. The ATS urges Congress to provide \$75 million in fiscal year 2019 for implementation of the COPD National Action Plan through the NHLBI and CDC. We also urge CDC to include COPD-based questions to future CDC health surveys, including the National Health and Nutrition Evaluation Survey (NHANES), the Behavioral Risk Factor Surveillance System (BRFSS) and the National Health Information Survey (NHIS).

Centers for Disease Control and Prevention

In order to ensure that health promotion and chronic disease prevention are given top priority in Federal funding, the ATS supports a funding level for the Centers for Disease Control and Prevention (CDC) that enables it to carry out its prevention mission, and ensure a translation of new research into effective State and local public health programs. We ask that the CDC budget be adjusted to reflect increased needs in chronic disease prevention, infectious disease control, including TB control and occupational safety and health research and training. The ATS recommends a funding level of \$8.445 billion for the CDC in fiscal year 2019.

ANTIBIOTIC RESISTANCE

According to the Centers for Disease Control and Prevention's (CDC) 2013 report, Antibiotic Resistance Threats in the United States, as many as 23,000 deaths occur in the US annually due to antibiotic resistant bacterial and fungal pathogens including drug resistant pneumonia and sepsis infections. The rise of antibiotic resistance demonstrates the need to increase efforts through the CDC, NIH and other Federal agencies to monitor and prevent antibiotic resistance and develop rapid new diagnostics and treatments. This includes the following recommendations for CDC programs:

- \$200 million for the Antibiotic Resistance Solutions Initiative
- \$21 million for the National Healthcare Safety Network (NHSN)
- \$30 million for the Advanced Molecular Detection (AMD) Initiative

We urge the committee to provide \$5.575 billion for the National Institutes of Allergy and Infectious Disease (NIAID) to spur research into rapid new diagnostics, new treatments and other activities and \$700 million for the Biomedical Advanced Research and Development Authority (BARDA) to support antimicrobial research and development.

TOBACCO CONTROL

Tobacco use is the leading preventable cause of death in the U.S., responsible for one in five deaths annually. Tobacco cessation and prevention activities are among the most effective and cost-effective investments in disease prevention. The CDC's Office on Smoking and Health (OSH) is the lead Federal program for tobacco prevention and control and created the "Tips from Former Smokers" Campaign, which has prompted hundreds of thousands of smokers to call 1-800-QUIT-NOW or visit smokefree.gov for assistance in quitting—with even more smokers making quit attempts on their own or with the assistance of their physicians. The ATS recommends a total funding level of \$220 million for the Office of Smoking and Health in fiscal year 2019.

ASTHMA

Asthma is a significant public health problem in the U.S. Approximately 24.6 million Americans currently have asthma. In 2014, 3,651 Americans died as a result of asthma exacerbations. Asthma is the third leading cause of hospitalization among children under the age of 15 and is a leading cause of school absences from chronic disease. African Americans have the highest asthma prevalence of any racial/ethnic group and the age-adjusted death rate for asthma in this population is three times the rate in whites. A study published in the American Journal of Respiratory Critical Care in 2012 found that for every dollar invested in asthma interventions, there was a \$36 benefit. We ask that the subcommittee's appropriations request for fiscal year 2019 funding for CDC's National Asthma Control Program be maintained at a level of at least \$30 million.

SLEEP

Several research studies demonstrate that sleep-disordered breathing and sleep-related illnesses affect an estimated 50–70 million Americans. The public health impact of sleep illnesses and sleep disordered breathing is still being determined, but is known to include increased mortality, traffic accidents, cardiovascular disease, obesity, mental health disorders, and other comorbidities. The ATS recommends a funding level of \$1 million in fiscal year 2019 to support activities related to sleep and sleep disorders at the CDC, including surveillance activities and public educational activities. The ATS also recommends an increase in funding for research on sleep disorders at the NHLBI's Nation Center for Sleep Disordered Research (NCSDR).

TUBERCULOSIS

Tuberculosis (TB) is the leading global infectious disease killer, ahead of HIV/AIDS, claiming 1.7 million lives each year. In the U.S., every State reports cases of TB annually and in 2017, 20 States reported TB increases. Drug resistant tuberculosis was identified as a serious public health threat to the U.S. in CDC's 2013 report on antimicrobial resistance. Drug-resistant TB strains poses a particular challenge to domestic TB control due to the high costs of treatment, intensive healthcare resources and burden on patients. Treatment costs for multidrug-resistant (MDR) TB, which is up to 2 years in length, range from \$100,000 to \$300,000. The continued global pandemic of this airborne infectious disease and spread of drug resistant TB demand that the U.S. strengthen our investment in global and domestic TB control and research to develop new TB diagnostic, treatment and prevention tools.

The ATS recommends a funding level of \$195.7 million in fiscal year 2019 for CDC's Division of TB Elimination and \$21 million for CDC's Global TB program through the Center for Global Health. We urge the NIH to expand research to develop new tools to address TB. Additionally, in recognition of the unique public health threat posed by drug resistant TB, the ATS urges BARDA to support research and development into new drug-resistant TB diagnostic, treatment and prevention tools.

PEDIATRIC LUNG DISEASE

The ATS is pleased to report that infant death rates for various lung diseases have declined for the past 10 years. Many of the precursors of adult respiratory disease start in childhood. For instance, many children with respiratory illness grow into adults with COPD. It is estimated that 7.1 million children suffer from asthma. While some children appear to outgrow their asthma when they reach adulthood, 75 percent will require life-long treatment and monitoring of their condition. The ATS encourages the NHLBI and NICHD to sustain and expand research efforts to study lung development and pediatric lung diseases.

CRITICAL ILLNESS

The burden associated with the provision of care to critically ill patients is enormous, and is anticipated to increase significantly as the population ages. Approximately 200,000 people in the United States require hospitalization in an intensive care unit because they develop a form of pulmonary disease called Acute Lung Injury. Despite the best available treatments, 75,000 of these individuals die each year from this disease. This is the approximately the same number of deaths each year due to breast cancer, colon cancer, and prostate cancer combined. Another critical illness, sepsis, affects over 1.5 million Americans annually, and, according to the AHRQ, is the most expensive condition treated in hospitals, amounting to over \$23 billion annually. Investigation into diagnosis, treatment and outcomes in critically ill patients should be a priority, and the NIH should be funded and encouraged to coordinate investigation in this area in order to meet this growing national imperative.

RESEARCHING AND PREVENTING OCCUPATIONAL LUNG DISEASE

As Congress considers funding priorities for fiscal year 2019, the ATS urges the subcommittee to provide at least \$339.1 million in funding for the National Institute for Occupational Safety and Health (NIOSH). NIOSH, within the CDC, is the primary Federal agency responsible for conducting research and making recommendations for the prevention of work-related illness and injury. The ATS appreciates the opportunity to submit this statement to the subcommittee.

[This statement was submitted by Polly Parsons, MD, President, American Thoracic Society.]

PREPARED STATEMENT OF THE ARTHRITIS FOUNDATION

On behalf of the more than 54 million adults and 300,000 children living with doctor-diagnosed arthritis in the United States, the Arthritis Foundation thanks Chairman Blunt and Ranking Member Murray for the opportunity to provide written testimony to the Appropriations Subcommittee on Labor, Health and Human Services (HHS), and Education and Related Agencies for fiscal year 2019. We respectfully request \$16 million for the Centers for Disease Control and Prevention (CDC) Arthritis Program and sufficient funding for the National Institutes of Health (NIH) for fiscal year 2019.

Arthritis affects 1 in 4 Americans and is the leading cause of disability in the United States, according to CDC. It limits the daily activities of nearly 24 million Americans and causes work limitations for 40 percent of the people with the disease. This translates to over \$300 billion a year in direct and indirect costs. There is no cure for arthritis, and for some forms of arthritis like OA, there is no disease-modifying pharmaceutical therapy. Research is critical to build towards a cure, develop better treatments with fewer severe side effects, and identify biomarkers and therapies for types of arthritis for which none exist. A strong investment in public health research and programs is essential to making breakthroughs in treatments, finding a cure for arthritis, and for delivering those breakthroughs to the people who suffer from this debilitating disease.

CENTERS FOR DISEASE CONTROL AND PREVENTION ARTHRITIS PROGRAM

The CDC Arthritis Program is the only Federal program dedicated solely to arthritis. Today, the program provides grants to 12 States to support evidence-based disease management programs. Its goal is to connect all Americans with arthritis to resources to help them manage their disease. Evidence-based programs like EnhanceFitness help keep older adults active, and have shown a 35 percent improvement in physical function, resulting in fewer hospitalizations and lower health costs compared to non-participants. Further, 1 in 3 veterans has doctor-diagnosed

arthritis, and these evidence-based exercise programs are recommended by the CDC to help our veterans reduce the impact of arthritis on their lives.

Not only does the Arthritis Program provide resources to people with arthritis, it also supports data collection on the prevalence and severity of arthritis. Due to this support, we know that 1 in 4 Americans has doctor-diagnosed arthritis, including 28 percent of people in Oklahoma and 25 percent of people in Connecticut; 419,000 of those people in Oklahoma and 290,000 of those people in Connecticut are limited by their arthritis. CDC completed 17 publications in 2017, including updated prevalence statistics, data on medical expenditures and earnings losses due to arthritis, and causes of workplace disability. This type of data is essential to setting research priorities and developing a targeted public health agenda for defeating arthritis in communities that are suffering the most. Without the Arthritis Program, the robust level of data collection we have now would not exist.

Given the high prevalence and severity of this disease, the Arthritis Program is woefully under-funded compared to the investment in other chronic diseases. Funding for the program was cut by 25 percent in fiscal year 2015, bringing the fiscal year 2015 total down from \$13 million to \$9.5 million. As a result, program staff had to cut program activities between 10–50 percent, with some eliminations, and were unable to make new investments in arthritis programs. While \$1.5 million was restored in fiscal year 2016, the Arthritis Program is still not operating at its full funding level of \$13 million; combined with previous flat funding, the program has lost millions of dollars in purchasing power over the last 7 fiscal years.

In 2013 for the first time, data showed that arthritis affects at least 20 percent of the population in every State. All 50 States need funding from the Arthritis Program. While this is a long-term goal, a critical first step is to increase funding in fiscal year 2019 by \$5 million so it can continue its current level of operations in the 12 States it supports and begin to expand into additional States. With this increase, the Arthritis Program could operate in an additional 2 States, support more national grants, and increase its investment in public health research and data collection. Therefore, we urge you to fund the CDC Arthritis Program at \$16 million in fiscal year 2019.

NATIONAL INSTITUTES OF HEALTH

As previously stated, there is no cure for arthritis, and for some forms of the disease, no effective pharmaceutical therapies. Even for autoimmune forms of the disease like RA, biologic medications—which have revolutionized treatment by halting the progress of disease in many patients—have severe side effects. There is also no “gold standard” diagnostic for many forms of arthritis like RA and juvenile arthritis, and therefore it can take a long time to diagnose these diseases. It is not uncommon for children to go months without an official diagnosis, which can delay the start of critical treatment. Research is the key to identifying better diagnostics and better treatments, so that people have access to treatments early in their disease, ensuring a higher quality of life and better health outcomes.

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) is one of the primary NIH Institutes that supports arthritis research. There are a number of initiatives supported by NIAMS to better understand arthritis. The Osteoarthritis Initiative is a public-private, multi-center, longitudinal study of knee OA that was launched in 2002 with the goal of identifying biomarkers for OA as potential surrogate endpoints for onset and progression. The Accelerating Medicines Partnership was launched in 2014 as a public-private partnership that includes RA/lupus as one of three disease topics with the goal of accelerating drug development.

Research currently supported by NIAMS is addressing major questions necessary to unlocking the unknowns of arthritis, including: gene-environment interactions can help determine the relationship between RA and environmental and genetic factors that trigger onset; which biological pathways are affected in people with RA and how drug development can target those pathways to expand the pool of drugs available to people with RA; and how existing successful anti-rheumatic drugs may be used for other arthritis-related diseases.

Future research efforts can explore how changes to DNA regions can lead to disease, with the goal of uncovering additional targeted treatments. A strong overall NIH funding level is critical to maintaining the investment in research on arthritis in all its forms. Therefore, we urge you to provide sufficient funding for NIH in fiscal year 2019 to keep pace with the growing research needs in the arthritis community.

We thank the Subcommittee for its commitment to public health. As you write the fiscal year 2019 Labor-HHS-Education appropriations bill, we urge you to fund

the CDC Arthritis Program at \$16 million and provide sufficient funds to the NIH to continue the investment in improving the lives of people with arthritis. Please contact Anna Hyde, Vice President of Advocacy and Access, at ahyde@arthritis.org, or Vincent Pacileo, Director of Federal Affairs, at vpacileo@arthritis.org, with any questions.

PREPARED STATEMENT OF THE ASSOCIATION FOR CAREER AND TECHNICAL EDUCATION

Chairman Blunt, Ranking Member Murray and 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, I write to urge a strong Federal investment in the Carl D. Perkins Career and Technical Education Act (Perkins) for the coming fiscal year. To ensure that students are equipped with the academic, technical and employability skills they need for the jobs of today and the careers of tomorrow, we respectfully request that the subcommittee increase funding for the Perkins Basic State Grant program, administered by the U.S. Department of Education, Office of Career, Technical, and Adult Education, to \$1.3 billion in the fiscal year 2019 Labor, Health and Human Services, Education, and Related Agencies appropriations bill.

Perkins is the principal source of dedicated Federal funding for CTE programs in our Nation's high schools and postsecondary institutions, providing capacity-building resources through a need-based formula. This Federal investment is essential to ensuring that students are prepared for careers in expanding fields like engineering, information technology, advanced manufacturing and healthcare. In a rapidly changing job market, CTE equips students with the transferable skills they will need for long-term career success, while offering reskilling opportunities to many working and displaced adults.

Investing in CTE has provided substantial benefits for States and communities across the country. In Wisconsin, taxpayers receive \$12.20 in return for every dollar invested in the technical college system.¹ Oklahoma's economy reaps a net benefit of \$3.5 billion annually from graduates of the CTE system.² Individuals who receive a certificate or degree from California Community Colleges almost double their earnings within 3 years,³ while Colorado Community College System alumni in the workforce contribute \$5.1 billion annually to the State economy.⁴ Every dollar spent on secondary CTE students in Washington State leads to \$26 in lifetime earnings and employee benefits.⁵

Moreover, students involved in CTE programs are more engaged, graduate at higher rates and typically go on to postsecondary education. The average high school graduation rate for students concentrating in CTE is 93 percent, compared to an average national freshman graduation rate of 80 percent.⁶ Taking one CTE class for every two academic classes minimizes the risk of students dropping out of high school.⁷ Additionally, CTE students were more likely to develop time management, critical-thinking and other essential skills while in high school.⁸ Those students are also likely to persist in their education—91 percent of high school graduates who earned 2–3 CTE credits enrolled in college.⁹

CTE programs prepare students for careers in in-demand fields and provide an affordable pathway to the middle class. Healthcare occupations, many of which require an associate degree or industry credential, are projected to grow 18 percent

¹ Wisconsin Technical College System, *The Technical College Effect*, 2014.

² OKCareerTech, *PoweredbyOKCareerTech.com*.

³ Foundation for California Community Colleges, *Facts and Figures*.

⁴ Colorado Community College System, *The Economic Value of the Colorado Community College System*, May 2017.

⁵ Workforce Training and Education Coordinating Board, *Secondary CTE: State Core Indicator Results*, 2017.

⁶ U.S. Department of Education, Office of Career, Technical and Adult Education data; Civic Enterprises et al, *Building a Grad Nation: Progress and Challenge in Ending the High School Dropout Epidemic: Annual Update*, 2014.

⁷ Plank et al, *Dropping Out of High School and the Place of Career and Technical Education*, National Research Center for CTE, 2005.

⁸ Lekes et al., *CTE Pathway Programs, Academic Performance and the Transition to College and Career*, National Research Center for CTE, 2007.

⁹ U.S. Department of Education, National Center for Education Statistics, *Data Point: Career and Technical Education Course-taking and Postsecondary Enrollment and Attainment: High School Classes of 1992 and 2004*, 2016.

by 2026—adding more than 2 million new jobs.¹⁰ Half of all STEM occupations, which offer students high-skilled, high-wage career opportunities, require less than a bachelor's degree.¹¹ Middle-skill jobs are a significant part of the economy. Of the 55 million job openings that will be created by 2020, 30 percent will require some college or a 2-year associate degree.¹² Congruently, the demand for workforce credentials, and the value of those credentials, continues to grow. The number of individuals earning certificates or associate degrees in CTE fields rose 71 percent from 2002 to 2012.¹³ Twenty-seven percent of young workers with licenses and certificates earn more than those with a bachelor's degree.¹⁴ Moreover, students can pursue these credentials at community and technical colleges for a fraction of the cost of tuition at other institutions: \$3,520, on average for the 2016–2017 academic year.¹⁵

Highly skilled workers also 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. Almost half of the energy workforce may need to be replaced by 2024.¹⁶ A projected 3 million workers are needed to fill infrastructure jobs in the next decade, including careers in construction, transportation and telecommunications.¹⁷ Meanwhile, more than 80 percent of manufacturers report that the skills gap will impact their ability to meet customer demands.¹⁸ Perkins funding ensures that educators can equip students with the skills they will need for high-demand fields.

Despite CTE's impressive outcomes and a growing need for career education and workforce training, the Federal investment in Perkins has declined by 13 percent over the past decade—nearly \$170 million less in funding for CTE programs. Though the Trump Administration proposed to cut CTE funding in its fiscal year 2018 budget request, Congress approved a \$75 million increase for the Perkins Basic State Grant program in the recent omnibus appropriations bill. However, more needs to be done to support our Nation's high schools, community colleges and technical institutions.

Restoring Federal funding for CTE by increasing the Perkins Basic State Grant to \$1.3 billion in fiscal year 2019 could expand access to high-quality CTE programs for students nationwide. Moreover, it will strengthen the capacity of school districts and postsecondary institutions to deliver academically rigorous CTE content, ensure support for special populations, afford the latest technology and equipment for the classroom, strengthen employer partnerships, provide college and career counseling services, and deliver educator professional development opportunities.

Recently, 38 Senators, including distinguished members of this subcommittee, sent a letter in support of increased funding for Perkins. We applaud their commitment to growing our investment in Perkins, and we urge the subcommittee to make CTE a top priority in the fiscal year 2019 Labor, Health and Human Services, Education, and Related Agencies appropriations bill. Thank you for your thoughtful consideration of our request. For more information, please contact ACTE's Legislative and Regulatory Affairs Manager Mitch Coppes (mcoppes@acteonline.org).

[This statement was submitted by Stephen DeWitt, Deputy Executive Director, Association for Career and Technical Education.]

¹⁰ U.S. Department of Labor, Bureau of Labor Statistics, *Occupational Outlook Handbook, Healthcare Occupations*.

¹¹ Rothwell, *The Hidden STEM Economy*, Brookings Institution, 2013.

¹² Carnevale et al., *Recovery: Job Growth and Education Requirements Through 2020*, Georgetown University Center on Education and the Workforce, 2013.

¹³ 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.

¹⁴ Georgetown University Center on Education and the Workforce, *Valuing Certificates*, Presentation, 2009.

¹⁵ College Board, *Average Published Undergraduate Charges by Sector, 2016–17*.

¹⁶ Center for Energy Workforce Development, *Gaps in the Energy Workforce Pipeline: 2015 CEWD Survey Results*.

¹⁷ Kane and Tomer, *Infrastructure Skills: Knowledge, Tools, and Training to Increase Opportunity*, Brookings Institution, 2016.

¹⁸ Deloitte and The Manufacturing Institute, *The Skills Gap in U.S. Manufacturing: 2015–2025 Outlook*, 2015.

PREPARED STATEMENT OF THE ASSOCIATION FOR PROFESSIONALS IN INFECTION CONTROL AND EPIDEMIOLOGY AND THE SOCIETY FOR HEALTHCARE EPIDEMIOLOGY OF AMERICA

The Association for Professionals in Infection Control and Epidemiology (APIC) and the Society for Healthcare Epidemiology of America (SHEA) thank you for this opportunity to submit testimony on Federal efforts to detect dangerous infectious diseases, protect the American public from preventable healthcare-associated infections (HAIs) and address the rapidly growing threat of antibiotic resistance (AR). We ask that you support the following programs: within the Centers for Disease Control and Prevention (CDC) National Center for Emerging and Zoonotic Infectious Diseases: \$427.9 million for Core Infectious Diseases including \$200 million for the Antibiotic Resistance Solutions Initiative, \$21 million for the National Healthcare Safety Network (NHSN), and \$30 million for the Advanced Molecular Detection (AMD) Initiative. Additionally, we request \$36 million for HAI research activity conducted by the Agency for Healthcare Research and Quality (AHRQ) and \$4.9 billion for the National Institutes of Health (NIH)/National Institute of Allergy and Infectious Diseases (NIAID).

HAIs are among the leading cause of preventable harm and death in the United States. One in 25 patients will contract an HAI on any given day, totaling approximately 722,000 infections and 75,000 deaths annually. The CDC estimates that HAIs cost the healthcare system up to \$45 billion every year. An increasing number of these infections are untreatable due to resistance to our current arsenal of antibiotics. Without immediate intervention, minor infections may become life-threatening and put our ability to perform routine medical procedures or treat diseases at risk. The CDC conservatively estimates that over two million illnesses and about 23,000 deaths are caused by AR infections. According to a 2016 report from the Review on Antimicrobial Resistance, if actions are not taken to combat AR, antibiotics could be rendered ineffective resulting in the deaths of 10 million people annually worldwide by the year 2050.

CENTERS FOR DISEASE CONTROL AND PREVENTION

SHEA and APIC request \$427.9 million for Core Infectious Diseases for fiscal year 2019, which includes funding for HAI prevention, AR prevention, and the Emerging Infections Program (EIP). Through this funding, the EIP can continue to work with state health departments and their academic partners, with the goal of conducting a portfolio of enhanced public health surveillance and applied research to detect, prevent, and control emerging infectious diseases. Core activities of the EIP Network include:

- Active Bacterial Core surveillance (ABCs): Active population-based laboratory surveillance for invasive bacterial disease.
- FoodNet: Active population-based laboratory surveillance to monitor the incidence of foodborne diseases.
- Influenza activities: Active population-based surveillance for laboratory confirmed influenza-related hospitalizations.
- Healthcare Associated Infections-Community Interface (HAIC) projects: Active population-based surveillance for HAIs.

We urge you to support \$200 million for the Antibiotic Resistance Solutions Initiative. The AR Solutions Initiative has distributed a large portion of its funds to all 50 State health departments, six large local health departments, and Puerto Rico. By working with State and local health departments the AR Solutions Initiative is protecting life-saving antibiotics and the future of medical innovation from the threat of antibiotic resistance. The program also supports the Antibiotic Resistance Lab Network, which provides the infrastructure and lab capacity for seven regional labs to detect resistant organisms. Through these labs, CDC is able to identify unusual resistance germs, which are resistant to all or most antibiotics. Lab tests uncovered unusual resistance more than 200 times in 2017 in “nightmare bacteria” alone. Early and aggressive action, when even a single case is found, can keep germs with unusual resistance from spreading in healthcare facilities and causing hard-to-treat or even untreatable infections.

We urge you to support \$21 million for CDC’s National Healthcare Safety Network (NHSN). This request supports HAI prevention and reporting efforts in healthcare facilities across the continuum of care. These funds will enable CDC to continue to provide data for national HAI elimination, support assessment of antibiotic prescribing, and enhance prevention efforts by identifying healthcare facilities for improvement. This support will also provide NHSN infrastructure and critical user support, and provide innovative HAI prevention approaches. NHSN is the vehicle CDC uses to track central line-associated bloodstream infections (CLABSI), cath-

eter-associated urinary tract infections (CAUTI), surgical site infections (SSI), methicillin-resistant *Staphylococcus aureus* (MRSA), and *Clostridium difficile* infections reported by more than 22,000 healthcare facilities.

We urge your continued support of \$30 million for the Advanced Molecular Detection (AMD) Initiative in bioinformatics and genomics, which allows CDC to more quickly determine where emerging diseases come from, whether microbes are resistant, and how microbes are moving through a population. This initiative is critical because it strengthens CDC's epidemiologic and laboratory expertise to effectively guide public health action.

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

We request your support of \$36 million for AHRQ's HAI research activity. This funding supports projects to advance the science of HAI prevention, develop more effective approaches for reducing HAIs, and help clinicians apply proven methods to prevent HAIs on the front lines of care. The projects funded by AHRQ's HAI Program accelerate the implementation of evidence-based methods to reduce HAIs in acute care hospitals as well as ambulatory and long-term care settings. Distinct from the research funded through NIH, AHRQ funds critical research focused on improving the safety and quality of the U.S. healthcare system.

NATIONAL INSTITUTES OF HEALTH/NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASE

SHEA and APIC support \$4.9 billion for the National Institute of Allergy and Infectious Diseases (NIAID) within NIH. NIAID plays a key role in advancing research to understand how microbes develop resistance and studies to identify novel ways to combat them; translation of laboratory findings into potential treatments, vaccines, and new diagnostic tests; clinical validation of diagnostic tests; and clinical trials to evaluate vaccines and new and existing therapies against drug-resistant microbes.

We thank you for the opportunity to submit testimony and greatly appreciate your leadership in the effort to eliminate preventable HAIs, combat antibiotic resistance and improve patient safety and outcomes.

About APIC: APIC's mission is dedicated to creating a safer world through prevention of infection. The association's more than 15,000 members direct and maintain infection prevention programs that prevent suffering, save lives and contribute to cost savings for hospitals and other healthcare facilities. APIC advances its mission through patient safety, implementation science, competencies and certification, advocacy, and data standardization. Visit APIC online at www.apic.org. Follow APIC on Twitter: <http://twitter.com/apic> and Facebook: www.facebook.com/APICInfectionPreventionandYou. For information on what patients and families can do, visit APIC's Infection Prevention and You website at www.apic.org/infectionpreventionandyou.

About SHEA: SHEA is a professional society representing more than 2,000 physicians and other healthcare professionals globally that have expertise in and passion for healthcare epidemiology, infection prevention, and antibiotic stewardship. SHEA's mission is to prevent and control healthcare-associated infections and advance the field of healthcare epidemiology and promote strong antibiotic stewardship programs. The society promotes science and research, develops expert guidelines and guidance for healthcare workers, provides high-quality education, encourages transparency in public reporting related to HAIs, works to ensure a safe healthcare environment, and facilitates the exchange of knowledge in all healthcare settings. SHEA upholds the value and critical contributions of healthcare epidemiology to improving patient care and healthcare worker safety. Visit SHEA online at www.shea-online.org, www.facebook.com/SHEApreventingHAIs and @SHEA_Epi.

PREPARED STATEMENT OF THE ASSOCIATION FOR PSYCHOLOGICAL SCIENCE

APS RECOMMENDATIONS FOR FISCAL YEAR 2019 APPROPRIATIONS

- As a member of the Ad Hoc Group for Medical Research, APS recommends at least \$39.3 billion for the NIH in fiscal year 2019. This would be a \$2 billion increase in base funding to be spread across all Institutes and Centers, in addition to the \$215 million increase scheduled through the 21st Century Cures Act's Innovation Account, for a total \$2.215 billion increase.
- APS asks the Committee to continue to engage with NIH regarding NIH's proposed re-definition of clinical trials to include basic research. The Committee included very direct report language in the fiscal year 2018 Omnibus directing

NIH to “delay enforcement of the new policy—including NIH’s more expansive interpretation of ‘interventions’- in relation to fundamental research projects involving humans.” However, NIH is choosing to ignore the intent of the Committee, and is continuing to move forward with a new policy that will reclassify a significant amount of basic research as a clinical trials and will subject this research to the added regulations and cost of clinical trials.

- APS asks the Committee to encourage the National Institute of Mental Health to diversify its research portfolio to establish a better balance between neuroscience and basic and applied behavioral research, to increase the development of more effective treatments for reducing the urgent public health and economic burdens resulting from the prevalence of these conditions.
- APS urges the Committee to monitor that NIH is complying with Federal statute (Title 42 of the U.S. Code, Subchapter III; Part B, Subsection 284A) that all NIH Directors Advisory Councils have at least two representatives from the fields of public health and the behavioral or social sciences.
- Behavior is involved in the development, treatment or prevention of virtually every public health issue facing this Nation, including opioid addiction, heart disease, cancer, diabetes, mental illness, AIDS, violence, traumatic brain injury, and alcoholism. APS asks Congress to support a stronger basic, applied and clinical behavioral science research and training enterprise at NIH in recognition of the central role of behavior in health.
- APS also joins the Friends of HRSA in urging fiscal year 2019 \$8.5 billion for discretionary Health Resources and Services Administration programs and specifically recommends that the eligibility requirements for the Behavioral Health Workforce and Training Program and the Graduate Psychology program be updated to reflect the changes made in accreditation by 35 of the Nations’ pre-eminent clinical psychology programs.

Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to provide testimony as you consider funding priorities for fiscal year 2019. I am Sarah Brookhart, Executive Director of the Association for Psychological Science (APS).

APS is a nonprofit organization dedicated to the advancement of scientific psychology nationally and internationally. APS’s 33,000 members are scientists and educators at the Nation’s universities and colleges, conducting NIH-supported basic, applied and clinical research. They look at such things as: the connections between emotion, stress, and biology and the impact of stress on health; they look at how children grow, learn, and develop; they use brain imaging to explore thinking and memory and other aspects of cognition; they develop ways to manage debilitating chronic conditions such as diabetes and arthritis as well as depression and other mental disorders; they look at how genes and the environment influence behavioral traits such as aggression and anxiety; and they address the behavioral aspects of smoking and substance abuse.

Mr. Chairman, APS joins the Ad Hoc Group for Medical Research Funding, a coalition of 300 patient and voluntary health groups, medical and scientific societies, academic research organizations and industry, in recommending \$39.3 billion for the National Institutes of Health, an increase of \$2.215 billion. While APS recognizes there are demands on our Nation’s resources, we believe the ever-increasing health threats and expanding scientific opportunities continue to justify increased funding for NIH. APS further urges that the increase be distributed across all the Institutes and Centers.

In addition, there are a number of policy issues at NIH that we encourage the Committee to address through report language.

RECOGNIZING THE LEADERSHIP OF THE SUBCOMMITTEE

Mr. Chairman, APS recognizes and appreciates your leadership and the leadership of this Subcommittee in supporting public health research. We applaud the Committee’s commitment to improving health through science and to allocating increased funding to these programs during periods of fiscal austerity so that the pace of scientific discovery needed to address the Nation’s health needs remain vital. We are particularly grateful for your leadership in securing a \$3 billion increase for the NIH in fiscal year 2018. While over half of those funds are set aside for specific projects, we appreciate your vision in ensuring that every Institute and Center has growth above fiscal year 2017 levels. This will help expand the agency’s capacity to make progress across the full spectrum of scientific opportunity and increase funding available for investigator initiated scientific research. We do, however, share the concern of many groups that the increasing trend to earmark NIH funding is troublesome.

FUNDING FOR THE NATIONAL INSTITUTES OF HEALTH AND POLICY ISSUES

As previously noted, APS recommends an fiscal year 2019 funding level of \$39.3 billion for the NIH, which would enable real growth over health research inflation as an important step to ensuring stability in the Nation's research capacity over the long term. Securing a reliable, robust budget trajectory for NIH will be important in positioning the agency—and the public which relies on it—to capitalize on the full range of health research being conducted in the biomedical, behavioral, social, and population-based sciences. The Administration's request of \$35.517 billion in fiscal year 2019, translating to approximately a \$2 billion cut, is reckless and short sighted. Cuts to NIH would affect every American, including patients, their families, researchers, and communities where NIH investment spurs economic growth. APS, and the entire health research community, is in fierce opposition to the Administration's proposal.

In addition to funding priorities, APS is concerned about several policy issues at the NIH.

1. *Clinical Trials Definition.*—We were incredibly pleased and appreciative when the Committee included language in the fiscal year 2018 Omnibus directing NIH to delay enforcement of the new clinical trials policy published in September 2016, except for research projects that would have been considered clinical trials under the prior policy, until NIH can consult with the basic research community. This language followed NIH's receipt of over 3,500 comments in opposition to their new clinical trials policy change as it has the unintended consequence of reclassifying a significant amount of basic research as a clinical trials and subjecting this research to the added regulations of clinical trials. However, we are continuing to receive word that the NIH is choosing to ignore the Committee's directive, and is moving forward with implementation of this new policy. Specifically, they are continuing to require that certain basic research be subject to all the requirements of clinical trials completions and regulations—the very provision that increases regulatory burden and cost to universities. We urge the Committee to continue to impress upon NIH the need to consult with the basic research community to determine the reporting standards best suited to this kind of research prior to moving forward with the new policy.

2. *Behavioral Science at NIH.*—APS continues to be concerned about the inadequate recognition at NIH of the role of behavior in health, as reflected in the absence of behavioral science among the priorities at many institutes. Specifically, we share the concern expressed by the National Institute of Mental Health (NIMH) National Advisory Mental Health Council that over the past decade the NIMH research portfolio has increasingly become focused on basic and molecular neuroscience research at the expense of research focused on finding ways to ease the burden of those currently suffering from devastating mental conditions. In fact, in January 2018, the NIMH Director noted that over the last 10 years, this policy shift has resulted in a 50 percent decline in applications for applied and translational science. This decline illustrates the signal NIMH has sent to the research community that basic science grants are the priority over applied science. APS believes that the individual, social, and economic burdens of mental illness will not begin to be alleviated until there is a more comprehensive research approach. The NIMH mission to support research and training to reduce the public health burden of mental illness has never been more urgent; it is imperative that the Institute employ the full range of scientific resources that are available in pursuit of its mission. Therefore, APS urges the Committee to include the following language instructing the NIMH to diversify its research portfolio to better balance between neuroscience and basic and applied behavioral research to increase the development of more effective treatments for people who need them now:

Improving the Treatment of Mental Illness.—The Committee is pleased that at the January 2018 National Advisory Mental Health Council Meeting the NIMH Director noted the strong Congressional interest in funding more applied and translational research in order to have a positive impact on helping people with mental illness in the near term. The Committee continues to be concerned that over the past decade the NIMH research portfolio has increasingly become focused on basic neuroscience research at the expense of a more balanced portfolio that would also fund behavioral and psychosocial research focused on finding ways to meet the public health mission to ease the burden of those affected today. This NIMH policy shift has led to a 50 percent decline in applied and translational applications in this 10 year period as NIMH has signaled to the research community a prioritization of basic science over applied science. The Committee urges NIMH to take steps to diversify its research portfolio to better balance between neuroscience and basic behavioral and psychosocial research

and requests a report from NIMH within 90 days of enactment of this bill into law on NIMH plans to rebalance the portfolio to increase the funding of short and medium term scientific investments.

3. *NIH Advisory Committees.*—Congress recognized the important role that behavioral and social science plays in addressing the Nation’s health needs by including a requirement in Section 284 of Title 42, Subchapter III of the U.S. Code that membership of each NIH Advisory Committee should include “not less than two individuals who are leaders in the fields of public health and the behavioral or social sciences” relevant to the activities of the national research institute for which the advisory council is established. While there are some Institutes, such as the National Institute of Mental Health, that work diligently to adhere to this Federal requirement, other institutes are not in compliance. Therefore, APS requests the following language be included in the fiscal year 2019 Labor-HHS report to address this issue:

Advisory Committees.—The Committee is aware of concerns that despite the legal requirement of Federal statute (Title 42 of the U.S. Code, Subchapter III; Part B, Subsection 284A) that all NIH Directors’ Advisory Councils have at least two representatives from the fields of public health and the behavioral or social sciences, there are Directors’ Advisory Councils that are not adhering to this requirement. The Committee urges compliance with this statute and requests a report on compliance including a list of each Advisory Council’s behavioral, social sciences and public health members.

HRSA’S BUREAU OF HEALTH WORKFOCE

Mr. Chairman, APS joins the Friends of HRSA in urging fiscal year 2019 \$8.5 billion for discretionary Health Resources and Services Administration programs and specifically recommends that the eligibility requirements for the Behavioral Health Workforce and Training Program and the Graduate Psychology program be updated to reflect the changes made in accreditation by 35 of the Nation’s preeminent clinical psychology programs. The eligibility requirements of these two programs require that applicants must be accredited by accrediting organizations recognized by the Department of Education. This fails to recognize the well-established and respected Council for Higher Education Accreditation (CHEA) which has 3,000 university members and accredits over 60 different accrediting bodies. In September 2012 CHEA recognized the Psychological Clinical Science Accreditation System (PCSAS) which has since that date has accredited 35 clinical psychological doctoral programs which are all recognized to be among the 50 top schools of clinical psychology in the country. In order to insure that HRSA’s health workforce programs continue to have access to the best qualified applicants, including those who graduate from PCSAS programs, the Committee needs to add the necessary language to update the HRSA program eligibility requirements, as follows: “*Provided further, eligibility for workforce programs is limited to schools or programs accredited by a recognized body or bodies approved for such purposes by the Secretary of Education or the Council of Higher Education Accreditation.*”

SUMMARY AND CONCLUSION

Mr. Chairman, again we wish to thank the Subcommittee for its past leadership. Significant progress has been made in meeting the many public health concerns facing this Nation, due to your efforts. Mr. Chairman, if this country is to continue to see advances in improving the health and well-being of our Nation, adequate funding for the public health service is paramount. Within that, we believe that reducing barriers to research and training in behavioral science is warranted by the central role of behavior in many of our most pressing health problems and by the enormous potential of psychological science and other behavioral disciplines to reduce the suffering experienced by the millions of people who are suffering with behavior-based conditions. APS shares your commitment to addressing the health needs of the Nation and appreciates the opportunity to provide this testimony.

[This statement was submitted by Sarah Brookhart, Executive Director, Association for Psychological Science.]

PREPARED STATEMENT OF THE ASSOCIATION OF AMERICAN MEDICAL COLLEGES

The Association of American Medical Colleges (AAMC) is a not-for-profit association dedicated to transforming healthcare through innovative medical education, cutting-edge patient care, and groundbreaking medical research. Its members comprise all 151 accredited U.S. and 17 accredited Canadian medical schools; nearly 400

major teaching hospitals and health systems, including 51 Department of Veterans Affairs medical centers; and more than 80 academic societies. Through these institutions and organizations, the AAMC serves the leaders of America's medical schools and teaching hospitals and their 173,000 faculty members, 89,000 medical students, 129,000 resident physicians, and more than 60,000 graduate students and postdoctoral trainees in the biomedical sciences.

The AAMC is exceptionally grateful for the investment in key programs in the fiscal year 2018 Consolidated Appropriations Act. In fiscal year 2019, the AAMC requests the following for Federal priorities essential in assisting medical schools and teaching hospitals to fulfill their missions of education, research, and patient care: at least \$39.3 billion for the National Institutes of Health (NIH), including funds provided through the 21st Century Cures Act for targeted initiatives; \$454 million in budget authority for the Agency for Healthcare Research and Quality (AHRQ); \$690 million for the Title VII health professions and Title VIII nursing workforce development programs; \$330 million for the Children's Hospitals Graduate Medical Education (CHGME) program, at the Health Resources and Services Administration (HRSA)'s Bureau of Health Workforce; and continued support for student aid through the Department of Education. The AAMC appreciates the Subcommittee's longstanding, bipartisan efforts to strengthen these programs.

National Institutes of Health. Congress's longstanding bipartisan support for medical research through the NIH has contributed greatly to improving the health and well-being of all Americans. The foundation of scientific knowledge built through NIH-funded research drives medical innovation that improves health through new and better diagnostics, improved prevention strategies, and more effective treatments. At least half of the life-saving research supported by the NIH takes place at America's medical schools and teaching hospitals nationwide, where scientists, clinicians, fellows, residents, medical students, and trainees work side-by-side to improve the lives of Americans through research. This partnership is a unique and highly-productive relationship, one that lays the foundation for improved health and quality of life and strengthens the Nation's long-term economy.

The AAMC thanks Congress for the bipartisan support that resulted in the inclusion of \$37.1 billion in the fiscal year 2018 omnibus spending bill for medical research conducted and supported by the NIH, which builds off substantial increases for NIH in fiscal year 2016 and 2017. Additionally, the AAMC thanks the Subcommittee for recognizing the importance of continuing Federal support for facilities and administrative expenses, and retaining the salary cap at Executive Level II of the Federal pay scale.

In fiscal year 2019, the AAMC supports the Ad Hoc Group for Medical Research recommendation that Congress provide at least \$39.3 billion for NIH, including funds provided through the 21st Century Cures Act for targeted initiatives. This funding level would continue the momentum of recent years by enabling meaningful base budget growth over biomedical inflation to help ensure stability in the Nation's research capacity over the long term. Securing a reliable, robust budget trajectory for NIH is key in positioning the agency—and the patients who rely on it—to capitalize on the full range of research in the biomedical, behavioral, social, and population-based sciences.

Scientific discoveries rely on support from Congress. We must continue the current trajectory if we are to strengthen our Nation's research capacity, ensure a biomedical research workforce that reflects the racial and gender diversity of our citizenry, and inspire a passion for science in current and future generations of researchers.

Agency for Healthcare Research and Quality. Complementing the medical research supported by NIH, AHRQ sponsors health services research designed to improve the quality of healthcare, decrease healthcare costs, and provide access to essential healthcare services by translating research into measurable improvements in the healthcare system. The AAMC greatly appreciates the renewed investment in AHRQ in fiscal year 2018 and joins the Friends of AHRQ in recommending \$454 million in budget authority for AHRQ in fiscal year 2019.

As the only Federal agency with the sole purpose of generating evidence to make healthcare safer; higher quality; and more accessible, equitable, and affordable, AHRQ also works to ensure such evidence is available across the continuum of healthcare stakeholders, from patients to payers to providers. Working with NIH, the Patient Centered Outcomes Research Institute (PCORI), and other Federal agencies, AHRQ's work will better guide and enhance consumer and clinical decisionmaking, provide improved healthcare services, and promote efficiency in the organization of public and private systems of healthcare delivery.

Health Professions Funding. HRSA's Title VII health professions and Title VIII nursing workforce development programs are the only Federal programs designed

to improve the supply, distribution, and diversity of the Nation's primary care workforce. Through loans and scholarships to students, and grants and contracts to academic institutions and non-profit organizations, the Title VII and Title VIII programs fill the gaps in the supply of health professionals not met by traditional market forces.

Titles VII and VIII are structured to allow grantees to test educational innovations, respond to changing delivery systems and models of care, and address timely topics in their communities. By assessing the needs of the communities they serve and emphasizing interprofessional education and training, Title VII and VIII programs bring together knowledge and skills across disciplines to provide effective, efficient and coordinated care. Further, studies demonstrate that the programs graduate more minority and disadvantaged students and prepare providers that are more likely to serve in Community Health Centers (CHC) and the National Health Service Corps (NHSC).

In addition to promoting educational innovations and preparing the workforce for changing delivery systems, the programs also support faculty development, curriculum development, and continuing education opportunities. These are all important components to ensure faculty and providers are equipped to meet the Nation's changing needs and train the next generation of health professionals.

The AAMC is grateful for the enhanced investment in Title VII and Title VIII in fiscal year 2018 and joins the Health Professions and Nursing Education Coalition (HPNEC) in recommending \$690 million for these important workforce programs in fiscal year 2019. This funding level is necessary to ensure continuation of all existing Title VII and Title VIII programs while also supporting promising new initiatives.

The full spectrum of Title VII programs, including the Area Health Education Centers (AHEC) program and the Health Careers Opportunity Program (HCOP), is essential to prepare our next generation of medical professionals to adapt to the changing healthcare needs of the Nation's aging and increasingly diverse population. As an example of their impact, in academic year 2015–2016, AHECs trained more than 38,000 health professions students across the country, including in community-based and ambulatory care settings and CHCs. Further, research shows that HCOP has helped students from disadvantaged and underrepresented backgrounds throughout the educational pipeline achieve higher grade point averages and matriculate into health professions programs—critical to improving the cultural competency of our health workforce and promoting health equity nationwide.

In addition to funding for Title VII and Title VIII, HRSA's Bureau of Health Workforce also supports the Teaching Health Center Graduate Medical Education (THCGME) and Children's Hospitals Graduate Medical Education (CHGME) program. We appreciate the mandatory appropriations provided under the Bipartisan Budget Act of 2018 for THCGME in fiscal year 2018 and fiscal year 2019 to support new and expanded primary medical residency programs in community-based ambulatory patient care settings. The CHGME program provides critical Federal graduate medical education support for children's hospitals to prepare the future primary care and specialty care workforce for our Nation's children. We strongly support full funding for the CHGME program at \$330 million in fiscal year 2019.

Student Aid and the National Health Service Corps (NHSC). The AAMC urges the Subcommittee to sustain student loan and forgiveness programs for graduate and professional students at the Department of Education. The average graduating debt of medical students is currently \$192,000, and total repayment can range from \$348,000 to \$418,000.

The AAMC appreciates the funding provided under the Bipartisan Budget Act of 2018 for NHSC, and supports full funding for the program in fiscal year 2019. As the Nation faces multiple health professional shortages, sustained investments in workforce programs are necessary to help care for our Nation's most vulnerable populations. Recognizing that mandatory funding may be provided through other mechanisms, the appropriations committees retain primary responsibility for funding the administrative functions of the NHSC and for avoiding budgetary lapses in future years. We look forward to working with Congress to help ensure a long-term investment in the NHSC without sacrificing other Federal health professions training support.

Once again, the AAMC appreciates the opportunity to submit this statement for the record and looks forward to working with the Subcommittee as it prepares its fiscal year 2019 spending bill.

PREPARED STATEMENT OF THE ASSOCIATION OF FARMWORKER
OPPORTUNITY PROGRAMS

Dear Chairman Roy Blunt and Ranking Minority Member Patty Murray:

Thank you for the opportunity to present to you and your subcommittee the testimony of the Association of Farmworker Opportunity Programs (AFOP) in support of the Nation's more than 50-year commitment to providing eligible agricultural workers the opportunity to achieve the American Dream for themselves and their families. As you begin work on your fiscal year 2019 Labor-Health and Human Services-Education appropriations bill, AFOP encourages you to build on the solid foundation laid by the highly successful programs described below by fully funding their authorized amounts in the coming fiscal year. 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 deeply 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 the most vulnerable in our society.

NATIONAL FARMWORKER JOBS PROGRAM

The 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: hard-working, committed, well-trained, skilled workers. Administered by the United States Department of Labor (DOL), NFJP provides funding through a competitive grant process to 52 community-based organizations and public agencies nationwide that assist workers and their families 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 training and enter new careers. NFJP housing assistance helps to 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 the training they need 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 work in 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, these workers must be low-income, depend primarily on agricultural employment, and provide proof of American citizenship or verification they are authorized to work in the United States. Additionally, male applicants must have registered for the Military Selective Service.

Agricultural workers are some of the hardest working individuals you will find in this country, enduring tremendous physical and financial hardships in providing the fruits, vegetables, and other foods 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 \$17,500 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 8th grade, according to the 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 of the major goals established by DOL. In 2012 alone, NFJP service organizations provided more than 21,000 agricultural workers with services, according to DOL. Extrapolating, these NFJP providers have served more than 200,000 agricultural workers and their family members over the last 10 years. Funding this year at the program's full authorized amount would allow NFJP to have a greater impact training dependable, capable workers to take on the Na-

tion's most challenging jobs, such as the vast number of skilled workers a new robust infrastructure rebuilding plan would generate. 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, like infrastructure construction, and to establish themselves as productive and successful members of society.

AGRICULTURAL WORKER HEALTH & SAFETY

AFOP also recommends continued appropriations for the DOL Occupational Safety and Health Administration Susan B. 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, and to understand how to be safe around farm tractors. 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 210 trainers in 23 States trains agricultural workers on how to protect against pesticide poisoning and farm work injuries. Trainers then follow up with agricultural workers to assess knowledge gained and retained, and changes in labor practice. Since 1995, more than 400,000 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, heat stress prevention, and/or tractor 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.

Again, thank you for your continuing strong support of these worthy programs. AFOP stands ready to assist you in any way as you proceed with your very important work.

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 \$39.3 billion in fiscal year 2019, in addition to funds included in the 21st Century Cures Act for targeted initiatives. AIRI also urges the Subcommittee to push back against the harmful salary support and salary cap policies proposed in the President's fiscal year 2019 budget request.

First, we would like to deeply thank the Subcommittee for providing an increase of \$3 billion for NIH in fiscal year 2018. The Subcommittee's support of NIH is strongly demonstrated by these much-needed funds for life-saving biomedical research. However, there is still much more to do. NIH is tackling vast, interdisciplinary problems such as the opioid crisis, the development of a universal flu vaccine, and the widespread problem of obesity, but the last several years of budget uncertainty has made it difficult for the agency to predictably fund new and ongoing grants and consider new initiatives necessary to improving human health. To ensure cutting-edge research at independent research institutes is not disrupted, AIRI strongly supports enactment of a final fiscal year 2019 spending bill with \$39.3 billion for NIH.

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. Researchers at independent research institutes consistently exceed the success rates of the overall NIH grantee pool, and they receive about 10 percent of NIH's peer-reviewed, competitively-awarded extramural grants.

The partnership between NIH and America's scientists, research institutions, universities, and medical schools is unique and highly-productive, leveraging the full

strength of our Nation's research enterprise to foster discovery, improve our understanding of the underlying cause of disease, and develop the next generation of medical advancements that deliver more treatments and cures to patients. Not only is NIH research essential to advancing health, it also plays a key economic role in communities nationwide.

In fiscal year 2017, NIH invested \$26.1 billion, or over 75 percent of its budget, in the biomedical research community. This investment supported more than 400,000 research positions and generated nearly \$69 billion in economic activity across the U.S. AIRI member institutes are particularly relevant in this regard, as they are located across the country, including in many smaller or less-populated States that do not have major academic research institutions. In many of these regions, independent research institutes are major employers and local economic engines, and they exemplify the positive impact of investing in research and science.

The NIH model for conducting biomedical research, which involves supporting scientists at universities, medical centers, and independent research institutes, provides an effective approach to making fundamental discoveries in the laboratory that can be translated into medical advances that save lives. AIRI member institutions are private, stand-alone research centers that set their sights on the vast frontiers of medical science. However, AIRI member institutes are especially vulnerable to reductions in the NIH budget, as they do not have other reliable sources of revenue to make up the shortfall.

In addition, AIRI member institutes oppose the harmful proposals in the President's fiscal year 2019 budget request to reduce the salary caps for extramural researchers and cap the amount of salary payable on a grant. These policies would disproportionately affect early-career investigators and independent research institutes. They hinder AIRI members' research missions and their ability to recruit and retain talented researchers. The caps also damage the confidence of future researchers in the viability of a career in biomedical sciences, severely harming the competitiveness and capacity of the U.S. biomedical enterprise. The continued success of the biomedical research enterprise relies heavily on the imagination and dedication of a diverse and talented scientific workforce. NIH initiatives focusing on career development and recruitment of a diverse scientific workforce are vital to innovation in biomedical research and public health. However, one of the most destructive and long-lasting impacts of the NIH budget's instability is on the next generation of scientists, who have seen training funds slashed and the possibility of sustaining a career in research diminished.

The Federal Government has an irreplaceable role in supporting investigators and medical research. No other public, corporate, or charitable entity is willing or able to provide the broad and sustained funding for the cutting-edge research necessary to yield new innovations and technologies of the future. NIH supports long-term competitiveness for American workers, forming one of the key foundations for U.S. industries like biotechnology, medical devices, and pharmaceutical development, among others. Unfortunately, continued erosion of the national commitment to medical research could threaten our ability to support a medical research enterprise that can take full advantage of existing and emerging scientific opportunities.

The U.S. has the most robust medical research capacity in the world, but our leadership in biomedical research is being compromised by the investments being made in the research capacity of other nations, such as China. While the most recent \$3 billion increase 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 member institutes' flexibility and research-only missions provide an environment particularly conducive to creativity and innovation. Independent research institutes possess a unique versatility and culture that encourages them to share expertise, information, and equipment across research institutions, as well as neighboring universities. These collaborative activities help minimize bureaucracy and increase efficiency, allowing for fruitful partnerships in a variety of disciplines and industries. Also, unlike institutes of higher education, AIRI member institutes focus primarily on scientific inquiry and discovery, allowing them to respond quickly to the research needs of the country.

AIRI 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 provide \$39.3 billion for NIH in fiscal year 2019, in addition to funds included in the 21st Century Cures Act for targeted initiatives. Additionally, we urge the Subcommittee to push back against the President's proposal to cap investigator salaries and limit the amount of salary payable from a grant.

PREPARED STATEMENT OF THE ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS

Chairman Blunt, Ranking Member Murray and distinguished Subcommittee Members—My name is Susan Chacon and I am grateful for this opportunity to provide written testimony on behalf of the Association of Maternal & Child Health Programs (AMCHP), our members, and the millions of women, children, children with special healthcare needs, and families that are served by the Title V Maternal and Child Health (MCH) Services Block Grant administered by the Maternal and Child Health Bureau within the Health Resources and Services Administration. I am currently serving as President of the Board of Directors of AMCHP and am also the Title V Children and Youth with Special Health Care Needs Director in New Mexico. I am asking the Subcommittee to support an increase of \$8.3 million in funding for the Title V MCH Services Block Grant, for a total of \$660 million in fiscal year 2019.

I would like to begin by expressing our sincere gratitude for the increase provided to the Title V Block Grant in the fiscal year 2018 omnibus and for recognizing the role that Title V grantees play in improving the health of women, children, children with special healthcare needs, and their families. As you may know, the Title V MCH Block Grant is driven by evidence, flexibility, and results to (1) ensure access to quality maternal and child health services, (2) reduce infant mortality and preventable diseases and conditions, and (3) provide and promote family-centered, community-based, coordinated care for children with special healthcare needs and facilitate the development of community-based systems of services for such children and their families.

I know that you and your colleagues understand that the current level of funding does not allow us to address all the health needs of our Nation's women, children, fathers, and families. We are certainly proud of recent progress in lowering our Nation's infant mortality rate, reducing teen pregnancy, and decreasing the incidence of childhood injury. However, we are currently faced with many other maternal and child health challenges that require a sustained investment in public health approaches. The flexibility of the Title V MCH Block Grant allows States and jurisdictions to design and implement a wide range of maternal and child health programs that respond to locally-defined needs. In addition to formula funding to States, Special Projects of Regional and National Significance, or "SPRANS," funding complements and helps ensure the success of State Title V by driving innovation, promoting evidence-based programming, and training young professionals interested in maternal and child health.

As you well know, our country is steeped in an opioid epidemic with implications for every sector of the population, including for newborns of mothers addicted to opioids. In some counties in West Virginia, for example, over 10 percent of newborn babies in 2017 were diagnosed with Neonatal Abstinence Syndrome (NAS); that number has grown to as much as 14 percent already this year. The Title V Block Grant is playing an important role to address the maternal and child health aspect of the crisis. In Tennessee, the Title V program is leading several efforts to address Neonatal Abstinence Syndrome, such as conducting public health surveillance for NAS, utilizing local health educators to partner with correctional institutions to provide health prevention education on NAS for female inmates, and implementing a pilot project in East Tennessee to provide support for women in recovery to prevent recurrent NAS. The Massachusetts Title V program played a role in developing an interactive web-based resource for pregnant and postpartum women in treatment or recovery for substance use disorders, or with substance use issues or concerns, as well as a webinar series for obstetric providers caring for women with opioid use disorders.

Another issue that has gained a lot of attention recently is the rising maternal mortality rate in the United States. Once again, the Title V Block Grant is playing a critical role to assess and address the causes of this trend as well as efforts to reverse it. Through SPRANS, the Maternal and Child Health Bureau is implementing the Alliance for Innovation on Maternal Health or "AIM." Working through State teams and health systems, this project is aligning national-, state-, and hospital-level quality improvement efforts to improve maternal health outcomes. Just recently, the Michigan Department of Health and Human Services announced that participation in the AIM effort is showing early signs of reducing pregnancy complications. Since participating in the AIM project, complications during labor and delivery among women who experience hemorrhage have decreased 17.9 percent. In Oklahoma, Title V funds are also being used to facilitate the State's Maternal Mortality Review. As you likely know, maternal mortality review committees are the

gold standard for understanding why women die during pregnancy, childbirth, and the first year postpartum.

An important element to keep in mind as we confront the opioid epidemic and maternal mortality is that tackling these challenges requires us to look further upstream, to invest in prevention. When it comes to improving maternal and child health outcomes, we know a lot about low-tech ways to conduct prevention and improve health outcomes throughout the life course. For example, ensuring that women have access to preconception care is key to protecting maternal and infant health. That's why nearly every State and jurisdiction has chosen a Title V National Performance Measure focused on increasing the number of women who have a preventive medical visit. In Idaho, for example, the Title V program is collaborating with and providing training to the Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Program and the Family Planning program to increase pre- and inter-conception education and referrals to prenatal care and well-woman care using One Key Question®.

Finally, I would like to discuss another primary focus area for State Title V programs, which is supporting systems of services for children and youth with special healthcare needs (CYSHCN). These systems serve a diverse group of children ranging from children with chronic conditions, such as asthma or diabetes, to children with autism, to those with more medically complex health issues, such as spina bifida, other congenital disorders, and children with behavioral or emotional conditions. Overall, CYSHCN are defined as children birth to age 21 who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and require health and related services of a type or amount beyond that required by children generally. Nearly 20 percent of children in the United States have a special healthcare need. Maybe you have child or know a family that has a child with special healthcare needs and thus understand the need for a coordinated system of care.

Care coordination is an essential component of delivering services to children and youth with special healthcare needs and can help to address the fragmentation that occurs in the health care system. State Title V programs improve care coordination by working collaboratively with parents, providers, and payers. New Mexico, where I serve as Director of the Title V Children and Youth with Special Health Care Needs Program, known as Children's Medical Services, utilizes licensed medical social workers to link families to needed health and social services. We also have a program that focuses on improving transition for youth with special healthcare needs as they move into adulthood. We begin with assessments at age 14 to address youth knowledge of and ability to manage their medical condition, use of healthcare services, daily living activities, what areas they continue to need assistance with or anticipate needing assistance with, living arrangements, transportation, recreation and social relationships, and future planning for education, training, or employment. Our social workers work with the youth to identify adult providers that will assume care during the transition process and assist in addressing healthcare financing.

We also implemented a pilot program to address diabetes in children and adolescents. In 2015, American Indians in New Mexico had the highest rate of death due to diabetes, so we developed a project in Santa Fe with the local hospital's diabetes educator, the Children's Medical Services nutritionist, and social workers, along with a community farm, to provide education, cooking classes, support, and access to fruits and vegetables to children with diabetes. The program addressed multigenerational beliefs and barriers around healthy behaviors while honoring culture and traditions. While the pilot project showed positive outcomes, it had to be discontinued due to lack of funding. However, there is a lot of interest in reviving this program and we are hopeful that even a small increase for Title V will enable us to get this successful program up and running again.

Thank you again for your support. We hope to continue to build on recent successes and that you can support our request of \$660 million for the cost-effective and accountable Title V MCH Block Grant.

[This statement was submitted by Susan Chacon, MSW, LISW, President, Association of Maternal & Child Health Programs.]

PREPARED STATEMENT OF THE ASSOCIATION OF SCIENCE-TECHNOLOGY CENTERS

Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee:
Thank you for accepting this statement submitted by the Association of Science-Technology Centers (ASTC). I am Cristin Dorgelo, the President and Chief Executive Officer for ASTC. I appreciate the opportunity to present the views of ASTC

to the Subcommittee for its consideration as it prepares to write the fiscal year 2019 Labor, Health and Human Services, Education, and Related Agencies Appropriations bill.

ASTC represents more than 670 members in nearly 50 countries, including not only science centers and museums, but also nature centers, aquariums, planetariums, zoos, botanical gardens, and natural history and children's museums, as well as companies, consultants, and other organizations that share an interest in informal science education.

Of those members, more than 380 are science centers and museums located throughout the United States. Taken together, our global reach demonstrates the universal recognition of the importance of science in our lives. Our centers are leading institutions in the efforts to promote education in science, technology, engineering, and mathematics (STEM), through innovative and creative informal and classroom experiences. We are helping to create the next generation of scientific leaders and inspiring people of all ages about the wonders and the meaning of science in their lives.

In the past we have testified on behalf of the specific funding numbers for programs under this Subcommittee's jurisdiction. But today I also want to commend this Subcommittee through a look at the bigger picture—the overall science budget of the U.S. Federal Government.

As you are well aware, last year the Administration proposed significant cuts to the budgets of a number of domestic agencies. Included in the list of impacted programs were a number of science agencies and science programs. Similar cuts have been proposed in the Administration's fiscal year 2019 budget.

I want to personally thank you for not agreeing to the cuts. You, the members of this Subcommittee, and indeed, the entire Congress, rejected the proposed budget and instead passed a budget with robust funding for science. The Subcommittee increased funding for the National Institutes of Health, museum funding at the Institute of Museum and Library Services, and programs serving science education within the U.S. Department of Education.

Other Subcommittees increased funding for the National Science Foundation, the National Oceanic and Atmospheric Administration, the National Aeronautics and Space Administration, the National Institute of Standards and Technology, the science programs of the U.S. Department of Energy, and the science programs of the U.S. Department of Agriculture, among other agencies.

Taken together, the science budget of the U.S. Federal Government is larger than ever. Total R&D funding increased 12.8 percent or \$20 billion in the fiscal year 2018 budget over the fiscal year 2017 budget according to Science Magazine, to a total of \$176.8 billion. On behalf of the all the members of ASTC, I want to say thank you, with gratitude for a job well done.

ASTC and its member centers were involved in the effort to support a robust science budget last year and will continue our efforts in the future. Many of our centers hosted science days, participated in marches, and reached out to their elected representatives to make the case for the importance of science and STEM education. ASTC will continue to advocate for science funding at every opportunity.

Every day, our science centers and museums open their doors for students and the public. And every day, our centers across the United States reach out to students of underserved populations in both urban and rural areas, so that quality STEM education can be accessed by every American student. Every day, our centers provide these educational experiences with science and technology in interesting and innovative ways. Every day, our centers reach out to every student in their community, to ensure that our Nation has the trained STEM workforce we will need for the future. With continued Congressional support for informal STEM education programs, you will make our efforts more effective.

Turning to specifics, ASTC strongly urges the Subcommittee to appropriate \$18.5 million for the Science Education Partnership Awards (SEPA) at the National Institutes of Health.

We also urge you to fully fund the Institute of Museum and Library Services (IMLS), and provide \$38.6 million for its Office of Museum Services. The museum programs at IMLS provide crucial resources for the informal science activities at science centers throughout the country.

Finally, within the U.S. Department of Education, we urge you to provide \$2.065 billion for the Title II Effective Teaching Program, \$1.1 billion for the Title IV–A Students Support and Academic Enrichment program, and \$1.2 billion for the Title IV–B 21st Century Learning Centers.

In short, ASTC strongly urges you to maintain this level of funding in the fiscal year 2019 budget and to again reject the Administration's proposals to cut these programs.

In summary, we continue to thank this Subcommittee for all its support of a robust science budget. You have demonstrated your support for crucial programs that promote STEM education for our Nation's students. Like ASTC, you recognize these are vital investments in our future, and we thank you in advance for taking action accordingly.

[This statement was submitted by Cristin Dorgelo, President and Chief Executive Officer, Association of Science-Technology Centers.]

PREPARED STATEMENT OF THE ASSOCIATION OF UNIVERSITY CENTERS
ON DISABILITIES

The Association of University Centers on Disabilities (AUCD) is a membership organization that supports and promotes a national network of university-based interdisciplinary programs. Network members consist of:

- 67 University Centers for Excellence in Developmental Disabilities (UCEDDs), funded by the Administration on Intellectual and Developmental Disabilities (AIDD);
- 52 Leadership Education in Neurodevelopmental Disabilities (LEND) Programs funded by the Maternal and Child Health Bureau (MCHB); and
- 14 Intellectual and Developmental Disability Research Centers (IDDRCs), funded by the Eunice Kennedy Shriver National Institute for Child Health and Development.

All of AUCD's member programs have unique strengths that they share with each other and with the greater disability community. Some are exemplary educators: they train professional leaders, healthcare specialists, individuals with disabilities, and family members in areas such as early care and education, primary healthcare, special education, and innovative housing and employment programs. Others excel in basic and applied research, model demonstration programs, systemic reform, and/or policy analysis. Because these programs work collaboratively, innovations from one program can be implemented rapidly in communities throughout the country, thus affecting more lives than any one program could touch.

By working together, UCEDDs, LENDs and IDDRCs engage in significant research that informs State and national policy and best practices. The network emphasizes implementation of evidence-based innovations in disability-related education, healthcare, and supports and services. It offers leadership on major social problems affecting all people with disabilities or special health needs across the lifespan. Below is a summary of each of these programs and their funding requests for the upcoming fiscal year.

UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES

AUCD requests \$43.5 million in fiscal year 2019 within the Administration for Community Living (ACL) to provide continued support to maintain the existing 67 UCEDDs. The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (Public Law 106-402, Subtitle D) authorizes this network to provide interdisciplinary pre-service preparation of students and fellows, continuing education, community training, research, model services, technical assistance, and information dissemination. UCEDDs exist to provide a unique, expert State and community resource to facilitate the independence and full participation in the community of people of all ages living with developmental and other disabilities.

Due to the funding formula in the Developmental Disabilities Act that requires appropriated funds to provide cost of living adjustments to Centers before funding National Training Initiatives (NTI) and technical assistance to Centers, this level of funding is necessary to support the core functions of the Centers in addition to being able to fund emerging national issues.

Developmental disabilities are disabilities that significantly affect three or more activities of daily living, occur prior to the age of 22, and include such disabilities as autism, behavioral disorders, cerebral palsy, brain injury, fragile X, Down syndrome and other genetic syndromes, fetal alcohol syndrome, intellectual disabilities, and spina bifida.

The national network of UCEDDs is well situated to facilitate communication across agencies, schools, and other providers as they are accustomed to blending resources and have extensive experience working with multiple State and local agencies, interdisciplinary academic departments, and community partners. Continued funding will be used to address obstacles to improve outcomes for youth in ways that can save money and lead to greater independence. Youth with intellectual and developmental disabilities want to graduate from school, find a job that pays a liv-

ing wage, and participate fully in society as contributing citizens. Often standing in the way of these goals are poorly coordinated and poorly supported transitions from school to post-secondary education and/or work, including needed services in the housing, transportation, health and direct supports sectors.

Continued funding will also be used to leverage the UCEDDs' existing relationships with State agencies, disability organizations, youth with disabilities and families to help implement provisions under the recently passed Workforce Innovations and Opportunities Act and the Every Student Succeeds Act. This will be accomplished by training education professionals regarding the use of evidence-based practices in educating students with disabilities and improving comprehensive transition outcomes from adolescence to adulthood in ways that lead to successful post-secondary education and meaningful employment.

Additionally, this funding will help the UCEDD network to address other critical national and emerging needs. These include developing evidence-based interventions to support the rising numbers of individuals on the autism spectrum, addressing the impact of the opioid crisis on children and families and adults with disabilities, demonstrating cost-effective long-term services and supports for adults with disabilities and those aging with disabilities, developing science-based information for parents with children newly diagnosed with developmental disabilities, and supporting returning veterans with disabilities.

LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL DISABILITIES

AUCD recommends \$35,245,159 for the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program within the Maternal and Child Health Bureau under the Health Care Resources and Services Agency. This amount would restore funding to each LEND site that was cut to increase the number of sites available (from 43 to 52) to screen, diagnose and provide evidence-based interventions to individuals with ASD/DD as authorized under the Autism CARES Act.

LEND programs provide advanced training to students and fellows from a broad array of professional disciplines in the identification, assessment, and treatment of children and youth with a wide range of developmental disabilities, including autism, intellectual disability, fragile X syndrome, cerebral palsy, spina bifida, Down syndrome, epilepsy and many other genetic and metabolic disorders. Nationally, there are tremendous shortages of personnel trained to screen, diagnose and treat individuals with DD, and as a result, families often must wait months to get a comprehensive diagnosis and begin to receive supports and services. In addition to these practitioners, the program also trains parents and self-advocates living with disabilities. It's a critical capacity building program that greatly expands the disability competency of thousands of professionals each year.

In 2006, the Combating Autism Act (Public Law 109-416) amended the Public Health Service (PHS) Act to add an emphasis on the early identification, diagnosis and treatment of children with Autism Spectrum Disorder (ASD) because of the rising epidemic of children in the US with an ASD diagnosis. This law was reauthorized in 2014 as the Autism CARES Act (Public Law 113-157). The law recognizes the benefits of the LEND network to address this significant public health issue by authorizing the expansion of the network.

The LEND network is currently made up of 52 programs in 44 States, with an additional six States and five territories reached through program partnerships. With the expanded number of LEND grant recipients and trainees, the LEND programs provided interdisciplinary diagnostic evaluations for over 109,000 infants and children in 2016-2017. By continuing to meet the growing demand for these services, the LEND programs and their graduates are reducing wait times for diagnostic evaluation and entry into intervention services.

Each LEND receives approximately \$600,000 each year; that number varies based on number of trainees and faculty disciplines represented. Trainees from LEND programs go on to serve in hospitals, clinics, schools and other community settings. They not only provide exemplary services to children and their families, but display leadership in local, State, and national efforts to develop more effective systems of care. LEND disciplines include: audiology, family leadership, genetic counseling, health administration, nursing, nutrition, occupational therapy, pediatrics, neurology, pediatric dentistry, physical therapy, psychology, psychiatry, public health, self-advocacy, social work, rehabilitation counseling, special education, and speech-language pathology.

EUNICE KENNEDY SHRIVER INTELLECTUAL AND DEVELOPMENTAL DISABILITY
RESEARCH CENTERS

AUCD supports \$1.531 billion, an increase of \$79 million over fiscal year 2018, for NICHD in fiscal year 2019 including a proportionate increase for the national network of IDDRCs. Since their inception in the late 1960s, IDDRCs have been the 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. The IDDRCs also contribute to the development and implementation of evidence-based practices by evaluating the effectiveness of biological, biochemical, and behavioral interventions. For example, exciting research results from our IDDRC network were recently published, the University of Washington Intellectual and Developmental Disabilities Research Center (IDDRC), based at the Center on Human Development and Disability (CHDD). The study reveals that autism may be predicted from an array of neurobehavioral susceptibilities, many appreciable before the syndrome is diagnosed, and each potentially traceable to specific sets of genetic influence.

AUCD urges NICHD to provide additional resources to the IDDRCs for research infrastructure and expansion of cores so that they can conduct basic and translational research to develop effective prevention, treatment, and intervention strategies for children and adults with developmental disabilities.

[This statement was submitted by Andrew J. Imparato, Executive Director, Association of University Centers on Disabilities.]

PREPARED STATEMENT OF THE ASSOCIATION OF UNIVERSITY PROGRAMS IN
OCCUPATIONAL HEALTH AND SAFETY

My name is Elaine Symanski and I am the President of the Association of University Programs in Occupational Health and Safety (AUPOHS). On behalf of AUPOHS, an organization representing the 18 multidisciplinary, university-based Education and Research Centers (ERCs), eleven Agricultural Centers for Disease and Injury Research, Education, and Prevention (Agricultural Centers), and six Centers of Excellence in Total Worker Health, funded by the National Institute for Occupational Safety and Health (NIOSH), we respectfully request that the fiscal year 2019 Labor, Health and Human Services Appropriations bill include no less than the Fiscal 2016 level of \$339.121 million for NIOSH, including \$29 million for the Education and Research Centers, \$25.5 million for the Agriculture, Forestry and Fishing (AFF) Program, and no less than the fiscal year 2017 level for the Total Worker Health Program.

Occupational injury and illness represent a striking burden on America's health and well-being. Despite significant improvements in workplace safety and health over the last several decades, daily, about 13,000 U.S. workers sustain injuries on the job that are serious enough to require medical consultation, 12 workers die from an unintentional injury suffered at work, and 145 workers die from work-related diseases. This burden costs industry and citizens an estimated \$4.8 billion per week. This is an especially tragic situation because work-related fatalities, injuries and illnesses most often affect the most productive individuals in our society and are preventable with effective, professionally directed, health and safety programs.

NIOSH is the primary Federal agency responsible for conducting research and making recommendations for the prevention of work-related illness and injury. The ERCs provide regional and national resources for those in need of occupational health and safety assistance- industry, labor, government, academia, and the public. Collectively, the ERCs provide training and research resources to every Federal Region in the US. ERCs contribute to national efforts to reduce losses associated with work-related illnesses and injuries by offering:

- Prevention Research*: Developing the knowledge and associated technologies to prevent work-related illnesses and injuries;
- Professional Training*: ERCs support graduate degree programs in Occupational Medicine, Occupational Health Nursing, Safety Engineering, Industrial Hygiene, and other related fields to provide qualified professionals to enter the workforce in essential disciplines;
- Research Training*: Preparing doctoral-trained scientists who will respond to future research challenges and who will train the next generation of occupational health and safety professionals;
- Continuing Education*: Short courses focused on workforce development in the occupational health and safety disciplines that enhance professional skills and maintain professional certification for those employed in U.S. industries; and

—*Regional Outreach*: Responding to specific requests from employers, healthcare professionals, workers and other stakeholders on issues related to occupational health and safety.

The rapidly changing workplace continues to present new health risks to American workers that need to be addressed through occupational safety and health research. In addition, newly emerging risks, such as Ebola and other infectious disease outbreaks, and industrial disasters like the Deepwater Horizon Spill require swift responses and evidence-based worker protections. In response to risks posed by potential Ebola exposure, ERCs have delivered educational programs and provided expertise in developing protocols and policies to prevent hazardous worker exposures. Additionally, NIOSH is the Federal agency that is charged with certifying and approving the respirators that are necessary to protect U.S. workers from inhalation exposures in the workplace to numerous chemical and biological agents.

The heightened awareness of terrorist threats, and the increased responsibilities of first responders and other homeland security professionals, illustrates the need for strengthened workplace health and safety in the ongoing war on terror. The ERCs play a crucial role in preparing occupational safety and health professionals to identify and mitigate vulnerabilities to terrorist attacks and to increase readiness to respond to biological, chemical, or radiological attacks. In addition, occupational health and safety professionals have worked for several years with emergency response teams to minimize disaster losses, including taking a lead role in protecting the safety of 9/11 emergency responders in New York City and Virginia, with ERC-trained professionals applying their technical expertise to meet immediate protective needs and to implement evidence-based programs to safeguard the health of clean-up workers. More recently, in 2018, occupational health and safety professionals worked to minimize hazards among workers involved in clean up and restoration in the face of the extreme devastation caused by Hurricanes Harvey, Irma and Maria in Texas, Florida, Puerto Rico and the US Virgin Islands.

We need manpower to address these challenges and it is the ERCs that train the professionals who fill key positions in health and safety programs, locally, regionally and around the Nation. ERCs provide multi-disciplinary training and as a result, ERC graduates protect workers in virtually every occupation.

NIOSH also focuses research and outreach efforts on the Nation's most dangerous worksites. People who work in agriculture, forestry and fishing experience occupational fatality rates that are 6 times to more than 171 times higher than the average for American workers. The Centers for Agricultural Safety and Health were established by Congress in 1990 (Public Law 101-517) in response to evidence that agricultural, forestry and fishing workers were suffering substantially higher rates of occupational injury and illness than other U.S. workers.

Today the Agriculture, Forestry, and Fishing (AFF) Initiative includes ten regional Agricultural Centers and one national center to address children's farm safety and health. The AFF program is the only substantive Federal effort to meet the obligation to ensure safe working conditions in these vital production sectors. While agriculture, forestry, and fishing constitute some of the largest industry sectors in the U.S. (DOL 2011), most AFF operations are themselves small: nearly 78 percent employ fewer than 10 workers, and most rely on family members, immigrants, part-time, contract and/or seasonal labor. Many of these agricultural workers are excluded from labor protections, including OSHA oversight, on the vast majority of American farms.

The AFF sector averages 540 fatalities per year resulting in the highest fatality rate of any sector in the Nation. More than 1 in 100 AFF workers incur nonfatal injuries resulting in lost work days each year. These reported figures do not even include men, women, and youths on the most dangerous farms—those with fewer than 11 full-time employees. In addition to the harm to individual men, women, and families, these deaths and injuries inflict serious economic losses including medical costs and lost capital, productivity, and earnings. The life-saving, cost-effective work of the AFF program is not replicated by any other agency. For example, State and Federal OSHA personnel rely on NIOSH research in the development of evidence-based standards for protecting agricultural workers and would not be able to fulfill their mission without the AFF program. In addition, staff members of USDA's National Institute of Food and Agriculture interact with NIOSH occupational safety and health research experts in order to learn about the cutting-edge research and new directions in this area. Agricultural Center activities include:

—AFF research that has shown that the use of rollover protective structures (ROPS or rollbars) and seatbelts on tractors can prevent 99 percent of overturn-related deaths. The National ROPS Rebate Program has assisted thousands of farmers with retrofitting unprotected tractors and program participants have reported over 200 near misses with no injuries for those farmers who had in-

stalled ROPS through the program. The program makes retrofitting remarkably easy and 99 percent of program participants said they would recommend the program to other farmers. Similar programs are also offered to prevent serious injuries due to Power take-off (PTO) entanglements in farm machinery.

- Working in partnership with producers and farm owners, the Agricultural Centers have partnered to develop evidence-based solutions for reducing exposure to pesticides and other farm chemicals among farmers, farm workers and their children.
- Commercial Fishing has an annual fatality rate approximately 30 times higher than the rate for all U.S. workers. Research has shown that knowledge of maritime navigation rules and emergency preparedness means survival. One Agricultural Center team produced an interactive navigation training CD in three languages, demonstrating the effectiveness of refresher survival drill instruction. Other Centers are partnering with fishing communities to develop improved life-jacket designs that are comfortable enough to wear while working and will markedly improve survival and recovery in the event of a fall overboard.
- The Agricultural Centers have partnered with producers, employers, the Federal migrant health program, physicians, nurses, and Internet Technology specialists to educate farmers, employers, and healthcare providers about the best way to treat and prevent agricultural injury and illness. For example, one agricultural center has identified processes that occur during recovery from agricultural dust-induced inflammation and this research has led to novel treatments for respiratory diseases common in farmers and ranchers. Another center has collaborated with farmworker communities in Alabama, Florida, Georgia, Mississippi, North Carolina, South Carolina, Puerto Rico, and the U.S. Virgin Islands to address health concerns related to chronic heat stress and low-level pesticide exposure.
- The logging industry has a fatality rate more than 30 times higher than that of all US workers. The Agricultural Centers have conducted ongoing studies and outreach efforts to ensure the safety of our Nation's 86,000 workers in forestry & logging. An example of these efforts is provided by the Southeast Agricultural Center, which has been working to reduce logging injuries and fatalities through the implementation of an industry specific safety and health management program and by evaluating the Timber-Safe program's impact on workplace hazard reduction in logging operations.

NIOSH also supports six Centers of Excellence for Total Worker Health (TWH) that complete multidisciplinary research, intervention, outreach and education, and evaluation activities advancing the overall safety, health, and well-being of the diverse population of workers in our Nation. The TWH Centers supports the development and adoption of ground-breaking research and health and safety best practices with a primary focus on the overall health of the worker and worksite improvements. The TWH Centers partner with government, business, labor, and community to improve the health and productivity of the workforce. Most TWH research, education, and outreach activities occur in workplaces, such as hospitals, factories, offices, and construction sites, and result in immediate improvements in health and safety. Examples include:

- Aspects of the workplace (e.g., scheduling, shift work, heavy lifting, toxic exposures) not only increase risk of injury and illness, but also impact health behaviors (e.g., physical activity, substance use, sleep) and health outcomes (e.g., musculoskeletal disorders, mental health, obesity). In turn, ill health and chronic conditions impact performance at work, increasing risk for serious injury, absenteeism, and reduced productivity.
- Workers in some industries experience higher rates of cardiovascular disease, obesity, depression, and even premature death. We also see higher rates of smoking and drinking among certain working populations. Wellness programs focus on changing individual behaviors (e.g., eat a healthy diet, exercise more), but they do not take into account aspects of the workplace that impact health. For example, nationally we have seen a reduction in smoking rates. However, certain industries, such as construction, continue to have higher than national average rates of smoking. Therefore, the conventional public health approaches addressing smoking are not reaching this population. TWH Centers are conducting research to understand the underlying causes and to implement interventions to address these causes.
- TWH Centers have also developed and evaluated interventions to reduce injuries and disease among workers in corrections, construction, healthcare, retail, food service, and manufacturing. The TWH Centers partner with small and large enterprises to address the needs of workers of all ages. These interven-

tions have shown changes in biomarkers of health (e.g., blood pressure), behaviors (e.g., smoking rates), mental health, fewer lost work days due to injury, as well as savings for employers.

In summary, the TWH Centers conduct and disseminate scientific, evidence-based research and practices with the goal of improving the overall safety, health, well-being and the productivity of the American workforce. The TWH Centers are an investment in the American economy that work to help businesses and communities reduce the impact and cost of injuries and illness.

We urge you to recognize the important contribution of NIOSH, including the ERCs, the AFF Program, and the TWH Program to the health and productivity of our Nation's workforce. Thank you for the opportunity to submit testimony.

[This statement was submitted by Elaine Symanski, President, Association of University Programs in Occupational Health and Safety.]

PREPARED STATEMENT OF THE ASSOCIATION OF YOUNG AMERICANS

Dear Senators Shelby, Leahy, Blunt, and Murray:

On behalf of our 8,000 members across all 50 States, the Association of Young Americans (AYA) urges Congress to support ongoing investments in fiscal year 2019 in programs that help make higher education more accessible and affordable and that alleviate the crushing college debt facing 44 million Americans today. Formed in 2016, AYA advocates for the issues that affect all young Americans today, including the rising cost of obtaining a higher education, the insurmountable debt students take on to attend college, and the threat of elimination of important programs like the Public Student Loan Forgiveness Program (PSLF).

On the subject of college affordability, AYA urges Congress to increase Pell funding or at least maintain it at the levels in the fiscal year 2018 omnibus, which raised the maximum award by \$175 to \$6,095. Additionally, AYA supports maintaining the recent year-round Pell expansion, which allows students to attend summer courses and complete college in a shorter amount of time, thus reducing overall costs. AYA also encourages Congress to continue increased investments in programs that help first generation students, low-income families, and non-traditional students attend and afford college including the GEAR Up and TRIO programs. Lastly, to give high school students academic and financial legs up for college, AYA urges Congress to increase investments in dual-enrollment programs that allow students to complete college courses during high school, thereby increasing college completion rates and affordability.

AYA strongly supports the Public Service Loan Forgiveness (PSLF) Program and urges Congress to appropriate additional funds, if necessary, to protect individuals unwittingly enrolled in non-qualifying loan programs. Launched in 2007, PSLF forgives the remaining balance on student Direct Loans after students have made 120 qualifying monthly payments under a qualifying repayment plan while working full-time for a qualifying employer. According to USED, 800,000 borrowers submitted at least one employer certification form that showed their intention to apply for forgiveness and whether they are participating in a loan program that would make them eligible for forgiveness. In fiscal year 2018, Congress appropriated \$350 million to assist income-driven repayment plan participants who wrongfully believed that they were participating in an eligible loan program. Hundreds of thousands of students have relied in good faith on the availability of PSLF, basing their decisions to attend college and work in the public sector—both public goods—based on the availability of loan forgiveness. This funding will protect some of those who diligently repaid their loans and worked in the private sector but who applied for ineligible PSLF loans mistakenly. AYA believes Congress should continue to live up to the promise to young Americans that PSLF represents by not only maintaining this program but also strengthening it with additional funding if necessary.

AYA is committed to ensuring the voice of young Americans is represented in Congress and we appreciate your consideration of our fiscal year 2019 appropriations requests. We sincerely urge you to continue investing in the programs that help make college more accessible and affordable for future generations.

Sincerely,

[This statement was submitted by Ben Brown, Founder and CEO, Association of Young Americans.]

PREPARED STATEMENT OF BOYS & GIRLS CLUBS OF AMERICA

Boys & Girls Clubs of America (BGCA) would like to thank the Members of the Subcommittee for their leadership and continued support. We appreciate the opportunity to comment on issues and programs related to fiscal year 2019 appropriations and the impact on our Nation's youth.

BGCA serves 4.3 million youth each year, with 458,000 children and teens entering the doors of a Boys & Girls Club every day. Our nearly 4,400 Clubs represent a cross-section of American culture and heritage—with 1,659 school-based Clubs, 1,008 Clubs in rural areas, 287 Clubs in public housing facilities, 492 affiliated youth centers on military installations worldwide, and 177 Clubs on Native lands. We are the largest provider of youth services on Native lands and the second largest provider of afterschool programs in rural America, with public schools being the largest.

At BGCA, we believe every young person deserves a great future. Our vision is to provide a world-class Club Experience that ensures success is within reach of every young person who enters our doors, with all members on track to graduate from high school with a plan for the future, demonstrating good character and citizenship, and living a healthy lifestyle. Clubs offer young people a safe and positive place to learn and grow so that they become productive, caring and responsible citizens.

A growing body of evidence proves out-of-school time and summer learning programs are effective at helping youth to improve grades and school attendance, while fostering higher aspirations for graduating high school and attending some form of post-secondary education. According to our evidence-informed National Youth Outcomes Initiatives (NYOI)* report (<https://www.bgca.org/about-us/club-impact/>):

- 97% of Club teens expect to graduate from high school and 87 percent plan to attend college
- 84% of Club members believe they can make a difference in their community
- 84% of Club 12th graders abstain from alcohol use, compared to 58 percent of their peers nationally
- 54% of alumni save the Club saved their life

The impact of Clubs extends far beyond the young people who walk through our doors every day. A study by the Institute for Social Research and the School of Public Health at the University of Michigan found that for every dollar invested in Boys & Girls Clubs, \$9.60 is returned to communities, approximately \$13.8 billion annually. Clubs provide underserved youth with regular access to and engagement in areas such as STEM, sports leagues, homework help and tutoring, summer learning loss prevention, and engagement in the arts. As a result, Club youth are able to leverage and create opportunities that shift the course of their life trajectories and undermine cycles of inequity. Additionally, access to affordable, reliable and safe out-of-school time programs allows parents and caregivers the opportunities to participate in the workforce. While their children are actively engaged at the Club, families can rest assured knowing that they have access to enhanced academic support to ensure youth are on track to graduate, nutritious food, opportunities to be physically active and health education, all provided by caring staff within the context of a safe and supportive Club environment. As a result, Clubs contribute to major savings for society by helping to prevent costly expenditures for healthcare, public assistance programs, and criminal justice system involvement and incarceration.

As you know, programs funded under the Labor, Health & Human Services, Education, and Related Agencies subcommittee have a major impact on the health and well-being of youth across the country. As Congress negotiates fiscal year 2019 appropriations bills, we urge you to support the following investments for the youth of this country.

DEPARTMENT OF LABOR—YOUTH WORKFORCE DEVELOPMENT

By 2020, 60 percent of jobs will require education and/or training beyond high school and if the lack of a skilled workforce is not addressed, the U.S. economy will face a shortage of 5 million workers.¹ Many U.S. employers say the inability to find qualified workers is their biggest obstacle to growth. Today, 44 percent of employers say their greatest needs are in the area of soft skills (e.g. communication, customer

*NYOI is the largest set of privately-held youth development data. It enables us to leverage member-provided data to adjust our strategies in real-time to maximize outcomes for youth.

¹Carnevale, A.P., Smith, N., & Strohl, J. (2013, June). Recovery: Job Growth and Education. Georgetown Center on Education and the Workforce. Retrieved from <https://cew.georgetown.edu/cew-reports/recovery-job-growth-and-education-requirements-through-2020/>.

service, creativity, collaboration, critical thinking),² and 70 percent of young adults do not qualify for military service due to character, education or fitness concerns.³

—BGCA has the reach, scale and the experience to be a key partner in preparing today's youth for success in tomorrow's workforce.

—Organizations like BGCA with a national network in all 50 States (touching virtually every community) are uniquely positioned to align funding where it is needed most and provide the technical assistance to local communities to ensure youth are getting the job readiness skills needed to be a strong workforce for tomorrow.

We urge the Subcommittee to support \$25 million to be administered by the Department of Labor's Employment & Training Administration dedicated to national out-of-school time, youth-serving organizations providing career exploration, job skills development, work-based learning and career mapping.

HEALTH & HUMAN SERVICES—YOUTH OPIOID PREVENTION

Opioid abuse and overdose have reached epidemic levels. The traumatic experience of growing up within a family and community where substance use and misuse is prevalent disrupts a young person's ability to thrive. The associated adverse experiences put young people at increased risk for substance use and other behaviors that lead to poor health outcomes. Over 11 million young people are unsupervised after school, when juvenile violent crime and risky behaviors escalate. Boys & Girls Clubs are open during a time of day when youth are most likely to get involved in high-risk activity. This uniquely positions Clubs to disrupt the cycle of addiction and abuse by providing a high quality youth experience that employs evidence-informed prevention strategies as its universal approach.

—Clubs help provide improved social & emotional resilience for all youth by enhancing high quality youth development and risk prevention practices and messages in programs.

—Boys & Girls Clubs effective substance abuse prevention strategies and practices include:

—Creating meaningful opportunities to build social and emotional development skills, specifically: self-regulation, communication, emotional awareness, healthy decision-making, self-efficacy, and healthy peer and adult relationships.

—Using a trauma-informed approach that realizes the widespread impact of trauma and responds with fully integrated trauma-informed practices, policies and procedures.

—Creating high-yield, small group opportunities that allow youth to develop a sense of emotional safety, peer support, trust and transparency, collaboration, and leverage youth choice and voice.

—Implementing prevention programs and activities that are developmentally responsive and address all forms of substance use.

—Engaging families intentionally within the Club, and creating strong community partnerships to support youth and families with needs beyond the scope of the Club.

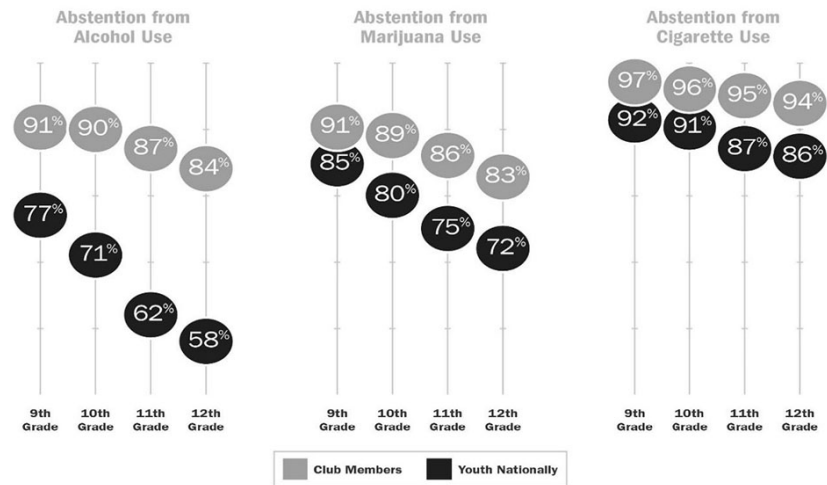
BGCA compared regularly attending Club members and youth nationally by grade level. Across almost all health-risk behavior indicators, with each successive grade, the difference between Club members' abstention rates and those of Youth Risk Behavior Surveillance System⁴ respondents increased.

² Watch the Skills Gap. (2017, October 25). Retrieved from <https://www.adecousa.com/employers/resources/skills-gap-in-the-american-workforce/>.

³ Feeney, N. (2014, June 30). Pentagon: 7 in 10 Youths Would Fail to Qualify for Military Service. Retrieved from <http://time.com/2938158/youth-fail-to-qualify-military-service/>.

⁴ The Youth Risk Behavior Surveillance System (YRBSS) is a national survey administered by the Centers for Disease Control and Prevention that monitors health-risk behaviors among youth and young adults. The survey is administered every 2 years to students in 6th through 12th grades in their school classrooms. The NYOI member survey includes questions from the YRBSS.

Club Teens Are More Likely to Abstain from Alcohol and Drug Use than Teens Nationally
 The Difference Is Larger for Older Teens



In other words, teens who stay connected to a BGCA Club as they get older seem better able to resist engaging in high-risk behaviors than their counterparts nationally at the same ages.

In order to combat the opioid epidemic, greater investments in prevention must be made. Our Clubs have widespread reach across all 50 States, with a targeted goal of servicing the most at-risk youth in the hardest hit communities.

We urge the Subcommittee to support \$25 million for national, out-of-school time, youth-serving organizations providing prevention services; reducing risk factors leading to addiction; and promoting resilience in children, families and communities.

DEPARTMENT OF EDUCATION—21ST CENTURY COMMUNITY LEARNING CENTERS

21st CCLC (21st Century Community Learning Centers) is the only source of Federal funding dedicated to programming in the out-of-school time hours. Funding supports: before- and after-school, and summer programs with: tutoring, academic support and enrichment programs, STEM activities, and physical activities. In 2016, 21st CCLC funding supported 565 sites at 212 Boys & Girls Clubs in 48 States plus Puerto Rico and the Virgin Islands.

—This competitive grant provides crucial resources and establishes support systems to close existing educational opportunity and achievement gaps for underserved students.

—Among regularly attending students, seven in ten improved their homework completion, almost one in three improved their math and language arts grades, and two in three improved their behavior in class.

We urge the Subcommittee to support \$1.3 billion in funding for the 21st Century Community Learning Centers program.

CONCLUSION

We know that an investment in America’s youth will ensure our country’s success today and into the future. Prioritizing our youth not only leads to better individual outcomes but also to a healthier, safer and more prosperous nation. We stand willing to work with you to help build the next generation of American leaders by increasing the number of young adults who have the character, education, fitness and skills, needed to be successful.

Thank you for supporting these programs that are vital to our youth.

[This statement was submitted by Jim Clark, President & CEO, Boys & Girls Clubs of America.]

PREPARED STATEMENT OF THE BRAIN INJURY ASSOCIATION OF AMERICA

Chairman Blunt and Ranking Member Murray, thank you for the opportunity to submit this written testimony with regard to the fiscal year 2019 Labor-HHS-Education appropriations bill. This testimony is on behalf of the Brain Injury Association of America (BIAA), our network of State affiliates, and hundreds of local chapters and support groups from across the country.

In the civilian population alone every year, more than 2.5 million people sustain brain injuries from falls, car crashes, assaults, and contact sports. Males are more likely than females to sustain brain injuries. Children, teens, and seniors are at greatest risk. Currently, more than 5 million Americans live with a TBI-related disability.

Increasing numbers of service members returning from the conflicts in Iraq and Afghanistan with TBI and their families are seeking resources for information to better understand TBI and to obtain vital support services to facilitate successful reintegration into their communities.

BIAA is pleased that the fiscal year 2018 omnibus spending bill passed in March included an additional \$2 million for the HHS' Administration for Community Living (ACL) TBI Federal Grant Program, which will be split between grants for State Protection and Advocacy systems and the Federal TBI State Implementation Grant program. We thank you for that support.

Administration for Community Living.—The TBI Act authorizes the Administration for Community Living (ACL) in the Department of Health and Human Services (HHS) to award grants to (1) States, American Indian Consortia and territories to improve access to service delivery and to (2) State Protection and Advocacy (P&A) Systems to expand advocacy services to include individuals with traumatic brain injury. For the past 20 years the Federal TBI State Grant Program has supported State efforts to address the needs of persons with brain injury and their families and to expand and improve services to underserved and unserved populations including children and youth; veterans and returning troops; and individuals with co-occurring conditions.

In fiscal year 2009, the number of State grant awards was reduced to 15, later adding three more States, in order to increase each monetary award from \$118,000 to \$250,000. This means that many States that had participated in the program in past years have now been forced to close down their operations, leaving many unable to access brain injury care.

Increased funding of the program will provide resources necessary to sustain the grants for the 20 States currently receiving funding and to ensure funding for additional States. Steady increases over 5 years for this program will provide for each State including the District of Columbia and the American Indian Consortium and territories to sustain and expand State service delivery; and to expand the use of the grant funds to pay for such services as Information & Referral (I&R), systems coordination and other necessary services and supports identified by the State. This year, we respectfully request increased funding in the amount of \$5,000,000 for an additional 20 State grants, which would expand the total number of State grants to 39 bringing the total State grant allocation to just over \$11,000,000.

Similarly, the TBI P&A Program currently provides funding to all State P&A systems for purposes of protecting the legal and human rights of individuals with TBI. State P&As provide a wide range of activities including training in self-advocacy, outreach, information & referral and legal assistance to people residing in nursing homes, to returning military seeking veterans benefits, and students who need educational services. We request \$6,000,000 be allocated to the TBI P&A program to allow them to serve more individuals in each State.

Effective Protection and Advocacy services for people with traumatic brain injury are needed to help reduce government expenditures and increase productivity, independence, and community integration. However, advocates must possess specialized skills, and their work is often time-intensive. An increased appropriation in this area would ensure that each P&A can move towards providing a significant PATBI program with appropriate staff time and expertise.

CDC—National Injury Center—\$10 million (+ \$5 million) for the Centers for Disease Control and Prevention TBI Registries and Surveillance, Brain Injury Acute Care Guidelines, Prevention and National Public Education/Awareness.

The Centers for Disease Control and Prevention's National Injury Center is responsible for assessing the incidence and prevalence of TBI in the United States. The CDC estimates that 2.5 million TBIs occur each year and 5.3 million Americans live with a life-long disability as a result of TBI. The TBI Act as amended in 2014 requires the CDC to coordinate with the Departments of Defense and Veterans Affairs to include the number of TBIs occurring in the military. This coordination will

likely increase CDC's estimate of the number of Americans sustaining TBI and living with the consequences.

CDC also funds States for TBI registries, creates and disseminates public and professional educational materials, for families, caregivers and medical personnel, and has recently collaborated with the National Football League and National Hockey League to improve awareness of the incidence of concussion in sports. CDC plays a leading role in helping standardize evidence based guidelines for the management of TBI and \$1 million of this request would go to fund CDC's work in this area.

In 2013, the National Academies of Sciences, Engineering, and Medicine (formerly known as the Institute of Medicine, or the IOM) issued a report calling on the CDC to establish a surveillance system that would capture a rich set of data on sports- and recreation-related concussions among 5–21 year olds that otherwise would not be available. To meet this goal, we request an increase of \$5 million in the CDC budget to establish and oversee a national surveillance system to accurately determine the incidence of concussions, particularly among the most vulnerable of Americans—our children and youth. In the President's fiscal year 2017 budget, a \$5 million increase was included for the Centers for Disease Control and Prevention (CDC) Injury Prevention and Control Center to develop sports concussion surveillance to accurately determine the incidence of sports related concussions among youth ages 5–21.

NIDILRR TBI Model Systems of Care.—Funding for the TBI Model Systems in the Administration for Community Living is urgently needed to ensure that the Nation's valuable TBI research capacity is not diminished, and to maintain and build upon the 16 TBI Model Systems research centers around the country.

The TBI Model Systems of Care represents an already existing vital national network of expertise and research in the field of TBI, and weakening this program would have resounding effects on both military and civilian populations. The TBI Model Systems of Care is the only source of non-proprietary longitudinal data on what happens to people with brain injury. They are a key source of evidence-based medicine, and serve as a “proving ground” for future research.

In order to address TBI as a chronic condition, Congress should increase funding in fiscal year 2019 for NIDILRR's TBI Model Systems of Care program to add one new Collaborative Research Project and increase the number of centers from 16 to 18. In addition, given the national importance of this research program, the TBI Model Systems of Care should receive “line-item” status within the broader NIDILRR budget. Over the next 5 years, BIAA requests increased funding by \$15 million to expand the TBI Model Systems program:

- Increase the number of multicenter TBI Model Systems Collaborative Research projects from one to three, each with an annual budget of \$1.0 million.
- Increase the number of competitively funded centers from 16 to 18 while increasing the per center support by \$200,000; and
- Increase funding for the National Data and Statistical Center by \$100,000 annually to allow all participants to be followed over their lifetimes.

We ask that you consider favorably these requests for the Administration for Community Living, the CDC, and the NIDILRR's TBI Model Systems of Care to further data collection, increase public awareness, improve medical care, assist States in coordinating services, protect the rights of persons with TBI, and bolster vital research.

If you wish any additional information, please contact Amy Colberg, director of government affairs at acolberg@biausa.org. Thank you for your continued support of individuals with brain injury and their families.

PREPARED STATEMENT OF THE BUREAU OF LABOR STATISTICS

Chairman Blunt, Ranking Member Murray, and members of the subcommittee, thank you for taking the time to consider my testimony on behalf of the Bureau of Labor Statistics. I speak to you as the Chair of the Friends of the Bureau of Labor Statistics (BLS), and as a former commissioner of the BLS, regarding the fiscal year 2019 Appropriation for that agency. I urge you to provide \$650 million in funding. This is a 6 percent increase over the fiscal year 2018 appropriation, but represents an important, efficiency-enhancing investment in America's data infrastructure.

Accurate, timely, and readily available statistics are an essential public good in a free enterprise economy. Good statistics help private entities and governments make better decisions and investments, while bad or missing statistics can undermine efficiency in private markets and lead to bad choices that waste tax payer dollars. Federal investment in the agencies that gather the most essential data for America's economic and social wellbeing have flatlined, and we are funding our Fed-

eral data infrastructure at irresponsibly low levels. The additional funding provided for BLS in fiscal year 2018 was a good start, but we must increase the fiscal support of the BLS to maintain American's position as the world's leading economy, and to advance the wellbeing of our children, families, businesses and communities.

For more than 125 years, the BLS produced vital information about jobs and unemployment, wages, working conditions and prices, serving as a key pillar of the data infrastructure of the Nation. The incredible importance of these data can be seen in their use for consequential policy and private decisions. I have provided an appendix to this testimony that include numerous examples of the uses and users of BLS data, from the Federal Government, to nonprofits, to university, and families. I will only highlight a few here.

First, the Federal Reserve System's (Fed) dual mandate requires it to pursue price stability and full employment. The inflation measures produced by the BLS such as the Consumer Price Index, Producer Price Index, Employment Cost Index, and the U.S. Import and Export Price Indices are central to Fed policy decisions regarding prices. Similarly, the Fed's assessment of employment conditions are most strongly informed by the monthly measures of payroll jobs (from the Current Employment Statistics) and the unemployment rate (from the Current Population Survey), both produced by BLS.

In addition to helping the Fed make good decisions, changes to the Consumer Price Index help the Social Security Administration make cost-of-living adjustments to payments for its retirees and other beneficiaries, which helps nearly 62 million Americans. In these cases, the accuracy of BLS data is paramount.

Local Area Unemployment Statistics (LAUS) estimates are used by Federal agencies to transparently allocate funds for important programs such as the SNAP, Temporary Emergency Food Assistance Program, and Temporary Assistance for Needy Families.

But it's not just the Federal Government that depends on data from the BLS. State and Local governments use Employment Projections, Occupational Employment Statistics and the Occupation Outlook Handbook to make occupation projections, identify skill gaps and market geographic areas to prospective employers. Thus, the data collected and shared by the BLS provide a stable foundation for government decisionmaking.

When urban and rural communities, as well as businesses of all sizes, and families use on the data produced by BLS, they fuel economic development. Business can find the right workers, pay them competitive wages, while job seekers and students can make career decisions that will lead the right workers to the right employes.

The burgeoning new world of "Big Data" analytics relies heavily on official statistics to reach their conclusions as they benchmark estimates, weight samples and validate results. Many of the most well-known examples, including the Billion Prices Project, and products from Indeed and Burning Glass depend on data infrastructure provided by BLS.

The increase in funding BLS received in fiscal year 2018 was beneficial, but it cannot reverse nearly a decade of flat funding. The BLS's purchasing power has fallen by nearly 14 percent since 2009. The BLS has taken many steps to implement cost saving measures to make the most of its budget. Currently, BLS is exploring options that include centralizing more data collection, moving to a multi-year sampling and collection protocols, using a combination of collected and modeled data, expanding web scraping techniques and autocoding. Even though these efforts have gone a long way, the current level of funding is not sustainable, and means BLS cannot adequately innovate and rise to new challenges in understanding our changing economy.

First, BLS cannot devote enough staff, data purchases, IT hardware and software to better cover emerging economic trends, including the growing service sectors and the gig and digital economies and expand the use of big data. Without these, BLS data risks becoming irrelevant, and the businesses and communities will lose the ability to make informed, evidence-based decisions that fuel the economy.

Second, short staffing risks serious errors or last-minute delays in major statistical releases. Less training, outdated equipment and software, and fewer back-ups raise risks from mistakes and unforeseen events. And these mistakes can be costly. A mistake of just 0.1 percent in the CPI would result in an over- (or under-) payment of almost \$1 billion in annual Social Security benefits. Financial markets could also be roiled by sudden delays or large errors in jobs or inflation data releases. BLS staff works hard to make sure this does not happen, but the risk is growing.

With a return to full funding, BLS could reduce the risk of operational failure, and accomplish many improvements to its programs, and help ensure the wellbeing of American families.

Some key examples are:

- Measure the Gig Economy.* The May 2017 fielding of the CPS Continent and Alternative Employment Arrangement Supplement (CWS) was funding as a one-time reimbursable by the DOL Chief Evaluation Office. Without continual funding, the BLS cannot residing the questions in the CWS and other supplements to track emerging trends in the labor market. In addition, the employer perspective (incentives, type and degree of use) is still missing.
- Modernize the Consumer Expenditure Survey.* BLS is redesigning the Consumer Expenditure Survey to take advantage of new technologies that reduce the high respondent burden and improve data quality.
- Measure Employer-Provided Training.* BLS last measured employer-provided training in 1995. So, our country has no gold-standard information on whether employers are providing more or less training than in the past. What sort of training to they provide? To whom? How do they provide it? Gathering this type of data can help policy makers, educators and businesses understand and address our national skills needs.
- Increase Capacity for Computationally Intensive Automation.* Funds to enhance BLS hardware, software and expertise would advance BLS's ability to produce more detailed and improved products from its existing programs and administrative data. This capacity would increase the use of autocoding (to improve data quality and reduce reporting burden) and data matching, regional modeling, and merging.
- Design Surveys to Answer New Questions About Our Economy.* BLS seeks to add the capacity to field survey modules that can provide gold-standard answers to urgent questions as they arise. These modules will address key questions as they arise, such as who employs gig workers, impacts of capital constraints, effects of natural disasters, etc.

Good data fuels the national economy and empowers good decisionmaking. It is essential to any effort to advance the well-being of our children as they prepare for the labor market, for families as they plan for their living arrangements, small and large business owners as they plan for their future, and for policy makers as they evaluate programs and policies.

Funding the BLS is an investment in efficient government. Public officials and policy makers need reliable data and tools to advance sound and responsible policies. As a producer of gold-standard data, BLS has had a long history of independence and impartiality. Since its inception in 1884, BLS Commissioners have always supported the impartial and objective role of the agency. BLS follows the Office of Management and Budget directives to adhere to objective presentation of facts, as well as explicitly protecting data integrity and transparency with respect to its methodologies and practices.

The statistics collected by BLS provide a stable foundation for decisionmaking. Every community, including businesses both large and small, relies on Federal data to fuel economic development. The BLS's user metrics attest to the usefulness of their data. The BLS website averages 19 million page views per month, as people access more than 107 million BLS data series.

Re-investing in BLS means the agency will continue to gather, analyze and share the trustworthy data needed for the evidence-based decisions that will move our economy forward. Please provide the BLS with \$650 million in fiscal year 2019 so that America's economy can work at its best for all Americans.

Thank you for your time and consideration of this important agency.

[This statement was submitted by Erica Groshen, Industrial and Labor Relations School, Cornell University, Chair, The Friends of the Bureau of Labor Statistics.]

PREPARED STATEMENT OF 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 in support of funding for the Office on Smoking and Health (OSH) at the Centers for Disease Control and Prevention (CDC). We urge the Subcommittee to include at least \$216.5 million for CDC's OSH in the Labor-HHS-Ed appropriations bill for fiscal year 2019.

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 more than 16 million Americans are currently living with a tobacco-caused disease.¹

¹U.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-of-progress/>.

Tobacco use is responsible for 32 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.² Smoking shortens the life of a smoker by more than a decade and increases the risk of early death much more than other risk factors.³

Given the addictiveness of nicotine, smoking is not simply a matter of choice. Tobacco use almost always begins during adolescence. Ninety percent of adult smokers begin as teenagers, or earlier.⁴ As youth become adults, they typically continue to use tobacco because they have become addicted to nicotine. Most adult smokers want to quit (nearly 70 percent)⁵ and wish they never started (70 to 85 percent).⁶ But overcoming an addiction to nicotine is difficult, and tobacco users often must make multiple quit attempts before they succeed.

Fortunately, we know how to reduce tobacco use. Smoking rates have been cut by more than half since the first Surgeon General's report on the harms from smoking in 1964.⁷ According to recent surveys, the smoking rate among adults declined by one-third and the smoking rate among high schoolers declined 70 percent between 2000 and 2016.⁸ This progress has been driven by the implementation of policies and programs that have proven to be highly effective in preventing youth from starting to use tobacco products and helping adult tobacco users to quit.

These successful efforts to reduce tobacco use have generated enormous gains for public health. People who would otherwise be suffering from a tobacco-caused disease are living longer, healthier lives. Over the past 50 years, tobacco control measures have prevented at least eight million premature deaths from smoking.⁹ Thirty percent of the increase in life expectancy between 1964 and 2012 is due to reductions in smoking, an especially remarkable achievement when one considers the enormous medical innovations that occurred during this time.¹⁰

The CDC's Office on Smoking and Health plays a critical role in preventing young people from using tobacco products and helping current smokers to quit. OSH translates science into best practices for reducing tobacco use, provides funding and technical support to implement them, and monitors progress in reducing tobacco use rates.

Since 2012, OSH has funded a national media campaign, *Tips from Former Smokers* (Tips), to encourage smokers to quit. It features real people discussing the harsh reality of living with a disease caused by smoking, and it has proven to be highly successful and cost-effective. Since the campaign's inception, CDC estimates that millions of Americans have tried to quit smoking cigarettes, at least 500,000 cigarette smokers have quit for good and about 50,000 people have been saved from pre-

²HHS, *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>.

³HHS, *The Health Consequences of Smoking—50 Years of Progress: A Report of the Surgeon General*, 2014.

⁴Substance Abuse and Mental Health Services Administration (SAMHSA). Center for Behavioral Health Statistics and Quality. *National Survey on Drug Use and Health (NSDUH)*, 2014.

⁵Babb, S., et al., "Quitting Smoking Among Adults—United States, 2000–2015," *MMWR* 65(52), January 6, 2017. https://www.cdc.gov/mmwr/volumes/65/wr/mm6552a1.htm?s_cid=mm6552a1_w.

⁶Nayak, 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).

⁷HHS, *The Health Consequences of Smoking—50 Years of Progress: A Report of the Surgeon General*, 2014.

⁸Centers for Disease Control and Prevention (CDC), "Current Cigarette Smoking Among Adults—United States, 2016," *MMWR* 67(2):53–59, January 19, 2018; CDC, "Tobacco Use Among Middle and High School Students—United States, 2011–2016," *MMWR*, 66(23): 597–603, June 15, 2017, <https://www.cdc.gov/mmwr/volumes/66/wr/pdfs/mm6623a1.pdf>.

⁹Holford, T., et al., "Tobacco Control and the Reduction in Smoking-Related Premature Deaths in the United States, 1964–2012," *Journal of the American Medical Association*, January 8, 2014: 311(2).

¹⁰Holford, T., et al, *JAMA*, January 8, 2014: 311(2).

mature death.¹¹ It cost just \$393 for each year of life saved, which is considered a “best buy” in public health.¹²

CDC also provides funding to States for quitlines, which provide telephone-based counseling services to help tobacco users to quit and, in some States, provide tobacco cessation medications. Smokers who use quitlines are at least two to three times more likely to succeed than those who try to quit on their own.¹³

In addition, CDC provides grants to all 50 States and the territories to help establish and maintain tobacco prevention and cessation programs at the State and local level. Comprehensive State tobacco programs like the ones CDC helps to maintain have been found to be cost-effective. A study of Washington State’s tobacco prevention and cessation program found that for every dollar spent by the State on tobacco prevention, the State saved more than \$5 in reduced hospitalization costs.¹⁴

CDC also conducts important surveillance and other research on tobacco use and its impact on health. For example, the National Youth Tobacco Survey, which CDC conducts with FDA, found that e-cigarette use among high school students increased more than ten-fold (from 1.5 percent to 16.0 percent) from 2011 to 2015.¹⁵

We were pleased that the Senate Labor-HHS-Ed appropriations bill for fiscal year 2018 provided level funding for OSH and that the Consolidated Appropriations Act of 2018 (Public Law 115–141) provided a \$5 million increase for OSH, bringing overall funding for OSH to \$210 million.

Regrettably, the House Labor-HHS-Ed appropriations bill for fiscal year 2018 would have reduced funding for OSH by nearly 25 percent, from \$205 million to \$155 million. Such a significant reduction would have undermined CDC’s efforts to prevent youth from starting to use tobacco and to help adults to quit. Programs we know are working would have been curtailed and possibly eliminated. The House’s proposed funding cut would have made it virtually impossible for CDC to continue its successful and cost-effective Tips media campaign. This funding cut would also likely have reduced funding to States for quitlines and State and local tobacco prevention and cessation programs. In whole, such a funding cut would have led to more young people using tobacco products, fewer adult tobacco users quitting, and higher future healthcare costs for treating tobacco-caused disease.

We remain concerned that the President’s budget request for fiscal year 2019 would again eliminate funding for OSH. It would eliminate the Tips media campaign, eliminate dedicated funding for State quitlines and State tobacco control programs, and eliminate or seriously weaken CDC’s ability to collect data on tobacco use and identify emerging threats. While the President’s budget request indicates that States could use funding from a newly created America’s Health Block Grant to reduce tobacco use, there is no guarantee that States would do so, and States would almost certainly have to substantially cut back existing tobacco programs since the President’s budget request reduces overall funding for CDC’s chronic disease prevention programs.

We urge the Subcommittee to provide at least \$216.5 million for OSH for fiscal year 2019, which is the enacted level for fiscal year 2015. Without continued attention and resources, we risk undermining the progress that has been made in reducing the disease and death caused by tobacco use. We risk more cancers, heart dis-

¹¹Centers for Disease Control and Prevention (CDC), *Tips From Former Smokers Making an Impact*, Impact Sheet, April 2018, Centers for Disease Control and Prevention (CDC), fiscal year 2017 Justification of Estimates for Appropriations Committees <http://www.cdc.gov/budget/documents/fy2017/fy-2017-cdc-congressional-justification.pdf>; and CDC, “Impact of first federally funded anti-smoking ad campaign remains strong after 3 years,” March 2016 <http://www.cdc.gov/media/releases/2016/p0324-anti-smoking.html>; Centers for Disease Control and Prevention (CDC), “Tips from Former Smokers, About the Campaign” https://www.cdc.gov/tobacco/campaign/tips/about/index.html?s_cid=OSH_tips_D9393.

¹²Xu, Xin, et al., “Cost-Effectiveness Analysis of the First federally Funded Antismoking Campaign,” *American Journal of Preventive Medicine*, 2014.

¹³Fiore, MC, et al., *Treating Tobacco Use and Dependence: 2008 Update—Clinical Practice Guideline*, U.S. Public Health Service, May 2008, http://www.surgeongeneral.gov/tobacco/treating_tobacco_use08.pdf.

¹⁴Dilley, Julia A., et al., “Program, Policy and Price Interventions for Tobacco Control: Quantifying the Return on Investment of a State Tobacco Control Program,” *American Journal of Public Health*, Published online ahead of print December 15, 2011. See also, Washington State Department of Health, *Tobacco Prevention and Control Program, Progress Report*, March 2011, <http://www.doh.wa.gov/tobacco/program/reports/2011ProgReport.pdf>. Washington State Department of Health, *Tobacco Prevention and Control Program, News Release*, “Thousands of lives saved due to tobacco prevention and control program,” November 17, 2010, http://www.doh.wa.gov/Publicat/2010_news/10-183.htm.

¹⁵U.S. Centers for Disease Control and Prevention (CDC), “Tobacco Use Among Middle and High School Students—United States, 2011–2015,” *Morbidity and Mortality Weekly Report (MMWR)* 65(14):361–367, April 14, 2016, <http://www.cdc.gov/mmwr/volumes/65/wr/pdfs/mm6514a1.pdf>.

ease, respiratory disease, and other tobacco-caused diseases and more people dying years earlier than if they did not smoke. Without urgent action, 5.6 million children alive today will die prematurely from a smoking-related disease.¹⁶

The Federal Government cannot afford to take a hands-off approach to tobacco use. Tobacco use not only harms the health of tobacco users but also burdens families, the healthcare system, and government budgets. It is responsible for approximately \$170 billion in healthcare costs each year. More than 60 percent of these healthcare costs are paid by government programs such as Medicare and Medicaid.¹⁷

Just as the Subcommittee supports the development of new cures and treatments for devastating diseases, it should also support programs that have proven effective at preventing many of those same disease, including the cancers, heart disease, COPD and other diseases caused by tobacco. At a time of concern about high healthcare costs, the Subcommittee should invest in programs that reduce risk factors like tobacco use that, if left unaddressed, will lead to higher medical costs for treating preventable diseases in the future.

We appreciate the opportunity to share our views on the importance of OSH's work and the need to fund the Office on Smoking and Health at a minimum of \$216.5 million, its fiscal year 2015 funding level.

[This statement was submitted Matthew L. Myers, President, Campaign for Tobacco-Free Kids.]

PREPARED STATEMENT OF CANNONBALL KIDS' CANCER FOUNDATION

Chairman Blunt, Ranking Member Murray, and members of the Subcommittee, thank you for your dedication to public health and your continued efforts to adequately and appropriately invest in life-saving research to keep our Nation's health progressing forward. My name is Kelly King, and I am the education director at Cannonball Kids' cancer (CKc), a nonprofit foundation focused on funding innovative and accessible research for children fighting cancer and educating for change. On behalf of our foundation, the 40,000 children in the United States who are actively in treatment for pediatric cancers and the nearly 1,800 families who will lose a child to cancer in 2018, I am requesting you make pediatric cancer a greater national priority. Specifically, I am asking the Subcommittee to request the NCI to create dedicated categories of funding for the 10 under-researched forms of pediatric cancer, including relapsed and refractory cases, and direct \$50 million in fiscal year 2019 funds to these new line items.

On April 11, 2018, I was privileged and honored to be in attendance during the fiscal year 2019 budget hearing of your sister committee in the U.S. House of Representatives. The focus of this hearing was testimony from the National Institutes of Health Director Francis S. Collins, M.D., Ph.D. While I was not able to attend the corresponding hearing in the Senate, I viewed the video coverage on your committee's website.

Through those hearings, I gained greater appreciation for some of our Nation's top priorities in healthcare, such as Alzheimer's, precision medicine, and the opioid epidemic. I witnessed how integral this committee is to the upward trend of funding to the NIH and I respect your commitment to preserving that momentum.

I was also encouraged to hear several members of this committee raise the topic of pediatric cancer during the hearing, and then to see emphasis on this disease confirmed by unanimous passing of the Childhood Cancer STAR Act in both chambers. It is the unwavering support and attention of champions in the Senate and on this committee, like Senator Capito, Senator Murray, and Senator Reed, who made that significant accomplishment possible. I speak for many childhood cancer advocates when I say we are exceptionally grateful for the committee's recognition of this problem, its severity, and your willingness to stand up on our behalf.

In spite of all of the ways I've been bolstered, I wholeheartedly believe we can still do more for childhood cancer. Private, family-founded non-profits like CKc are required to exist to fill the funding gap for pediatric cancer research, especially for early-stage investigators, due to unnecessarily strong competition for NIH grants. While our Nation's people can't rely solely on government or industry to fund this important research, we can do better. That's why I'm submitting this written testimony. Here are four reasons why the NCI should be directed to re-allocate funding

¹⁶HHS, *The Health Consequences of Smoking—50 Years of Progress: A Report of the Surgeon General*, 2014.

¹⁷Xu, X et al., "Annual Healthcare Spending Attributable to Cigarette Smoking: An Update," *American Journal of Preventive Medicine*, 2014.

from other areas to the 10 types of pediatric cancers, and their hundreds of subtypes, that have seen little change in survivability:

1. *Government funding changes lives and saves lives.* National prioritization of health concerns and subsequent, designated Federal funding has helped our country make great strides in research, leading to revolutionary treatments and cures for many diseases. Before the discovery of insulin in the 1920s, children with diabetes rarely lived longer than 1 year. They also suffered side effects from their disease, such as blindness, loss of limbs, stroke, heart attacks, and kidney failure. (Coincidentally, these same conditions are all byproducts of pediatric cancer treatment, and those who survive often face them.) Diabetes may not yet be curable and still requires daily maintenance, but only 1 percent of childhood deaths (or about 35 per year) are now related to diabetes. This demonstrates it is possible to make drastic changes in the survival of pediatric diseases!

In oncology, hundreds of drugs have been approved for adult treatment in the last 40 years. Breast cancer is a supreme example of a disease that has benefited from these drug developments. Advocacy that began in the 1980s helped quadruple Federal research funding for breast cancer during the 1990s. By 2010, the mortality rate from all breast cancers fell by 36 percent, and Stage I breast cancer now sees nearly 100 percent survival.

By contrast, only four drugs have been developed specifically for use in children during that same timeframe. Yet, general pediatric cancer research remains at a dismal 4 percent of the NCI budget. Additionally, the NIH has previously given individual priority to 12 specific adult cancers, but only two specific pediatric cancers. Those same two cancers are the only ones that have seen drastic improvements in survival in recent years, which can presumably be tied to this subsidy. Namely, childhood leukemia and neuroblastoma have been allocated top-down Federal research funds since at least fiscal year 2013. Leukemia funding ranged from \$67 million to \$164 million and neuroblastoma from \$32 million to \$40 million. The 5-year survival rate for acute lymphoblastic leukemia (ALL) was less than 10 percent 50 years ago and is now over 88 percent. In a similar timeframe, the 5-year survival rate for neuroblastoma increased from 34 percent to 68 percent.

The changes for these cancers are commendable and have helped the overall pediatric cancer survival rates improve dramatically. In 1975, just over 50 percent of children diagnosed with cancer survived 5 years. Now, 83 percent of children diagnosed with cancer survive the same timeframe, as celebrated by Dr. Ned Sharpless, Director of the NCI, in your Subcommittee's hearing, "We're curing more and more kids."

The successful advances in treating these two forms of pediatric cancer are a core reason the STAR Act was necessary. Currently, there are half a million pediatric cancer survivors in the U.S. In addition to supporting necessary data gathering and management for pediatric cancer, STAR will help facilitate the study of these survivors' long-term toxicities as well as the management of the chronic and acute conditions that arise from it. As such, beyond the requests outlined in this testimony, I positively urge you to ensure the approved STAR Act comes to fruition by receiving funding during the appropriations process.

2. *It's time to increase survivability for all forms of pediatric cancer.* Although overall survival rates have increased for pediatric cancer, survival rates still remain very low for some childhood cancer types. And as a result, cancer remains the number one killer by disease of our children. In fact, cancer accounts for more deaths than all other childhood diseases combined. Additionally, childhood cancer incidence rates continue to rise, indicating that funding is not yet aligned with need. Dr. Sharpless highlighted this sentiment in the hearing, stating "It's not enough to make progress against some cancers. We need to make progress against all cancers." He added, "As the NCI, we need to focus not only on the cancers where we're having success, but perhaps even more so on the ones that have been recalcitrant and refractory to therapy to date."

Primary brain tumors are the most common solid tumor of childhood, and brain cancer has now replaced leukemia as the leading cause of cancer death among one- to 19-year-olds. Yet there remains no dedicated category of NIH funding specifically for childhood brain tumors.

As an example, there are zero survivors of diffuse intrinsic pontine glioma (DIPG), and, at diagnosis, families are told their child has less than 1 year to live. In 1961, astronaut Neil Armstrong's 2-year-old daughter, Muffy, was diagnosed with DIPG. She received the exact same prognosis that DIPG patients are given today and was administered much of the same treatment. She died on January 28, 1962. It is unacceptable and unnecessary that nothing has changed for DIPG in 57 years. It's time we do for children suffering from brain and other solid tumors what we've done for leukemia, neuroblastoma, and other pediatric diseases like diabetes.

3. *There's parallel legislative precedent.* Gun violence is a heated topic of discussion in our country. The news is consumed with reports of gun control, mass shootings, and murder. Fittingly, Congress echoes this sentiment of concern; and, the recent omnibus appropriated funding to the CDC for research on the causes of gun violence. Every day, four children are deliberately killed with guns. This is unimaginable and tragic, but, shockingly, this number is LESS than the number of deaths per day from pediatric cancer! However, the news media has not expressed outrage regarding pediatric cancer in the way they have for gun violence, nor did the omnibus expressly acknowledge it. If the Appropriations Committee can designate funds specifically for gun violence research, then I believe they should also have the means to further support research into a disease killing more children each day: pediatric cancer.

4. *It's personal.* There are many other facts and statistics I could use to support our request for additional funding. However, what matters most is that behind every statistic is a child's life, a family, who was impacted by pediatric cancer. The numbers aren't just numbers. They represent real life. And that real life can be unimaginable to you if you have not been personally touched by this disease. Many of the issues and concerns raised by the Subcommittee members during the hearings were a result of their personal experiences or interactions with family members and constituents. I'd like to help make childhood cancer personal to you.

1. *Meet Nolan.* My 3-year-old son, Nolan, died on April 1, 2017 from high-risk, Stage IV hepatoblastoma (the most common form of pediatric liver cancer). After 15 months of surgeries and treatments, we were told there were no clinical trials available, and we were left to face our only option of palliative care. However, before we could begin navigating this "wait to die" approach, Nolan's heart stopped unexpectedly as a result of toxicity from the 35-year-old chemotherapy drugs that failed to save him. Hepatoblastoma has a 20 percent survival rate when the disease has metastasized, yet it receives no dedicated NIH funding and there are no available treatment options for relapsed hepatoblastoma.
2. *Meet Emmi Grace.* Monica Angel, education liaison at CKC, lost her daughter, Emmi Grace, to atypical teratoid/rhabdoid tumor (AT/RT) at 5 months of age. AT/RT is the most common malignant central nervous system tumor in children less than 6 months old and the survival rate is dismal, with a reported median survival of less than 1 year. Yet there is no dedicated category of NCI funding for AT/RT or any brain cancers specific to children. Emmi Grace's treatments, some of which were designed for adult, male testicular cancer, were not meant for the tiny, rapidly developing organs of an infant. They caused multi-organ failure just 2 months after diagnosis.
3. *Meet Cannon.* Melissa Wiggins, executive director of CKC, has a 6-year-old son who is the namesake of our foundation and is now considered a "pediatric cancer survivor." He was diagnosed at 20 months old with high-risk, Stage IV neuroblastoma. At the time of his diagnosis, his parents were told he had a 50 percent chance of survival. However, by the time he finished treatment 3 years later, a new drug specifically for pediatric neuroblastoma had received FDA approval, and survival rates climbed to 68 percent. However, his treatments have left him with lifelong disabilities and obstacles, such as hearing aids, the inability to naturally father a child, small stature, visible scars, and an eight-times-higher mortality rate than his peers.

It's not a coincidence that our foundation's statistics mirror overall statistics. The child who faced a cancer receiving institutionally-directed NCI funding survived. The two who faced cancers without NCI-controlled funding did not. Yet Nolan, Emmi Grace, and Cannon are not just statistics. Their stories are real. My family's pain is real. My other two sons will grow up without their youngest brother. My husband and I will grow old with one less child. The proper order of life has been disrupted. And unless we place a higher priority on researching pediatric cancers, stories like ours will be repeated . . . daily. Every day in the U.S., 42 children will be diagnosed with cancer, and five are tragically lost. Ninety-five percent of those who survive 5 years will have a significant health issue by the time they are 45, which is typically the effect of hand-me-down adult treatments.

I cannot accept this as the status quo in the United States in 2018. I know that if we continue to appropriate funds to less-understood categories of childhood cancer, it is possible to increase survivability and quality of life for survivors. I strongly urge the Subcommittee to place a higher priority on those childhood cancers, which are less studied and have little or no effective treatment options, particularly in relapsed or refractory cases. The first step toward doing so is a reallocation of \$50 million in fiscal year 2019 funds from other diseases with improved survivability to basic science in pediatric cancers. These funds should be distributed evenly as \$5

million budget items for each of the 10 primary pediatric cancer types that do not currently receive top-down, directed funding. Basic research is the foundation that will help us better understand these distinct, difficult-to-treat diseases and eventually provide access to targeted, less toxic, and curative therapies for more children in our country.

This approach has worked before. It's time for change, there's precedent, and it's personal. It may be too late for my son, Nolan, but I refuse to accept the past as the only course of action for the future. We at Cannonball Kids' cancer believe it is unacceptable that cancer remains the number one problem in pediatric healthcare, and we also declare it unnecessary. Let this be the time in history that people remember as the turning point for childhood cancer.

[This statement was submitted by Kelly A. King, Education Director, Cannonball Kids' cancer Foundation.]

PREPARED STATEMENT OF CAST

CAST is a non-profit that uses educational technology coupled with expertise in the learning sciences to ensure all learners can and do reach their full potential. Our primary lever for change is Universal Design for Learning (UDL), a framework pioneered at CAST focused on harnessing technology and instructional practices to remove barriers to learning faced by individuals in digital as well as physical settings. UDL encourages the proactive design of flexible learning environments that anticipate learner variability and provides alternative routes or paths to success; UDL acknowledges that variability across all learners is the norm rather than the exception.

In fiscal year 2019, CAST requests the following: (1) U.S. Department of Education (ED)—continue to fund all education programs at levels provided in the bipartisan fiscal year 2018 Consolidated Appropriations Act, and prioritize UDL as a necessary component of all competitive grants made by ED. (2) U.S. Department of Labor (DOL)—promote through report language that all Federal investments in technical assistance for career and workforce training incorporate the principles of UDL as defined in section 103(a)(24) of the Higher Education Act,¹ and as referenced and endorsed as a best practice in the National Technology Plans of 2010 and 2016, as well as the National Ed Tech Developer's Guide of 2015.²

In its 30-year history, CAST has brought UDL into K–12 schools, postsecondary settings and increasingly into workforce development and the workplace. CAST's work is grounded in the vision of creating a world where “learning has no limits” whether it be in K–12 schools, colleges, apprenticeships, or the workforce. CAST works in partnership with other organizations that also focus on improving access to and inclusion in learning and work. Research, development and implementation of UDL is supported by multiple Federal agencies, state education systems, school districts, and private foundations.

Universal Design for Learning (UDL) is entering its third decade influencing policy, research, and practice. Substantial Federal investments in UDL began in the late 1990's and have steadily expanded since then. Over \$150 million has been invested via ED's competitive grants programs to ensure that flexible and accessible learning materials are made available to all the nation's K–12 students and UDL has emerged as a key element in Federal education policy.³

As a flexible approach to addressing learner variability, UDL is organized around three core principles: (1) multiple means of engagement, (2) multiple means of representation, and (3) multiple means of expression and action. The UDL core principles consider the variability of all learners—including learners who were formerly relegated to “the margins” of our educational systems but now are recognized as part of the predictable spectrum of variation among individuals. These principles guide the design of learning environments with a deep understanding and appreciation for individual variability. UDL is not a prescriptive checklist or formula with set methods and tools to be applied in every situation.

¹ § 103(a)(24), PL 110–315, Universal Design for Learning means “... a scientifically valid framework for guiding educational practice that—(A) provides flexibility in the ways information is presented, in the ways students respond or demonstrate knowledge and skills, and in the ways students are engaged; and (B) reduces barriers in instruction, provides appropriate accommodations, supports, and challenges, and maintains high achievement expectations for all students, including students with disabilities and students who are limited English proficient”.

² See <http://www.cast.org/whats-new/news/2016/udl-in-the-essa.html#.Wob36WbGzqQ>.

³ See: PL 110–315, PL 114–95.

Powerful digital technologies applied using UDL principles enable easier and more effective customization of curricula for learners. Advances in technology and the learning sciences have made “on-the-fly” individualization of curricula possible in practical, cost-effective ways, and many of these technologies have built-in supports, scaffolds, and challenges to help learners understand, navigate, and engage with the learning environment. While technologies are not the only means of implementing UDL, their use can free instructors to be creative and resourceful in designing flexible learning environments: providing additional challenges for advanced students or additional support to those that are struggling.

Interest in UDL in workforce development continues to grow. Specifically, UDL is a required component in online and technology-enabled courses developed by all grantees of the \$2 billion Trade Adjustment Assistance Community College & Career Training grant program from DOL and is a foundational element of large-scale employment training initiatives like YouthBuild and Jobs for the Future. An ongoing 2018 Schwab Foundation-funded partnership between CAST and Stanford University has established the UDL Innovation Studio⁴ to explore and research ways to use UDL to increase the postsecondary success of diverse learners and implement expanded and scalable opportunities to aid adults in successful workforce transition. CAST’s UDL in Higher Education⁵ initiative prompts faculty designing career pathway training to plan for ways in which industry partners and instructors can collaborate on course development to create authentic, engaging scenarios that enable students to learn skills in the context of a profession. UDL has also been introduced as a method to better serve all trainees in registered apprenticeships by the apprenticeship training leadership of the carpenters, sheet metal workers, and laborers unions in Boston, Massachusetts.

There is a great need for workforce-related training and assistance to assure we prepare adults to be lifelong learners, to gain the skills and knowledge for today’s careers as well as learning skills that will help them evolve as the needs of the workplace shift. Employers need highly skilled and qualified employees, and many are seeking ways to diversify and expand their workforce. The UDL framework proactively supports this by allowing a corporation, campus, business or any organization to strategically identify the unique ways it can meet identified needs and goals. Recent examples are: the Tennessee Board of Regents has mandated UDL training for all college faculty through its five-year accessibility plan; and in Syracuse, New York, Onondaga Community College has infused UDL in its new Pathways to Careers program.⁶

Increasingly, education and training programs of every level and type are incorporating significant digital and online components. Yet, despite the promise of flexibility, customized learning solutions, and anywhere/anytime educational opportunity often associated with digital learning, the reality is that the experience for many of today’s learners has been at best underwhelming, and at worst detrimental. Leveraging the UDL framework is essential to mitigating the current impact of digital learning, especially for learners with challenges—whether they be based in poverty, language, disability or something else. The population of digital learners that requires such training is predictably diverse and every federally-supported training program must plan for that.

It is imperative that all learners, including first-time career seekers or adults desiring new opportunities, have access to workforce development and career pathway strategies and programs that are designed from the beginning with the variability of their learning in mind. Continuing to invest in innovations and effective implementation of UDL in education while prioritizing the need to include UDL as part of the infrastructure of workforce training makes sense. This is the ideal time for Congress to recognize the payoff investments in UDL will continue to make for all learners.

CAST thanks you for the opportunity to provide a statement offering recommendations and reminds you of the emphases we hope to see in fiscal year 2019: (1) U.S. Department of Education(ED)—continue to fund all education programs at levels provided in the bipartisan fiscal year 2018 Consolidated Appropriations Act and prioritize UDL as a necessary component of all competitive grants made by ED. (2) U.S. Department of Labor (DOL)—promote through report language that all Federal investments in technical assistance for career and workforce training incorporate the principles of UDL as defined in section 103(a)(24) of the Higher Education Act, and as referenced and endorsed as a best practice in the National Tech-

⁴ See <https://slc.stanford.edu/getting-started/serving-community/students>.

⁵ See <http://udloncampus.cast.org/home#.Wte8tYjwY2w>.

⁶ See: <http://www.sunyocc.edu/index.aspx?menu=964&collside=544&id=35796>.

nology Plans of 2010 and 2016, as well as the National Ed Tech Developer's Guide of 2015.

PREPARED STATEMENT OF THE CDC ARTHRITIS COALITION

On behalf of the 54 million adults and children living with doctor-diagnosed arthritis in the United States, the CDC Arthritis Coalition thanks Chairman Blunt and Ranking Member Murray for the opportunity to provide written testimony to the Appropriations Subcommittee on Labor, Health and Human Services (HHS), and Education and Related Agencies for fiscal year 2019. To maintain the commitment to arthritis disease management, we respectfully request \$16 million as a line item for the Centers for Disease Control and Prevention (CDC) Arthritis Program for fiscal year 2019.

We are concerned about the impact the President's budget would have on people with arthritis. The budget cuts nearly \$900 million from the CDC, including \$138 million from the Chronic Disease Division, which contains the Arthritis Program. Further, the budget would create a block grant, allowing States to fund chronic disease programs as they choose. In the absence of categorical funding, a block grant would disadvantage smaller programs like the Arthritis Program. Arthritis is the leading cause of disability in the United States resulting in tens of billions of dollars in direct and indirect costs to States. Even so, we fear States would not prioritize arthritis funding and the functions of the program could cease to exist as we know them.

The CDC Arthritis Program is the only Federal program dedicated solely to arthritis, a chronic disease that affects 1 in 4 Americans. The program funds States, national partners and public health research with the goal of understanding prevalence and targeting evidence-based interventions to improve the health outcomes of people living with arthritis. Disease management through proven interventions like exercise programs and education is essential to helping people manage their symptoms and prevent worsening of disease. Proper disease management can save hundreds of millions of dollars in direct medical costs from preventable joint replacements, and indirect costs from disability compensation and lost productivity.

Below are some examples of the direct impact the CDC Arthritis Program has on communities and on people with arthritis.

Grant funding to States allows them to tailor programs to the needs of their communities. In Kentucky, the program's focus from 2013–2014 was to enhance its partnership with the Kentucky Department for Aging and Independent Living, and expand the number of community program leaders and course sites that provide evidence-based arthritis programs. During this time, efforts increased the number of new participants by approximately 58 percent, compared to the previous year's reach.

In Rhode Island, the Arthritis Program developed the Community Health Network, a centralized referral system that connects the healthcare system to evidence-based programs located in the community. As a result, the Rhode Island Arthritis Program reaches citizens in every county of the State through this network. We know that these programs are having a positive impact. One Rhode Island participant wrote, "I was in so much pain before this program that I couldn't walk half a block. I was hurting from arthritis in every joint. I now walk 3 miles every day." Many others have written about their experience with this program, noting they are able to move more with less pain and have found great benefit from participating in the program.

In addition, grant funding to national organizations allows evidence-based programs and other resources to be scaled up beyond the 12 funded States and reach more people with arthritis. The Arthritis Foundation's Help Line and Resource Finder are available 24 hours a day, 7 days a week to all people with arthritis, and offer people personal assistance, in addition to connecting them to community resources. The Resource Finder includes information on local evidence-based programs such as Walk with Ease and EnhanceFitness.

YMCA of the USA, a CDC Arthritis Program national partner, has offered EnhanceFitness since 2012 and, as of March 2018, has served over 25,000 participants in 44 States. EnhanceFitness is a proven community-based senior fitness and arthritis management program that helps older adults become more active, energized and empowered for independent living. In addition to empowering older adults for independent living, the program has shown a substantive return on investment. A 2013 CMS study showed that EnhanceFitness participants had fewer hospitalizations and saved \$945 in healthcare costs per year, compared to non-participants.

The best case for the success of programs like EnhanceFitness comes from participants themselves. A participant in Michigan had always been active until rheumatoid arthritis “attacked my body with a vengeance.” She was unable to lift things, walk far, or even get out of a chair without assistance. She said, “When the second class started I was able to get in...it is so wonderful. I have progressed so far I cannot believe it...I am now able to get up and down in a chair repeatedly...my whole body feels better. The exercise also helps with energy and I feel more energetic and positive. I cannot say enough good things about this program...I have to have this class to be able to keep moving and help decrease pain.”

Being able to assess the impact of arthritis, to substantiate positions, and make decisions based on facts begins with data on the prevalence, societal, and economic costs of arthritis. The CDC Arthritis Program undertakes the lead work in detailing the prevalence of arthritis in this country for *The Burden of Musculoskeletal Diseases in the United States: Prevalence, Societal and Economic Cost (BMUS)* (www.boneandjointburden.org). Published by the United States Bone and Joint Initiative, this is a critical publication for researchers, and for health policy analysts.

Because of the CDC Arthritis Program, we now have a rich data set on everything from activity limitations (24 million adults are limited due to arthritis) to comorbidities (49 percent of adults with heart disease and 47 percent of adults with diabetes have arthritis). We also know that about 2 out of 5 adults with arthritis can improve their function by 40 percent by being physically active. Despite all that is known about the importance of physical activity, 1 in 3 adults with arthritis are inactive and only 1 in 10 have taken part in physical activity programs. This exhibits a clear need to expand the CDC Arthritis Program’s resources and partnerships with States and national organizations.

Again, we thank you for the opportunity to provide written comment to the Subcommittee. As you write the fiscal year 2019 Labor-HHS-Education appropriations bill, we urge you to support our goal of reducing the impact of arthritis by funding the CDC Arthritis Program at \$16 million. Please contact Vincent Pacileo, Director of Federal Affairs at the Arthritis Foundation, at vpacileo@arthritis.org with any questions.

PREPARED STATEMENT OF THE CDC COALITION

The CDC Coalition is a nonpartisan coalition of more than 140 organizations committed to strengthening our nation’s prevention programs. We represent millions of public health workers, clinicians, researchers, educators and citizens served by CDC programs. We believe Congress should support CDC as an agency, not just its individual programs and urge a funding level of \$8.445 billion for CDC’s programs in fiscal year 2019. We are grateful for the important increases provided for CDC programs in the fiscal year 2018 omnibus bill and urge Congress to continue efforts to build upon these investments to strengthen all of CDC’s programs. We continue to oppose any effort to repeal or cut the Prevention and Public Health Fund which currently makes up approximately 10 percent of CDC’s budget. Congress must ensure that the CDC’s budget remains whole in the face of these efforts that threaten funding for many CDC programs. We also strongly oppose all of the proposed cuts to CDC programs contained in the president’s fiscal year 2019 budget proposal and urge the subcommittee to reject them.

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 Zika virus to playing a lead role in the control of Ebola in West Africa and detecting and responding to cases in the U.S., to monitoring and investigating disease outbreaks to pandemic flu preparedness to combating antimicrobial resistance, CDC is the nation’s—and the world’s—expert resource and response center, coordinating communications and action and serving as the laboratory reference center for identifying, testing and characterizing potential agents of biological, chemical and radiological terrorism, emerging infectious diseases and other public health emergencies. CDC serves as the lead agency for bioterrorism and other public health emergency preparedness and response programs and must receive sustained support for its preparedness programs. Given the challenges of terrorism and disaster preparedness we urge you to provide adequate funding for the Public Health Emergency Preparedness grants which provide resources to our state and local health departments to help them protect communities in the face of public health emergencies. We urge you to provide adequate funding for CDC’s infectious disease, laboratory and emergency preparedness and response activities in order to ensure we are prepared to tackle both ongoing challenges and

other public health challenges and emergencies that may likely arise during the coming fiscal year.

Injuries are the leading causes of death for people ages 1–44. Unintentional and violence-related injuries, such as older adult falls, firearm injury, child maltreatment and sexual violence, account for nearly 27 million emergency department visits each year. In 2013, injury and violence cost the U.S. \$671 billion in direct and indirect medical costs. In 2016, opioids killed more than 42,000 individuals nationwide. CDC provides states with resources for opioid overdose prevention programs and to ensure that health providers to have the information they need to improve opioid prescribing and prevent addiction and abuse. The National Center for Injury Prevention and Control must be adequately funded to conduct research, prevent injuries, and help save lives.

In 2016, over 635,000 people in the U.S. died from heart disease, the nation's number one, accounting for about 23 percent of all U.S. deaths. More males than females died of heart disease in 2016, 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 2016, over 142,000 people died of stroke, accounting for about one of every 19 deaths. CDC's Heart Disease and Stroke Prevention Program, WISEWOMAN, and Million Hearts work to improve cardiovascular health.

Nearly 1.7 million new cancer cases and over 600,000 deaths from cancer are expected in 2017. In 2014 the direct medical costs of cancer was \$87.8 billion. The National Breast and Cervical Cancer Early Detection Program helps millions of low-income, uninsured and medically underserved women gain access to lifesaving breast and cervical cancer screenings and provides a gateway to treatment upon diagnosis. The Colorectal Cancer Control Program focuses on improving screening rates among targeted, low-income populations aged 50 —75 years in targeted states and territories through evidence-based interventions using partner health systems. CDC funds grants to all 50 states, DC, 7 tribes and tribal organizations, and 7 U.S. territories and Pacific Island jurisdictions to develop comprehensive cancer control plans, bringing together public and private stakeholders to set priorities and implement cancer prevention and control activities to address each state's particular needs.

Cigarette smoking causes more than 480,000 deaths each year. CDC's Office of Smoking and Health funds important programs and education campaigns such as the Tips From Former Smokers campaign which has already helped more than 500,000 individuals quit smoking and millions more to make a serious quit attempt. We must continue to support this and other vital programs to reduce the enormous health and economic costs of tobacco use in the U.S.

Of the more than 29 million Americans living with diabetes, more than 7 million cases are undiagnosed. Each year, about 1.5 million people are newly diagnosed with diabetes. Diabetes is the leading cause of kidney failure, nontraumatic lower-limb amputations, and new cases of blindness among adults in the U.S. The total direct and indirect costs associated with diabetes were \$327 billion in 2015. We urge you to provide adequate resources for the Division of Diabetes Translation which funds critical diabetes prevention, surveillance and control programs.

Obesity prevalence in the U.S. remains high. More than one-third of adults are obese and 18.5 percent of children ages of 2 to 19 are obese. Obesity, diet and inactivity are cross-cutting risk factors that contribute significantly to heart disease, cancer, stroke and diabetes. The Division of Nutrition, Physical Activity and Obesity funds programs to encourage the consumption of fruits and vegetables, encourage sufficient exercise and develop other habits of healthy nutrition and physical activity and must be adequately funded.

Arthritis is the most common cause of disability in the U.S., striking more than 54 million Americans of all ages, races and ethnicities. CDC's Arthritis Program helps address this growing public health challenge and works to improve the quality of life for individuals affected by arthritis and we urge you to support adequate funding for the program.

CDC provides national leadership in helping control the HIV epidemic by working with community, state, national, and international partners in surveillance, research, prevention and evaluation activities. CDC estimates that about 1.2 million Americans are living with HIV with 12.8 percent undiagnosed. Prevention of HIV transmission is the best defense against the AIDS epidemic. Sexually transmitted diseases continue to be a significant public health problem in the U.S. Nearly 20 million new infections occur each year. STDs, including HIV, cost the U.S. healthcare system almost \$16 billion annually.

The National Center for Health Statistics collects data on chronic disease prevalence, health disparities, emergency room use, teen pregnancy, infant mortality and causes of death. The health data collected through the Behavioral Risk Factor Sur-

veillance 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 states address serious disparities in infant mortality, breast and cervical cancer, cardiovascular disease, diabetes, HIV/AIDS and immunizations and we urge the committee to provide continued funding for these important activities.

CDC oversees immunization programs for children, adolescents and adults, and is a global partner in the ongoing effort to eradicate polio worldwide. Childhood immunizations provide one of the best returns on investment of any public health program. For every dollar spent on childhood vaccines to prevent thirteen diseases, more than \$10 is saved in direct and indirect costs. Over the past 20 years, CDC estimates childhood immunizations have prevented 732,000 deaths and 322 million illnesses. We urge you to provide adequate funding for the Section 317 Immunization program.

Birth defects affect one in 33 babies and are a leading cause of infant death in the U.S. Children with birth defects often experience lifelong physical and mental disabilities. Over 500,000 children are diagnosed with a developmental disability and about 53 million adults in the U.S 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.

The National Center for Environmental Health works to control asthma, protect from threats associated with natural disasters and climate change, reduce, monitor and track exposure to lead and other environmental health hazards and ensure access to safe and clean water. We urge you to support adequate funding for all NCEH programs.

In order to meet the many ongoing public health challenges facing the nation, including those outlined above, we urge you to support our fiscal year 2019 request of \$8.445 billion for CDC's programs.

[This statement was submitted by Don Hoppert, Director of Government Relations, American Public Health Association.]

PREPARED STATEMENT OF THE CHILD WELFARE LEAGUE OF AMERICA

The Child Welfare League of America offers the following testimony requesting increased funds for the following six programs under the supervision of the Administration for Children and Families (ACF): Child Welfare Services (CWS), Promoting Safe and Stable Families, the Adoption and Kinship Incentives Fund, the Adoption Opportunities Act, the Child Abuse Prevention Treatment Act State grants, the Community-Based Child Abuse Prevention program.

In February, Congress passed the Family First Prevention Services Act (P.L. 115-123). The legislation has potential to expand services that can prevent the placement of children into foster care. It challenges States to reduce the number of children and youth in congregate placements. It will be a challenge to States to build the capacity and access to services (mental health, substance use, and in-home services) and to build the infrastructure of services and providers.

The challenge is against a backdrop of ever increasing foster care numbers driven by the opioid epidemic in parts of the country. Since 2012 the number of children in foster care has increased by 10 percent to 437,000 in 2016. CWLA believes it is critical for Congress to fully fund six programs to both build capacity to effectively implement the Family First Act, and help address the crisis many communities are facing as foster care placement demands explode.

The Family First Act provides funding for services to prevent the placement of children in foster care but does not fund services to prevent child abuse and neglect. Child welfare strategy must significantly increase funding for child abuse prevention. We urge appropriators to focus more attention on primary prevention through the Child Abuse Prevention and Treatment Act (CAPTA) and the Community-Based Child Abuse and Neglect Prevention (CB-CAP) program.

CWLA calls on Congress to fully fund Child Welfare Services from \$269 million to \$325 million and Promoting Safe and Stable Families from \$99 million in discretionary funding to \$200 million; increase funding to the Adoption Opportunities Act to \$60 million; fully fund the Adoption and Kinship Incentives Fund at \$75 million; fund the Child Abuse Prevention and Treatment Act (CAPTA) at \$120 million in State grants and double funding the Community-Based Grants for the Prevention of Child Abuse and Neglect/CB-CAP at \$80 million.

Impact of Opioids on Child Abuse and Neglect and Foster Care

Earlier this year HHS through the Secretary of Planning and Evaluation conducted an analysis of child welfare data and supplemented that work with field level research. Some of the key findings included:

- A 10 percent increase in overdose death rates correspond to a 4.4 percent increase in the foster care entry rate and a 10 percent increase in the hospitalization rate due to drug use corresponds to a 3.3 percent increase in the foster care entry rate.
- While in past drug epidemics family and communities could fill some of the gaps, today agencies report that family members across generations may be experiencing substance use problems forcing greater reliance on State custody and non-relative care.
- Parents using substances have multiple problems including domestic violence, mental illness, trauma history, and addressing substance abuse alone is unlikely to be effective.
- Substance use assessment is haphazard and there is a lack of “family-friendly” treatment that includes family therapy, child care, parenting classes and developmental services.
- There is a shortage of foster homes and this is exacerbated by the need to keep children longer in care which keeps existing homes full and unable to accept new placements.

PREVENTING CHILD MALTREATMENT

The Child Abuse Prevention and Treatment Act (CAPTA) State Grants

Investing in prevention is less costly to society and the government than trying to treat problems later. Successful prevention of child maltreatment means better outcomes for children and can prevent the need for future intervention services or foster care.

We are pleased with the 2018 \$60 million increase for CAPTA to \$85 million. As Congress looks to implement CAPTA provisions for plans of safe care, we ask the Committee to appropriate a full \$120 for CAPTA State grants. The Family First Act provides important intervention services to prevent foster care placements. It is the role of CAPTA and CB-CAP to fund the prevention of child abuse.

The 1974 Child Abuse Prevention and Treatment Act (CAPTA) has helped establish national standards for reporting and response practices for States to include in their child protection laws. CAPTA is the only Federal legislation exclusively dedicated to preventing, assessing, identifying, and treating child abuse and neglect. Successful prevention means better outcomes for children and can prevent the need for intervention services such as foster care.

According to Prevent Child Abuse America, child abuse and neglect affects over 1 million children every year. Child abuse and neglect costs our Nation \$220 million every day through increased investigations, foster care, healthcare costs, and behavioral health costs and treatment. Additional costs may include special education, juvenile and adult crime, chronic health problems, and other costs in a life span. According to PCA, we paid \$80 billion to address child abuse and neglect in 2012. Funding CAPTA State grants beyond the small allocation of \$25 million in recent years can help develop greater accountability and a stronger continuum of child prevention and child protection.

The Community-Based Grants for the Prevention of Child Abuse and Neglect (CB-CAP)

Another key prevention program is the Community-Based Grants for the Prevention of Child Abuse and Neglect (CB-CAP), which provides funds to States to support, develop, operate, and expand a network of community-based, prevention-focused family support programs. Funds coordinate family resources among a range of local public and private organizations.

CWLA asks for a doubling of funds from \$40 million to \$80 million. The advantage of this increase is that it is community-based, it is targeted to prevention and it is designed to leverage outside sources of funding. 70 percent of funding is allocated to States based on child population and 30 percent is based on leveraged State, Federal and private funds. The minimum grant award is \$200,000 and States must meet minimum 20 percent cash match (not in-kind).

In 2016, the National Resource Center for CB-CAP, (FRIENDS), funded activities covered over 295,000 adults and caregivers; 289,000 children and 200,000 families including those with disabilities. Over 29.4 million families were reached through public awareness activities funded by CBCAP. These services included 21,697 parents and 19,710 children with disabilities.

Each State application must describe actions the lead agency (frequently a Children's Prevention Trust Fund) will take to advocate systemic changes in State policies, practices, procedures and regulations to improve the delivery of community-based child abuse and neglect prevention programs and activities designed to strengthen and support families to prevent child abuse. Some of the recent work includes: 22 States working with tribes or tribal organizations, 14 States working on human trafficking initiatives, 43 States providing outreach and/or local programs to rural populations, and 33 States using CBCAP funds for fatherhood initiatives and programs.

A doubling of funding will support a significant expansion in the number of children and families served. More States might be able to move toward a comprehensive service system, particularly where family needs are more challenging, complex and complicated. Small States that have low child populations and, as a result receiving the lowest amounts from CBCAP, would likely be able to increase their ability to provide services that would show greater impact.

This doubling of funding could also assist in addressing a need for CBCAP State lead agencies to evaluate their efforts to know what is working, to refine and adjust services as needed and to ensure their services are the best fit for their population. In addition to supporting proven effective strategies, it has always been the role of CBCAP lead agencies to identify, assess and fund emerging, innovative ideas and to evaluate them to determine whether continued funding is warranted. This will help in the development of programs to be replicated in Family First.

FAMILY FIRST ACT

In fiscal year 2020, Families First will allow States to draw funds for children and families at risk of foster care. States taking the optional services will be limited to evidence-based services for families that need intervention, post-adoption, and reunification services. States must engage in and coordinate public-private agencies experienced with providing child and family community-based services, including mental health, substance use, and public health providers. There is a limited supply of foster homes and family-based aftercare support that can provide for post-discharge services for children leaving institutional care. Child welfare agencies need to find and support more family-based foster care homes. These four funds can help States develop evidence-based services that will meet the laws "well-supported," "supported," and "promising" standards and can assist the coordination of community based behavioral health and human services.

Child Welfare Services (CWS), Title IV-B part 1

We ask for \$325 million for Child Welfare Services, the full authorization and above the current total of \$269 million. Starting in fiscal year 2020, the Families First Act will allow States to draw funds for children and families at risk of foster care. CWS is flexible enough to allow States to test out and develop these services and provide the research required to meet these evidence standards.

Promoting Safe and Stable Families (PSSF), Title IV-B part 2

We also asking for full funding of \$200 million for Promoting Safe and Stable Families. Currently this appropriations is set at \$99 million despite being authorized at \$200 million. These funds supplement \$345 million in mandatory funds divided between services, the courts, substance use treatment grants and workforce development. Appropriations to \$200 million could be used for the four key services under PSSF: family reunification, adoption support, family preservation and family support. There are limited services for reunification services for children who return to their families and the same is true of post adoption services. These will all be eligible services under Family First but there are few models now eligible for funding.

The Adoption Opportunities Act

The Adoption Opportunities program is the Nation's oldest adoption program created to develop adoption promotion, post adoption services and strategies. It has funded grants to reduce barriers to adoption, reduce disproportionality, and more recently to promote adoptions of older youth in foster care and develop post-adoption services. It is funded at \$39 million. We ask for funding at \$60 million to develop evidence-based models for post adoption services to families.

The Adoption and Kinship Incentive Fund

We ask for a continued funding level of \$75 million for the adoption incentive fund. The fund was created in the Adoption and Safe Families Act (ASFA). In 2014 it became the Adoption and Legal Guardianship Incentive Payments Program. We

thank the Appropriations Committee for partially addressing a recent shortfall in this incentive fund with the 2018 appropriations of \$75 million. In recent years HHS has been not been able to fully award States because of a reduced appropriation. As a result, HHS has made up the previous year's shortfall with the following year's appropriations. The \$75 million for fiscal year 2018 was a significant step in addressing the shortfall of 2017. In the beginning years Congress would recognize this and provide an extra amount of appropriation. Your 2018 appropriation reestablished this practice. When HHS issues the latest awards for fiscal year 2018, this September, there will have \$25 million remaining. That will likely fall short to fully fund the incentives. And we again ask for an appropriation of \$75 million to fully fund 2018 awards and have enough in place for fiscal year 2019.

These funds are reinvested by States into adoption services. These funds can be used by States to build both the evidence-based adoption services include post-adoption counseling and services that can prevent and reduce adoption disruption. CWLA thanks you for this consideration and stands ready to respond to your questions and concerns.

[This statement was submitted by John Sciamanna, Vice President of Public Policy, Child Welfare League of America.]

PREPARED STATEMENT OF CHRISTOPHER & DANA REEVE FOUNDATION

Thank you for this opportunity to submit testimony in support of an appropriation of \$8,700,000 for the Paralysis Resource Center (PRC) within the Administration for Community Living.

I am proud to submit this testimony 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 16 years, competing in a rigorous, competitive bidding process every 3 years for renewal of the contract. For fiscal year 2019, we request a funding level of \$8.7 million for the Paralysis Resource Center, which would restore the PRC to previous funding levels and is an increase of \$1 million over the fiscal year 2018 omnibus.

Despite its tremendous success, the PRC has been recommended for elimination in the President's budget for the second year in a row. The proposed justification is that its initiatives "could be carried out with other existing funding streams to deliver services more efficiently." 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. Attempting to replicate the PRC's unique, well-established and thriving programs would take years and result in greater costs—precisely the opposite of what the Administration's budget aims to do.

Paralysis can happen to anyone at any time. According to the Cleveland Clinic, "A person can be born with paralysis due to a birth defect such as spina bifida, which occurs when the brain, spinal cord, and/or the covering that protects them do not form the right way. In most cases, people get paralysis as the result of an accident or a medical condition that affects the way muscles and nerves function. The most common causes of paralysis include stroke, spinal cord injury, head injury and multiple sclerosis."

All too often, when someone suffers an accident that leads to paralysis, they are unaware of existing communities that can support them and their caregivers. When my father, Christopher Reeve, was paralyzed from the neck down due to a spinal cord injury in 1995, we found ourselves in total darkness as to what to do next; as my stepmother, Dana Reeve, would later say, it was like trying to land on the moon without a map. There was no phone number to call for guidance or help. There were no experts reaching out to connect us to the right rehabilitation facilities, or discuss how we could support his return home and ongoing well-being. There was certainly no promise that an individual living with that level spinal cord injury could lead a full and active life as a father and husband. But, instead of accepting that life with paralysis would be full of limitations, my father dreamed of a brighter future.

That was the genesis of the Christopher & Dana Reeve Foundation: my father's dream to elevate the needs and rights of the 5.4 million Americans living with paralysis. But my father was far from alone. The real drive behind the Paralysis Resource Center came from my stepmother, Dana. As a caregiver herself, she knew that paralyzed individuals and caregivers around the country need a centralized place to call for resources and expertise.

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's Core Programs

Information Specialists.—One of the PRC's most essential functions is the team of certified, trained Information Specialists who provide personalized support on how to navigate the challenges of life with paralysis. This team of experts, many living with paralysis themselves, is often the first port of call for individuals who are newly injured or diagnosed. They are trained to answer any question related to paralysis, including Spanish language inquiries.

When Rutgers college football star Eric LeGrand sustained a spinal cord injury that left him paralyzed from the neck down, his mother had no idea how to care for her son when he returned home. She leaned on the PRC's Information Specialists to map out a plan for Eric that helped him thrive as a student and now college graduate. Even 7 years after his injury, Karen LeGrand credits the Information Specialists with being their go-to resource to keep Eric healthy and living an active life.

To date, our Information Specialists have provided direct counseling to 90,000 people. We have distributed 200,000 copies of our Paralysis Resource Guide, which is a staple in hospitals and rehabilitation facilities across the country.

Peer & Family Support Program.—A second pillar of the PRC is our Peer & Family Support Program, a national peer-to-peer network. 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. The ultimate goal of the Peer & Family Support Program is to help individuals find support and resources among the communities who best understand the daily realities and long-term challenges faced by individuals living with paralysis. Through the PRC, more than 280 peer mentors have been trained and certified in 43 States. These individuals have mentored 8,000 peers, including 1,500 caregivers.

Quality of Life Grants Program.—Our third pillar, the Quality of Life Grants Program, operates at the community level to fund nonprofit initiatives across the country. Since 1999, the Quality of Life Grants Program has directed over \$24 million dollars to assist over 3,000 projects in all 50 States. 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.

The growth of the Quality of Life Grants program, through budget and reach, continues to foster real, impactful change in the paralysis community. Targeted outreach has brought new organizations into the competition for funds, and significant efforts are made to connect with and fund organizations that work with underserved members of the community. The Reeve Foundation has expended considerable effort raising nationwide awareness of the grants program, resulting in more rich and diverse applications. Critically, these programs use the public attention that comes from receiving funding from a nationally-known Foundation to raise additional funds in their community, creating a powerful return on investment.

In addition, programs for military service members and veterans and their families continue to be strongly funded. The PRC has dedicated a minimum of \$50,000 annually to fund military- and veteran-focused nonprofit organizations through Quality of Life grants.

Military & Veterans Program; Multicultural Outreach Program.—The PRC has a comprehensive Military & Veterans Program (MVP), which provides dedicated resources to help individuals navigate military and civilian benefits and programs as they reintegrate into their communities. The MVP helps servicemen and women whether they are paralyzed through combat-related, service-related, or non-service related events, and serves all veterans regardless of the era in which they served or how their injury was obtained.

We are able to successfully address the needs of our veterans in part thanks to our Military & Veterans Program Advisory Council, which was formed with Reeve staff and volunteers who have direct ties to the military and veteran community. The Council's goals include identifying and defining the needs of the military and veteran community and determining how the PRC can best reach and aid our veterans, as well as helping leverage, develop and maintain collaborative relationships and partnerships with other national and local organizations that serve the military and veterans community.

The PRC also facilitates a Multicultural Outreach Program that is designed to engage and support underserved populations like ethnic minorities, older adults, low-

income earners, and LGBTQ individuals. No matter the individual, the PRC's goal is to promote wellness, independence, and an improved quality of life.

ChristopherReeve.org.—One of the most challenging aspects about living with paralysis is combating feelings of isolation and exclusion, especially for those who are unable to leave their homes due to physical and societal barriers. The Reeve Foundation's website, ChristopherReeve.org, provides a vibrant online community and resource hub that attracts close to two million visitors per year.

The Value of Integrated Services

There are many examples in which an individual living with paralysis has not only participated in one program of the PRC, but has benefitted from our suite of free services. When Joseph Preti, from Mill Creek, Washington, sustained a spinal cord injury in 2010, he and his wife, Pauline, were at a loss as to how to emotionally and physically cope with their "new normal" away from the structure of a hospital or skilled nursing. They turned to the Reeve Foundation's website to understand Joseph's prognosis and prepare for his future needs. They referred to the Paralysis Resource Guide as a critical tool for managing his health, and connected with an Information Specialist who provided guidance to further improve Joseph's quality of life, including connecting them to a local non-profit called HelpHopeLive, which helps people living with catastrophic injury raise funds to pay medical bills. Once Joseph and Pauline felt confident in their path forward, Joseph became a certified peer mentor through the Peer & Family Support Program to help other families in the Washington-area navigate life after paralysis. Joseph's story is one of many that demonstrates how the PRC serves as a lifeline to help families from the moment of injury or diagnosis through the many chapters of living with paralysis—providing a continuum of care made possible by the depth and breadth of the PRC's offerings.

The Importance of Federal Funding

Federal funding is essential to sustain the unique suite of services offered by the PRC. A resource center that is relied on by literally millions of Americans affected by paralysis needs consistent, regular funding. Because many individuals living with paralysis have 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 with comprehensive information, we need to promote and deliver these services at scale. Federal funds are essential for this valuable, life-changing resource to function well and in a cost-effective way.

Federal funding for the PRC is also a good investment. The PRC's resources help people adapt their homes and gain the tools they need to return to their communities, and eventually to work. The programs funded by the PRC make people less dependent on healthcare providers, so they can reduce their medical costs—saving dollars for Medicaid and Medicare. Our Military & Veterans Program provides an essential continuum of support for returning heroes as they transition out of the VA system. The PRC's national model, strong reputation and well-developed network allows us to leverage a small team to have maximum impact. The PRC is smart Federal funding at work.

Conclusion

My father 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 urge you to protect the Paralysis Resource Center and help individuals achieve greater quality of life, health and independence by supporting its vital work. Thank you.

[This statement was submitted by Alexandra Reeve Givens, Board Member, Christopher & Dana Reeve Foundation.]

PREPARED STATEMENT OF THE COALITION FOR
CLINICAL AND TRANSLATIONAL SCIENCE

FISCAL YEAR 2019 APPROPRIATIONS RECOMMENDATIONS

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- CCTS joins the broader medical research community in asking to provide the National Institutes of Health (NIH) with at least a \$2 billion funding increase for fiscal year 2019, to bring total funding up to a minimum of \$39.1 billion annually.
 - Please provide the Clinical and Translational Science Awards (CTSA) program at the National Center for Advancing Translational Sciences (NCATS) with a subsequent \$27 million increase for fiscal year 2019 to bring total funding up to \$570 million. Further, please provide adequate support to facilitate meaningful increases for all NCATS programs, particularly the Cures Acceleration Network.
 - Please provide the Institutional Development Awards (IDeA) program and the Research Centers at Minority Institutions (RCMI) program at NIH with meaningful funding increases for fiscal year 2019.
 - CCTS joins the broader medical research community in asking Congress to provide the Agency for Healthcare Research and Quality (AHRQ) with a \$120 million increase for fiscal year 2019 to bring total funding up to \$454 million annually.
 - Please continue to support research training and career development activities at NIH and AHRQ to ensure that the next generation of clinical and translational researchers is well-prepared.
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Chairmen Blunt and Shelby, Ranking Member Murray, Vice Chair Leahy, and distinguished members of the Subcommittee, thank you for considering the views of CCTS and the clinical and translational research community as work on fiscal year 2019 appropriations. Most importantly, thank you for providing NIH with a significant \$3 billion funding increase for fiscal year 2018, for notably increasing CTSA funding and improving stewardship of dedicated resources, and for increasing AHRQ funding.

ABOUT THE COALITION FOR CLINICAL AND TRANSLATIONAL SCIENCE

CCTS is the unified voice of the clinical and translational science research community. CCTS is a nationwide, grassroots network of dedicated individuals who work together to educate Congress and the Administration about the value and importance of Federal clinical and translational research and research training and career development activities. The Coalition includes the Nation's leading health research institutions. CCTS's 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.

Association for Clinical and Translational Science (ACTS)

ACTS supports investigations that continually improve team science, integrating multiple disciplines across the full translational science spectrum: from population based and policy research, through patient oriented and human subject clinical research, to basic discovery. Our goal is to improve the efficiency with which health needs inform research and new therapies reach the public.

ACTS is the academic home for the disciplines of research education, training, and career development for the full spectrum of translational scientists. Through meetings, publications, and collaborative efforts, ACTS will provide a forum for members to develop, implement, and evaluate the impact of research education programs.

ACTS provides a strong voice to advocate for translational science, clinical research, patient oriented research, and research education support. We will engage at the local, State, and Federal levels and coordinate efforts with other professional organizations.

ACTS will promote investigations and dissemination of effective models for mentoring future generations of translational scientists. Through collaborative efforts, ACTS will provide a forum for members to share studies, promote best practices, and optimize professional relationships among trainees and mentors.

Clinical Research Forum

Clinical Research Forum was formed in 1996 to discuss unique and complex challenges to clinical research in academic health centers. Over the past decade, it has convened leaders in clinical research annually and has provided a forum for discussing common issues and interests in the full spectrum of research. Through its activities, the Forum has enabled sharing of best clinical practices and increasingly has played a national advocacy role in support of the broader interests and needs of clinical research.

Governed by a Board of Directors constituted of clinical researchers from thirteen member institutions, Clinical Research Forum has grown to sixty members from academia, industry, and volunteer health organizations. Clinical Research Forum engages leaders in the clinical research enterprise including leaders from government, foundations, other not-for-profit organizations, and industry in addressing the challenges and opportunities facing the clinical research enterprise.

Parallel with our widening focus upon the broad needs of the entire national clinical research enterprise, Clinical Research Forum is committed to working in those areas where it is uniquely positioned to have a significant impact. Collaboration with other organizations with similar goals and synergizing with their efforts strengthens all approaches to the issues facing clinical research.

KEY COMMUNITY UPDATES AND REQUESTS

NIH continues to modernize our research infrastructure and now nearly every Institute and Center supports the full spectrum of medical research in a meaningful way. Recent investments in NIH have facilitated meaningful growth and development in the overall clinical and translational research enterprise. The IDeA program and the RCMI program both provide infrastructure resources to institutions that form a foundation for research and also provide training and career development opportunities.

The flagship initiative at NIH for advancing collaborative clinical and translational research activities is the CTSA program. This effort has grown and advanced its mission in a meaningful way. Following a positive Institute of Medicine Review in 2013, the program now includes nearly 60 hubs and is progressing towards full funding of \$750 million annually. The CTSA network is conducting important research into many meaningful questions by engaging local patient communities as well as improving implementation science and the dissemination of key findings. CSAAs also provide many important training slots for young investigators. As a result of your leadership, key concerns related to the stewardship of CTSA resources are now being addressed. The CTSA hubs are beginning to see the benefits of additional resources rather than facing constant requests to reduce and narrow opportunities. It is the community's hope moving forward that increased communication, transparency, and collaboration will allow the CTSA program to move forward with renewed vigor.

Finally, please continue to invest in AHRQ to ensure that important health systems research can progress and so training opportunities remain for young investigators. AHRQ plays a unique role in healthcare that often supplements the efforts of NIH and other public health entities. The fiscal year 2018 funding increase was an important step in the right direction, but a more robust allocation is needed to restore AHRQ.

Thank you for your time and your consideration of these requests. Please consider the CCTS a resource if you have any questions or if you would like additional information.

[This statement was submitted by Harry P. Selker, MD, MSPH, Chairman, Clinical Research Forum.]

PREPARED STATEMENT OF COALITION FOR HEALTH FUNDING

I am Donna Meltzer, CEO of the National Association of Councils on Developmental Disabilities, and I serve as President of the Coalition for Health Funding. The Coalition is an alliance of 95 national health organizations representing more than 100 million patients and consumers, health providers, professionals, and researchers. Together, we speak with one voice before Congress and the administration in support of federally funded health programs with the shared goal of improved health and well-being for all. We all have our own funding priorities within the Department of Health and Human Services (HHS), but we also all believe that to truly improve health, you need strong, sustained, predictable funding for all Federal agencies and programs across the public health continuum.

These HHS agencies have different roles in addressing our Nation's mounting health demands, but they are all interconnected. For example, investment in medical research at the National Institutes of Health (NIH) is important, but on its own won't improve health. You need the Food and Drug Administration (FDA) to approve new treatments. You need the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration (HRSA), the Substance Abuse and Mental Health Services Administration (SAMHSA), the Indian Health Service to ensure we have qualified health professionals who can move discoveries into healthcare and public health delivery, support Americans while they're awaiting new cures, and prevent them from getting sick in the first place. You need the Agency for Healthcare Research and Quality (AHRQ) to provide evidence on what treatments work best, for whom, 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 their best life every day. Without robust funding for all agencies and programs of the public health continuum, we're falling short on the promise to protect Americans and improve health. Shortchanging public health and health research programs—or cutting health programs at the expense of others—leaves Americans vulnerable to health threats and does nothing to prevent these problems from arising in the first place.

HHS agencies do all this important work protecting Americans health for relatively little money as a share of our Federal budget. In fiscal year 2017, discretionary health funding for these and other health agencies and programs was only \$60 billion, or 1.5 percent of all Federal spending. Of this, more than half supported medical research at the NIH, and the remainder supported all other public health activities, including disease prevention and response, health safety and security, workforce development, and access to primary and preventive care. Funding for most of these public health and health research programs is still well below 2010 levels.

Through our work with NDD United—a voluntary alliance of thousands of national, State, and local organizations joining forces to protect and promote non-defense discretionary programs—we have advocated to raise the caps on domestic funding and ensure that proportional relief is provided to HHS's agencies and programs. We thank you and your colleagues for the Bipartisan Budget Act of 2018 and the resulting Consolidated Appropriations Act of 2018 or “omnibus.” To be sure, there is still a long road ahead to rebuild our public health infrastructure after years of austerity, as most agencies and programs within your subcommittee's jurisdiction are still below fiscal 2010 levels when adjusted for inflation. But the new funding provided by these laws is an important first step in increasing our capacity to both prevent and respond to public health threats, train an adequate health workforce, conduct research into new treatments and cures, improve the delivery of care, and support caregivers.

The Coalition is deeply concerned about the White House's efforts to rescind unobligated funding, and rumored reports that the president may consider sending a list of rescissions from the fiscal 2018 omnibus for Congress to consider through the process outlined in the Impoundment Control Act of 1974. Such rescissions would negatively affect the programs identified for the rescissions and disrupt agencies efforts to obligate funding in an already compressed timeline. In addition, renegeing on the bipartisan compromise represented by the omnibus would be detrimental to bipartisan relations on Capitol Hill and would hinder future spending and legislative deals. The budget deal and omnibus were the result of more than a year of bipartisan talks about Federal spending limits and appropriations. Members from both sides of the Capitol and the aisle voted for this spending legislation not because it included all of their priorities, but because it represented a reasonable compromise. It is critical now that Congress protect that compromise and reject proposed rescissions to already appropriated funding.

Indeed, President Trump seems intent on rolling back funding for nondefense discretionary programs including public health, despite the 2-year budget deal recently signed into law. President Trump's proposed fiscal 2019 budget would double down on sequestration and shrink available funding for public health, health research, and all other domestic programs. In fact, the president proposes cutting this funding by about one-quarter by 2020.

It is worth noting that the president's budget does make an important and needed investment in combatting the opioid epidemic. Unfortunately, the budget request shows a fundamental disregard for the comprehensive role of Federal health agencies and programs in protecting and promoting Americans' health security in that crisis, and more broadly. The budget does not provide for public health programs that benefit all Americans such as disease surveillance, health research, emergency preparedness, and chronic disease prevention. It hampers the ability of those work-

ing on the frontlines of public health to protect and serve their fellow Americans—primary care providers, public health professionals, and caregivers. Moreover, it hits our Nation’s vulnerable particularly hard, slashing or eliminating programs designed to help the poor, women, infants and children, seniors, and people with disabilities.

The opioid epidemic is a public health emergency worthy of significant funding to be sure, but it is not the only health emergency. We hope the Subcommittee will continue its efforts to increase funding for all public health and health research programs within its jurisdiction to address all health threats. The Coalition for Health Funding will continue to work with our partners in the Labor-HHS community in urging lawmakers to provide the subcommittee receives a robust fiscal 2019 302(b) allocation in fiscal 2019.

Looking ahead, discretionary programs face a significant funding cliff in fiscal 2020 when the current budget deal expires—more than \$65 billion. Between now and then, we will continue to educate lawmakers about the value of public health, health research, and all nondefense discretionary programs with our partners in NDD United. We urge you and your colleagues to continue to demonstrate your commitment to keeping Americans safe and healthy by supporting another bipartisan budget deal to raise the caps on nondefense discretionary funding.

We hope in your ongoing deliberations on fiscal 2019 and beyond you will consider the costs of discretionary spending cuts, and the value of all public health and health research programs in improving the lives of American families. We look forward to working with the Subcommittee in these endeavors, and hope you will turn to the Coalition for Health Funding as a resource in the future.

[This statement was submitted by Donna Meltzer, President, Coalition for Health Funding.]

PREPARED STATEMENT OF THE COALITION ON ADULT BASIC EDUCATION

The Coalition on Adult Basic Education (COABE) appreciates the opportunity to submit testimony for the record about the funding level for adult education programs in fiscal year 2019. COABE is a membership organization comprised of more than 55,000 educators, administrators, mentors, and guides working to improve educational outcomes for adults and build strong communities. COABE serves to promote adult education and literacy programs and other State, Federal, and private programs that assist undereducated and/or disadvantaged adults to function effectively. COABE works to unify the profession, develop human resources, encourage teachers and students, promote best practices, and otherwise advance adult education and literacy. We develop and disseminate publications, research, methods, materials, resources, and programs to strengthen the field of adult education and literacy. We conduct and sponsor professional development conferences and webinars. We work tirelessly to help underserved adults master the skills they need to compete, build careers, and provide better futures for themselves, their families, and their communities.

COABE appreciates the support the Committee demonstrated for Adult Education in the fiscal year 2018 Omnibus Appropriations Act. We respectfully ask that in fiscal year 2019, Adult Education be funded at \$664.5 million, the level authorized in the Workforce Innovation and Opportunity Act (WIOA). WIOA recognizes the crucial role adult education plays in teaching English and civics and preparing adults to enter the workforce or improve their employment status. The Act established Adult Education as one of four key partners in a system of education and training that emphasizes greater integration of Adult Education and the workforce system and greater emphasis on college and career readiness. Adult Education is now a key element in a comprehensive system of education and training. WIOA’s progress in transforming the Adult Education system cannot be attained unless Congress supports it adequately.

Adult Education serves adults, 16 years of age and older, who are no longer enrolled in school or required by State law to be enrolled and who are functioning below the high school completion level. Services include teaching foundation skills in the disciplines of reading, math, and English, coupled with college and career readiness skills that lead to employment or the transition to post-secondary education. Adult Educators also help parents obtain the educational skills necessary to become full partners in the education of their children.

Public schools, community colleges, libraries, and community-based organizations offer programs at the local level.

Providers of Adult Education are accountable for improving the literacy and numeracy skills of their students as measured by regularly-administered standard-

ized assessments, transitioning students to postsecondary education, employment or job training, the attainment of a high diploma or its equivalent, and earnings outcomes.

Federally funded adult education programs serve only 1.5 million of these adults, down from 2.8 million in 2001. Enrollment has declined by 44 percent, falling most sharply among those who most need adult education and workforce skills services. Demand for services across the country far exceeds supply.

One in every six adults in the U.S. lacks basic reading skills; that means that more than 35 million people can't read a job application, understand basic written instructions, or read information on the Internet. One in every three adults in the U.S. cannot use basic arithmetic, work a cash register, read graphs, or understand a transit schedule. According to PIAAC (OECD's Program of International Assessment of Adult Competencies), Americans lag behind the international average for basic skills in literacy and numeracy and "problem-solving in technology-rich environments." Other nations show consistent progress in enhancing the education levels of their adult populations. The U.S. is losing ground.

We must invest in adult education because the jobs of the future will require postsecondary education. According to labor market economists at the Georgetown Center on Education and the Workforce, by 2020 65 percent of all jobs in the United States will require some level of postsecondary education or training. The American Action Forum projects that by 2020 the United States will be short an estimated 7.5 million private sector workers across all skill levels.

The Federal investment in Adult Education is cost-effective. Federal support for Adult Education leverages a significant investment by States. In fiscal year 2013, each Federal dollar invested in AEFLA generated \$2.49 in non-Federal matching funds. The Federal cost per participant in fiscal year 2012, the most recent year for which we have data, was \$298. The annual Federal cost for each Adult Education student who advanced at least one educational level or who earned a high school diploma or its equivalent was \$589.

Adult Education brings businesses options by preparing existing workers with the skills that companies need through flexible classrooms and curriculum. Both urban and rural areas need trained employees. As of 2016, there were 476 counties in the U.S. in which 20 percent or more of the working age population lacked a high school diploma or equivalent. Eighty percent are located in non-metro areas.

Significant underinvestment in adult education and workforce skills development is eroding America's global competitiveness. A robust adult education system is essential if we are to achieve our Nation's economic goals. It will be impossible to create a workforce skilled enough to compete in the global 21st century economy if we focus only on secondary schools and postsecondary institutions. We must also support adult education. High schools alone cannot provide business and industry with the workers that are needed. Most of America's workforce of tomorrow is already in today's workforce. They are beyond the reach of high schools and postsecondary education. A stronger economy will bring people back into the workforce but it won't train them. Adult education is the best way to re-engage them.

Low skilled adults are twice as likely to be unemployed, three times as likely to be in poverty, four times as likely to be in poor health, and eight times as likely to be incarcerated. Low education, and skill levels, in adults are fundamental barriers to virtually every major challenge we face including early childhood education, education reform, economic development, and improving the health and well-being of the Nation's families and communities.

By neglecting the adults who need services, we affect their children. A mother's education level is the greatest determinant of her children's future academic success, outweighing other factors such as neighborhood or family income. Almost 60 percent of children whose parents don't have a college education live in low-income families and are less likely to get a good education to qualify for family-sustaining jobs. Mothers and fathers who learn basic skills are better equipped to help their children succeed. Education levels have more effect on earnings over a 40-year span in the workforce than any other demographic factor. Research shows that "better-educated parents raise better-educated, more successful, children who are less likely to end up in poverty or prison." According to the U.S. Department of Education, individuals who participate in adult education and literacy programs have higher future earnings as a result, and their income differential grows with more intensive participation. Finally, children whose parents are involved with them in family literacy activities score 10 points higher on standardized reading tests.

Low skill levels and under-education are directly linked to inequality, higher rates of unemployment, lower income, crime, poor health, and increased hospitalizations. Adults without a high school diploma are more than twice as likely to live in poverty as high school graduates. They are three times more likely to be unemployed

than adults with college degrees. Experts estimate that the U.S. loses more than \$225 billion in lost tax revenue, reduced productivity, crime, and poor health because of under-education and low skills. Investing in adult education can improve health outcomes, reduce poverty, and reduce recidivism.

On the other hand, a person with a high school diploma or equivalent earns an average of \$9,620 more per year than a non-graduate. Adults with a high school degree were more likely to work full time and average 20percent higher earnings (\$30,000) well above the poverty line for a family of four.

Furthermore, the Census Bureau projects that between 2000 and 2015 net international immigration will account for more than half of our Nation's population growth, increasing the demand for adult English language programs to an even greater extent. Without adequate access to English language learning programs we lose the contributions immigrants make to our communities and our economy with their strong work ethic and drive to succeed.

Adult Education is about giving students a hand up by preparing them for college as well as career readiness. Take the case of Juliana Vrekaj, an asylum seeker from Albania, who received her GED in 2013 from the East Haven, Connecticut Adult Education program. After marrying and starting a family, Juliana rejoined the East Haven program to take citizenship classes. Today, both Juliana and her husband are American citizens. She received her Associate's Degree at Gateway Community College in December and will start classes this spring at Southern Connecticut State University where she intends to enter the Teacher's Program in Mathematics, specializing in elementary education. In the meantime, Juliana and her husband have opened a cellular phone store in East Haven. The Connecticut Association for Adult and Continuing Education (CAACE) named Juliana its Learner of the Year.

When Arturo Flores, 33, was a young man in California, he couldn't resist the lure of the streets and joined a gang at age 14. He dropped out of school during 8th grade. Between ages 19 and 25, he was in prison five times. Art discovered a new life when he entered Owensboro Regional Recovery in Owensboro, Kentucky, in 2010 and began working toward earning his GED diploma. Although his academic skills were at a 6th grade level, he didn't let that deter him and he earned his GED diploma within 3 months. Art didn't stop there. He graduated from Owensboro Community and Technical College with an Associate of Arts in May 2014. He's now a full-time student at Western Kentucky University-Owensboro, where he is working toward earning his bachelor's in social work. His goal is to earn a master's in social work to help troubled youth, especially those who are active in gangs, or older citizens who have experienced elder abuse. Art also works full-time at Owensboro Regional Recovery as a "Safe Off the Streets" (SOS) monitor, where he works with men in the first stages of recovery. Art says, "I let them know they don't have to live like they've been living. "When I was a kid, people tried to talk to me, but I didn't listen because they hadn't been where I was. I want to let people know there is hope to turn things around. At some point, I believe you've got to break the cycle."

FISCAL YEAR 2019 FUNDING REQUEST

COABE urges the Committee to fund Title II of the WIOA at the fiscal year 2019 authorized level so that the statute's ambitious goals can be realized.

Adult education is a gateway to a job and a career for under-educated, low skilled adults. Properly funding the adult education system would yield substantial economic benefits, adding to GDP growth, personal incomes, yielding increased tax revenues and saving on healthcare and incarceration.

Other nations are boosting the educational levels of their young and working age adults at a faster rate than the U.S. and are showing consistent progress while we are losing ground. We must invest adequately in our adult education system to remain economically competitive globally.

PREPARED STATEMENT OF THE COLLEGE ON PROBLEMS OF DRUG DEPENDENCE

Thank you for the opportunity to submit testimony in support of the National Institute on Drug Abuse. The College on Problems of Drug Dependence (CPDD), a membership organization with over 1000 members, has been in existence since 1929. It is the longest standing group of scholars in the U.S. addressing problems of drug dependence and abuse. CPDD serves as an interface among governmental, industrial and academic communities maintaining liaisons with regulatory and research agencies as well as educational, treatment, and prevention facilities in the drug abuse field. In the fiscal year 2019 Labor-HHS Appropriations bill, we request that the subcommittee provide at least \$2 billion above the fiscal year 2018 level

for the National Institutes of Health, and within that amount a proportionate increase for the National Institute on Drug Abuse using the Institute's conferenced level of \$1,383,603,000 as NIDA's base budget for Fiscal 2019. We also respectfully request the inclusion of the following NIDA specific report language.

Opioid Initiative.—With additional funding for NIDA targeted at addressing the opioid epidemic, the Institute's opioid specific allocation should be targeted for the following areas: development of safe and effective medications and new formulations and combinations to treat opioid use disorders and to prevent and reverse overdose; conduct demonstration studies to create a comprehensive care model in communities nationwide to prevent opioid misuse, expand treatment capacity, enhance access to overdose reversal medications, and enhance prescriber practice; test interventions in justice system settings to expand the uptake of medication assisted treatment and methods to scale up these interventions for population-based impact; and develop evidence-based strategies to integrate screening and treatment for opioid use disorders in emergency department and primary care settings.

Opioid Misuse and Addiction.—The Committee continues to be extremely concerned about the epidemic of prescription opioid, heroin, and illicit synthetic opioid use, addiction and overdose in the U.S. Approximately 174 people die each day in this country from drug overdose (over 100 of those are directly from opioids), making it one of the most common causes of non-disease-related deaths for adolescents and young adults. This crisis has been exacerbated by the availability of illicit fentanyl and its analogs in many communities. The Committee appreciates the important role that research can and should play in the various Federal initiatives aimed at this crisis. The Committee urges NIDA to 1) continue funding research on medication development to alleviate pain and to treat addiction, especially the development of medications with reduced abuse liability; 2) as appropriate, work with private companies to fund innovative research into such medications; and 3) report on what we know regarding the transition from opioid analgesics to heroin and synthetic opioid use and addiction within affected populations.

Alcohol's Role in Opioid Overdose.—The Committee is concerned that the role of alcohol in opioid and other drug overdoses is not receiving the attention it should. The CDC estimates that alcohol contributes to over 8000 annual overdose deaths that are primarily attributed to other substances, and that data suggest alcohol is commonly omitted from death certificates leading to underreporting. In order to address the opioid crisis, all avenues of investigation must be addressed. The Committee directs NIDA to work with NIAAA and any other appropriate agencies to better understand these linkages and to support research that will help to address this aspect of the problem.

Barriers to Research.—The Committee is concerned that restrictions associated with Schedule 1 of the Controlled Substance Act effectively limit the amount and type of research that can be conducted on certain Schedule 1 drugs, especially marijuana or its component chemicals and certain synthetic drugs. At a time when we need as much information as possible about these drugs, we should be lowering regulatory and other barriers to conducting this research. The Committee directs NIDA to provide a short report on the barriers to research that result from the classification of drugs and compounds as Schedule 1 substances.

Raising Awareness and Engaging the Medical Community in Drug Abuse and Addiction Prevention and Treatment.—Education is a critical component of any effort to curb drug use and addiction, and it must target every segment of society, including healthcare providers (doctors, nurses, dentists, and pharmacists), patients, and families. Medical professionals must be in the forefront of efforts to curb the opioid crisis. The Committee continues to be pleased with the NIDAMeD initiative, targeting physicians-in-training, including medical students and resident physicians in primary care specialties (e.g., internal medicine, family practice, and pediatrics). NIDA should continue its efforts in this space, providing physicians and other medical professionals with the tools and skills needed to incorporate drug abuse screening and treatment into their clinical practices.

Marijuana Research.—The Committee is concerned that marijuana public policies in the States (medical marijuana, recreational use, etc.) are being changed without the benefit of scientific research to help guide those decisions. NIDA is encouraged to continue supporting a full range of research on the health effects of marijuana and its components, including policy research focused on policy change and implementation across the country.

Adolescent Brain Development.—The Committee recognizes and supports the NIH Adolescent Brain and Cognitive Development (ABCD) Study. We know that the brain continues to develop into the mid-twenties. However, we do not yet know enough about the dramatic brain development that takes place during adolescence and how the various experiences people are exposed to during this time interact

with each other and their biology to affect brain development and, ultimately, social, behavioral, health and other outcomes. The ABCD study addresses this knowledge gap. The committee also recommends and recognizes that the cost of this comprehensive study should not inhibit investigator-initiated studies or any potential special appropriation for its ongoing support. The Committee understands that recruitment and data development efforts are proceeding well, and requests a summary report detailing activity and progress to date.

Drug Treatment in Justice System Settings.—The Committee understands that providing evidence-based treatment for substance use disorders offers the best alternative for interrupting the drug use/justice system cycle for offenders with drug problems. Untreated substance using offenders are more likely to relapse into drug use and criminal behavior, jeopardizing public health and safety and taxing criminal justice system resources. Treatment has consistently been shown to reduce the costs associated with lost productivity, crime, and incarceration caused by drug use. The Committee applauds NIDA's focus on adult and juvenile justice populations in its research, supports this important work and asks for a progress report in the next appropriations cycle.

Electronic Cigarettes.—The Committee understands that electronic cigarettes (e-cigarettes)/other vaporizing equipment are increasingly popular among adolescents. Lack of regulation, easy availability, and a wide array of cartridge flavors may make them particularly appealing to this age group. In addition to the unknown health effects, evidence continues to suggest that e-cigarette use may serve as an introductory product for youth who then go on to use other tobacco products, including conventional cigarettes, which are known to cause disease and lead to premature death. Evidence also reveals that these devices are widely used as tools for smoking derivatives of marijuana (hash oil, “shatter,” etc.) The Committee requests that NIDA fund research on the use and consequences of these devices.

Drug abuse is costly to Americans; it ruins lives, while tearing at the fabric of our society and taking a financial toll on our resources. Beyond the unacceptably high rates of morbidity and mortality, drug abuse is often implicated in family disintegration, loss of employment, failure in school, domestic violence, child abuse, and other crimes. We know that many of these problems can be prevented entirely, and that the longer we can delay initiation of any use, the more successfully we mitigate future morbidity, mortality and economic burdens.

Over the past three decades, NIDA-supported research has revolutionized our understanding of addiction as a chronic, often-relapsing brain disease -this new knowledge has helped to correctly emphasize the fact that drug addiction is a serious public health issue that demands strategic solutions. By supporting research that reveals how drugs affect the brain and behavior and how multiple factors influence drug abuse and its consequences, scholars supported by NIDA continue to advance effective strategies to prevent people from ever using drugs and to treat them when they cannot stop. 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, however areas of significant concern include the recent increase in lethality due to heroin and synthetic fentanyl, as well as the continued abuse of prescription opioids and the recent increase in availability of designer drugs and their deleterious effects. The need to increase our knowledge about the effects of marijuana is most important now that decisions are being made about its approval for medical use and/or its legalization. We support NIDA in its efforts to find successful approaches to these difficult problems.

The Nation's previous investment in scientific research to further understand the effects of abused drugs on the body has increased our ability to prevent and treat addiction. An obvious significant result of this type of research is the discovery and development of naloxone and other drugs to reduce deaths due to opioid overdose. This one success has saved many lives. As with other diseases, much more needs to be done to improve prevention and treatment of these dangerous and costly diseases. Our knowledge of how drugs work in the brain, their health consequences, how to treat people already addicted, and what constitutes effective prevention strategies has increased dramatically due to support of this research. However, since the number of individuals continuing to be affected is still rising, we need to continue the work until this disease is both prevented and eliminated from society.

We understand that the fiscal year 2019 budget cycle will involve setting priorities and accepting compromise, however, in the current climate we believe a focus on substance abuse and addiction deserves to be prioritized accordingly. Thank you for your support for the National Institute on Drug Abuse.

PREPARED STATEMENT OF THE COMPUTER SCIENCE EDUCATION COALITION

Chairman Blunt, Ranking Member Murray, I am Erin Siefring, chair of the Computer Science Education Coalition (CSEC). Thank you for the opportunity to provide this written testimony for the record in support of making funding available for computer science education for our country's K–12 students. This year, the CSEC is asking the subcommittee to dedicate \$250 million in funding for computer science K–12 education. This funding level will build upon the important work that has been done in the last year by this subcommittee on a bipartisan basis, and by the Administration, to prioritize computer science education.

Last year I stated in my submitted statement for the record,

[c]omputer science is a foundational skill for 21st century jobs. This skill is in high demand in our military and throughout the private sector. However, the United States is failing to take the necessary steps to equip our current and future workforce with the computer science skills needed to fill these positions. Critical jobs throughout our economy are going unfilled due to a lack of Americans qualified in computer science. The result is a weakened homeland and an economy not reaching its potential.

CSEC was grateful to see the fiscal year 2018 Labor, Health and Human Services, Education, and Related Agencies bill include report language underscoring the importance of K–12 computer science education programs and receive \$50 million under the Education Innovation and Research program for innovative STEM education and computer science projects.

Congress and the executive branch understand what students, parents, and teachers have been saying: computer science education is a key component of providing K–12 students with the skills they need to compete in the global economy.

In another significant development, last year President Trump issued a Presidential Memorandum for the Secretary of Education concerned with “Increasing Access to High-Quality Science, Technology, Engineering, and Mathematics (STEM) Education.” The memorandum highlighted the importance of computer science education, and stated that,

The Department of Education, therefore, should prioritize helping districts recruit and train teachers capable of providing students with a rigorous education in STEM fields, focusing in particular on Computer Science. This will help equip students with the skills needed to obtain certifications and advanced degrees that ultimately lead to jobs in STEM fields.

The President directed the secretary, “to the extent consistent with law, establish a goal of devoting at least \$200 million in grant funds per year to the promotion of high-quality STEM education, including Computer Science in particular.”

The combined commitment from Congress and the President is a crucial step in the right direction in helping to secure dedicated funding for K–12 computer science education. More work lies before us to help provide our students with the computer science education they need, and that our economy demands.

For example, the fields of software, computing and computer science are plagued by tremendous underrepresentation of women. In high school, the Advanced Placement exam in computer science has the worst gender diversity across all AP courses—78 percent percent of the participants are male. Just 12 percent of the students taking the exam are students of color. This disparity extends into the software workplace, which suffers a similar lack of diversity. Computer science majors can earn 40 times more than the average wage. If K–12 computer science education gets the dedicated Federal funding it deserves, then the current disparities in computer science can be more robustly addressed.

The dearth of computer science education in classrooms has left America in the midst of a STEM jobs crisis—which is really a crisis in computer science education. Today, there are over 500,000 computing jobs unfilled in the United States, while our universities only graduate about 43,000 computer scientists each year.

In order to meet the demand to fill these U.S. jobs, close the current skills gap, and boost America's competitive position globally, a sustained Federal investment in K–12 computer science education is critical. If students do not have the opportunity to learn computer science skills early in their academic careers, it is less likely that they will consider computer science careers. An investment of \$250 million annually can help spur students into computer science careers. But this isn't just an issue of providing economic opportunity and jobs. The security of the homeland and the effectiveness of our military depends in part on having graduates trained in computer science. In fact,

The new national defense strategy calls for the military to prepare for “contested environments,” including space. Enemies like Russia and China are rap-

idly developing electronic and cyber weapons, the strategy warns, and the U.S. military can no longer spend decades developing technology.

The United States needs many qualified cyberwarriors and others trained in computer science to provide rapid responses and proactive approaches to the fluid environment that is the cyber battlefield.

As the subcommittee considers its funding priorities for the upcoming fiscal year, CSEC, on behalf of its over 100 members, requests that the subcommittee provide \$250 million in funding specifically for computer science education for our country's K–12 students. This funding will pay significant dividends in preparing our students for the computer science jobs of today and tomorrow, helping to secure the homeland, and assisting our military in their vital mission.

Thank you for your consideration of this request.

[This statement was submitted by Erin Siefring, Chair, Computer Science Education Coalition.]

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 2019, COSSA urges the Committee to appropriate \$39.3 billion for the National Institutes of Health (NIH), in addition to the funds included in the 21st Century Cures Act; \$8.445 billion for the Centers for Disease Control and Prevention (CDC), including \$175 million for the National Center for Health Statistics (NCHS); \$454 million for the Agency for Healthcare Research and Quality (AHRQ); \$670 million for the Institute of Education Sciences (IES); and \$78.5 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, especially for the NIH. 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. COSSA serves as a united voice for a broad, diverse network of organizations, institutions, communities, and stakeholders who care about a successful and vibrant social science research enterprise. We represent the collective interests of all STEM disciplines engaged in the rigorous study of why and how humans behave as they do as individuals, groups and within institutions, organizations, and society. Social and behavioral science often refers to the disciplines of and fields within anthropology, communication, demography, economics, geography, history, law, linguistics, political science, psychology, sociology, and statistics, as well as countless multidisciplinary subfields.

National Institutes of Health—\$39.3 Billion

COSSA urges the Committee to appropriate \$39.3 billion for the National Institutes of Health (NIH) in fiscal year 2019 in addition to the funds included in the 21st Century Cures Act for targeted initiatives. COSSA appreciates the Subcommittee's leadership and its long-standing bipartisan support of NIH, especially during difficult budgetary times. There are, however, ongoing and emerging health challenges confronting the United States and the world, which COSSA believes merits continued investment in the NIH. This funding level would enable real growth over biomedical inflation, an important step to ensuring stability in the U.S. research capacity over the long term.

As this Committee knows, the NIH supports scientifically rigorous, peer-reviewed, investigator-initiated research, including basic and applied behavioral and social sciences research, as it works "in pursuit of 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." 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. Recognizing the value these disciplines add to preventing and treating most diseases, disorders, and conditions, NIH support for basic and applied social and behavioral science research can be found across its 27 institutes and centers (ICs). Knowledge about the behavioral influences on health is a crucial component in the Nation's battles against the leading causes of morbidity and mortality, namely, obesity, heart disease, cancer, AIDS, diabetes, age-related illnesses, accidents, substance abuse, and mental illness. The fundamental understanding of how disease works, including the impact of social environment on disease processes, underpins our ability to conquer devastating illnesses. NIH investment in social science research is an essential piece of the public health puzzle.

Centers for Disease Control and Prevention—\$8.445 Billion, Including \$175 Million for the National Center for Health Statistics

COSSA urges the Subcommittee to appropriate \$8.445 billion for the Centers for Disease Control and Prevention (CDC), including \$175 million for CDC's National Center for Health Statistics (NCHS). As the country's leading health protection and surveillance agency, the CDC works with State, local, and international partners to keep Americans safe and healthy. Social and behavioral science research plays a crucial role in helping the CDC carry out this mission. Scientists in fields ranging from psychology, sociology, anthropology, and geography to health communications, social work, and demography work in every CDC Center to design, analyze, and evaluate behavioral surveillance systems, public health interventions, and health promotion and communication programs that help protect Americans and people around the world from disease. Further, NCHS collects data on chronic disease prevalence, healthcare disparities, emergency room use, teen pregnancy, infant mortality, causes of death, and rates of insurance, to name a few. It provides critical data on all aspects of our healthcare system through data cooperatives and surveys that serve as the gold standard for data collection around the world. Data from NCHS surveys are used by agencies across the Federal Government (including NIH), State and local governments, public health officials, Federal policymakers, and demographers, epidemiologists, health services researchers, and other scientists to better understand the impact of policies and programs on Americans' health.

Agency for Healthcare Research and Quality—\$454 Million

COSSA urges the Subcommittee to appropriate \$454 million for the Agency for Healthcare Research and Quality (AHRQ). The requested funding level would allow AHRQ to strengthen its research portfolios and allow the agency to build up its base budget should the authorization of the Patient Centered Outcomes Research (PCOR) Trust Fund (which provides 25 percent of AHRQ's funding) lapse at the end of fiscal year 2019. AHRQ funds research on improving the quality, safety, efficiency, and effectiveness of America's healthcare system. It is the only agency in the Federal Government with the expertise and explicit mission to fund research on improving healthcare at the provider level (i.e., in hospitals, medical practices, nursing homes, and other medical facilities). Its work is complementary—not duplicative—of other HHS agencies. AHRQ-funded research provides us with the evidence and tools we need to tackle some of the healthcare system's greatest challenges, including identifying effective strategies for helping primary care practices cope with the challenges of the opioid epidemic and reducing the incidence of healthcare-associated infections (HAIs) and medical errors. AHRQ reports and data give us vital information about the State of the U.S. healthcare system and identify areas we can improve. AHRQ's Medical Expenditure Panel Survey (MEPS) collects data on how Americans use and pay for medical care, providing vital information on the impact of healthcare on the U.S. economy. COSSA urges the Committee to ensure robust support for AHRQ's critical health services research.

Institute of Education Sciences—\$670 Million

COSSA requests a funding level of \$670 million for the Institute of Education Sciences (IES) in fiscal year 2019. As the research arm of 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—\$78.5 Million

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 \$78.5 million (\$70.5 million for Title VI and \$8.0 million for Fulbright-Hays) for these programs, which would represent a modest increase over current budgets. In

addition to broadening opportunities for students in international and foreign language studies, such support would also strengthen the Nation's human resource capabilities in strategic areas of the world that impact our national security and global economic competitiveness.

Thank you for the opportunity to present this testimony on behalf of the social and behavioral science research community.

[This statement was submitted by Wendy Naus, Executive Director, Consortium of Social Science Associations.]

PREPARED STATEMENT OF THE COUNCIL OF ACADEMIC FAMILY MEDICINE

The member organizations of the Council of Academic Family Medicine (CAFM) are pleased to submit testimony on behalf of programs under the jurisdiction of the Health Resources and Services Administration (HRSA) and the Agency for Healthcare Research and Quality (AHRQ). CAFM collectively includes family medicine medical school and residency faculty, community preceptors, residency program directors, medical school department chairs, research scientists, and others involved in family medicine education. We urge the Committee to appropriate at least \$59 million for the Primary Care Training and Enhancement program, authorized under Title VII, Section 747 of the Public Health Service Act. In addition, we recommend the Committee fund the AHRQ at least \$454 million and direct \$100 million to the Center for Primary Care Research.

More than 44,000 primary care physicians will be needed by 2035, and current primary care production rates will be unable to meet the demand, according to the authors of an article in *Annals of Family Medicine* (Pettersen, et al Mar/Apr 2015). The primary care training and enhancement programs and AHRQ research enhance our Nation's workforce and health infrastructure, improving primary care services that produce better health outcomes and reduce healthcare costs. We were extremely pleased that the fiscal year 2018 funding measure included increases in both funding levels and hope that fiscal year 2019 will build on these increases.

Primary Care Training and Enhancement—Title VII

The Primary Care Training and Enhancement Program (Title VII, Section 747 of the Public Health Service Act) has a long history of funding training of primary care physicians. As experimentation with new or different models of care continues, departments of family medicine and family medicine residency programs will rely further on Title VII, Section 747, grants to help develop curricula and research training methods for transforming practice delivery. Future training needs include: training in new clinical environments that include integrated care with other health professionals (e.g. behavioral health, care coordination, nursing, oral health); development and implementation of curricula to give trainees the skills necessary to build and work in inter-professional teams that include diverse professions; and development and implementation of curricula to develop leaders and teachers in practice transformation. Moreover, new competencies are required for our developing health system.

The Advisory Committee on Training in Primary Care Medicine and Dentistry December 2014 report states that “[r]esources currently available through Title VII, Part C, sections 747 and 748 have decreased significantly over the past 10 years, and are currently inadequate to support the [needed] system changes.”¹ In order to address some of these challenges, the Advisory Committee recommended that Congress increase funding levels for training under the primary care training health professions program to meet the pent-up demand caused by reduced and stagnant funding levels. Only 35 schools or institutions could obtain grant funding in the fiscal year 2015 cycle; approximately another 37 awards were made in fiscal year 2016, but then no new large competitive award cycles were available since then, and only two very small competitions. Family medicine alone has over 100 departments, and over 520 residencies, while the other specialties of general internal medicine, general pediatrics and physician assistant programs have many more. More funding would allow for more participation across primary care.

Primary care health professions training grants under Title VII are vital to the continued development of a workforce designed to care for the most vulnerable populations and meet the needs of the 21st century. We thank you for the fiscal year 2018 increase and urge your continued support for this program with an increase in funding levels to \$59 million in fiscal year 2019 to allow for a robust competitive funding cycle. This funding level will help continue important Title VII programs

¹ <http://www.hrsa.gov/advisorycommittees/bhpradvisory/actpcmd/Reports/eleventhreport.pdf>.

such as the University of South Alabama who used primary care training funding to lead in curricular innovation that resulted in a new primary care patient curriculum for first and second year medical students.

Agency for Health Care Research and Quality (AHRQ)

Primary care clinical research is a core function of AHRQ. Primary care research includes: translating science into patient care, better organizing healthcare to meet patient and population needs, evaluating innovations to provide the best healthcare to patients, and engaging patients, communities, and practices to improve health. AHRQ has proved to be uniquely positioned to support best practice primary care research and to help disseminate the research nationwide. However, reduced levels of AHRQ funding in the past have exacerbated disparities in funding primary care research. 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 Primary Care Research.

With a funding increase for fiscal year 2018 to \$334 million, AHRQ is in a unique position to further primary care clinical research as well as the implementation science to identify how to deploy new knowledge into the hands of primary care providers and systems in communities. For this reason, we are supporting additional overall funding increases for fiscal year 2019 as well as specific funding for the Center for Primary Care Research. We hope additional funding will continue and expand the following research goals: (1) development of clinical primary care research and researchers (2) real world implementation of evidence, (3) the process of practice and health system transformation, (4) how high functioning primary care systems and practices should look, (5) how primary care practices serving rural and other underserved populations adapt and survive, and (6) how health extension systems serve as connectors for research institutions with practices and communities.

Oklahoma presents some real-world examples of successful AHRQ work that supports primary care practice and patient safety. The University of Oklahoma, College of Medicine, in Oklahoma City, created the Primary Healthcare Improvement Center to serve as a resource to the emerging Primary Healthcare Extensions System. Part of the Evidence Now Initiative, this grant supports the dissemination of research findings into practices, develop risk management interventions in practices and evaluate the intervention's impact on practice performance.

AHRQ research is used by practices across the Nation. Highlighting the success of AHRQ's patient safety initiatives, a 2014² report showed hospital care to be much safer in 2013 compared to 2010. The report noted a decline of 17 percent in hospital-acquired conditions, in harm to 1.3 million individuals, as well as 50,000 lives saved, and \$12 billion in reduced health spending during that period. AHRQ supports this research that is essential to create a robust system for our Nation that delivers quality of care while reducing the rising cost of care.

The Administration's fiscal year 2019 budget again proposed eliminating AHRQ and moving its functions into the National Institutes of Health (NIH). CAFM supports an alternative approach which includes further study of AHRQ's mission as described in report language contained in the fiscal year 2018 spending bill. It's critical that AHRQ retains its current unique purpose with an emphasis on primary care and health services research for improved patient outcomes.

In conclusion, we support increased funding for AHRQ at the level of \$454 million for fiscal year 2019 which would support important primary care and health services research efforts. We also support 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.

[This statement was submitted by Mary Hall, MD, Chair, Council of Academic Family Medicine.]

PREPARED STATEMENT OF COUNCIL OF CHIEF STATE SCHOOL OFFICERS

Dear Chairmen Shelby and Blunt and Ranking Members Leahy and Murray:

On behalf of chief state school officers across the country, I am writing to convey States' priorities for K-12 education in the fiscal year 2019 appropriations cycle. The Council of Chief State School Officers (CCSSO) is a nonpartisan, nationwide, nonprofit organization of public officials who head departments of elementary and secondary education in the States, the District of Columbia, the Department of De-

²Publication # 15-0011-EF.

fense Education Activity, and five U.S. extra-State jurisdictions. CCSSO provides leadership, advocacy, and technical assistance on major educational issues.

In February 2017, State chiefs renewed their commitment to creating a more equitable education system for every child by releasing *Leading for Equity*, a set of ten actions States are committed to taking to improve educational equity in their States. Across these commitments, States demonstrate how they can better align Federal, State, and local resources to advance equity for all students. Funding is a critical component, though not the only component, and State chiefs see the funding they receive from through the Federal budget as a significant resource to improve educational outcomes.

State chiefs appreciate Congress passing a bipartisan budget agreement on February 9 of this year that included higher spending caps for domestic programs, such as education. CCSSO supported the fiscal year 2018 omnibus appropriations act that Congress later passed to fund the remainder of the current fiscal year as it increased critical funding for major K–12 education programs, such as Title I and the Individuals with Disabilities Education Act.

As States implement the Every Student Succeeds Act (ESSA), which reauthorized the Elementary and Secondary Education Act (ESEA) in 2015, Federal funding is as critical as ever to ensure States can implement State plans aligned with ESSA with fidelity in and in keeping with the law.

As stewards of limited resources, State chiefs recognize that every taxpayer dollar is precious and must be administered efficiently and effectively to better meet the needs of all students. As States move to implement ESSA and other Federal programs, they are also working to improve State and local stewardship over limited Federal funds to ensure maximum impact to improve student achievement, particularly for disadvantaged or traditionally undeserved students, as well as children with disabilities and others with special needs. Chiefs also know and are eager to demonstrate the positive returns the Federal Government—and our country as a whole—can reap when investing in the next generation.

CCSSO and our members look forward to working with Congress to ensure that fiscal year 2019 appropriations provides the resources needed to improve outcomes for all children in every State. State chiefs emphasize the following K–12 funding priorities:

ELEMENTARY AND SECONDARY EDUCATION ACT

Increase funding for ESEA Title I, Part A

Title I, Part A of ESEA is at the core of the Federal-State partnership in K–12 education. As reauthorized by ESSA, Title I–A provides increased flexibility for States, while also calling on States to develop and implement new accountability and school improvement systems to support academic excellence and reduce achievement gaps. State chiefs have committed to creating a more equitable education system for all students, and this is the continued goal and purpose of Title I Federal funding. During school year 2019–2020, when States and school districts will be receiving fiscal year 2019 funding, they will be working to increase achievement and improve student outcomes in schools that have been identified for support and improvement through new State accountability systems. It is essential that States and their districts have the resources needed to bring those efforts to fruition. To support State leaders in meeting the educational needs of all students, we urge Congress to increase the fiscal year 2018 level of \$15.7 billion for Title I, Part A by \$300 million, the same increase as in fiscal year 2018, to \$16 billion for fiscal year 2019.

Provide Authorized Funding for ESEA State Assessment Grants

ESEA, as reauthorized by ESSA, continues to require that States administer annual assessments in specified grades in reading or language arts, in mathematics, and in science. These assessments provide much of the framework for States' systems of school accountability; that is, they provide the information that States use to determine which schools are succeeding in educating all their students to high standards. Yet high-quality assessment can be resource-intensive, and States continue to rely on Federal assistance in meeting this important requirement of the reauthorized statute.

Authorized under Title I of ESEA, State Assessment Grants support State efforts to develop and implement high-quality assessments to measure the academic achievement of all students. Under ESSA, States and school districts may also use these funds to audit assessment systems in order to reduce unnecessary or duplicative assessments. State chiefs understand that States have an important role to play in monitoring equitable implementation of standards and assessments. According to the Brookings Institution, States spend an estimated \$1.7 billion on assessments

each year, yet the Federal program pays for \$378 million of that cost. State chiefs ask Congress to maintain State Assessment Grants at the full authorized level of \$378,000,000 to ensure that students are appropriately assessed and effective targeted instructional supports to improve academic achievement are identified.

Provide Authorized Funding for ESEA Title II, Part A, to Support Effective Instruction

Under the Every Student Succeeds Act, every student is required to have a highly effective teacher. No longer can poor or minority students be disproportionately served by ineffective or out-of-field teachers. States have been working to address this critical issue both before and through ESSA plans. Title II, Part A funding is critical to support States and local districts in these efforts. We urge Congress to fund Title II, Part A funding at the full amount authorized under ESEA to reach these goals for every child.

Communities across the country use flexible Title II–A funds to develop the workforce they need to best serve the students who are the intended beneficiaries of ESEA. In New Mexico, for example, the State uses this funding to provide professional development and mentorship programs for teachers and principals in the State’s lowest-performing schools. As a result, these schools have improved proficiency rates for their students in English Language Arts by 4.5 times the rate of statewide growth and 2.7 times the statewide growth rate in mathematics. Under ESSA, Nevada plans to use Title II–A funds to modernize its licensure requirements to incorporate meaningful professional growth and educator effectiveness and make improvements in the statewide evaluation system to ensure reliability, validity, fairness, consistency, and objectivity. Massachusetts will use this funding to review its school districts’ use of Title II funds and make sure that professional development supports more effective educators, particularly those who serve students with disabilities, low-income students, and students of color.

These select examples of effective uses of and plans for Title II–A funding are just a sample of the efforts States are undertaking to support high-quality teaching and learning. Chiefs urge Congress to continue to support these Federal-State partnerships by funding the program at the authorized level of \$2,295,830,000 to increase teacher effectiveness and support the use of proven strategies to improve learning outcomes.

Preserve Funding for ESEA Title III

English learners (ELs) are a growing population group across our States, and in recent years their enrollment has increased particularly in States where schools have little previous experience in serving them. Enabling ELs to achieve English language proficiency and achieve to high standards in the regular, English-speaking classroom, is one of the key responsibilities given to States by ESSA. Under the re-authorized statute, States must set goals for ELs’ attainment of English proficiency and they must incorporate a measure of progress toward that goal in their systems of school accountability. For this reason, school year 2019–2020 will be a critical time during which States test all ELs for proficiency, implement systems for improving educational programs for the EL population, and provide services and supports to schools that are not making sufficient progress in that area.

Title III of ESEA funds State and local programs in English language acquisition for EL and immigrant students. In order to ensure the success of States’ efforts to improve outcomes for this high-need and growing population, we recommend that the Congress fund Title III at the full authorization of \$784,960,000.

Adequately Fund ESEA Title IV, Part A, the Student Support and Academic Enrichment Grant

Title IV, Part A, the Student Support and Academic Enrichment Grant program, provides Federal support for programs that support a well-rounded education, safe and healthy students, and education technology. Newly authorized by ESSA, this program received its first appropriation of \$400 million in fiscal year 2017, followed by an increase to \$1.1 billion in fiscal year 2018.

In addition to using these funds to provide students with a well-rounded education, States have committed to ensuring student safety by focusing on school culture, climate, and social-emotional development. In order to keep students safe, State leaders recognize this work cannot just be about best practices in securing school facilities, but also must focus on how to deepen and strengthen communities. Title IV is particularly critical as States and local communities seek to improve school safety; it is more important than ever that we support State and local leaders in providing safe, supportive school environments for all students, and we urge Congress to fund Title IV, Part A at the authorized level of \$1.6 billion.

Adequately Fund ESEA Title IV, Part B, 21st Century Community Learning Centers

One way in which State chiefs have worked to strengthen students' relationships with their communities is through afterschool programs. Chiefs urge Congress to adequately fund 21st Century Community Learning Centers so students have the supports they need outside of the classroom to ensure success in school and in life. This program provides students with activities to enhance their academic, social, and overall development during their out-of-school time. Approximately 1.9 million students benefit from these programs in schools, libraries, and communities across the country. Data show that students who participate in these programs miss fewer days of school, have fewer out-of-school suspensions, increase their chances of graduating, and are more likely to continue their education after high school. Congress should fund this program at no less than \$1,211,673,000, the amount provided in fiscal year 2018, to ensure that low-income students may access the out-of-school time supports they need to succeed.

Support Statewide Longitudinal Data Systems

For many years, Statewide Longitudinal Data Systems (SLDS) funding has helped State education agencies provide State leaders, district administrators, educators, and the education community with high-quality data on student achievement and other student outcomes and on school performance. States use these funds to create more efficient and effective data systems, including new ESSA requirements such as reporting on homeless, foster, and military-connected youth, and per-pupil expenditure at the school level. For example, one State used SLDS grants to streamline the data collection process that school districts must navigate annually, thereby reducing administrative burden. Through automation this State has saved over \$500,000 annually on a single data collection requirement. These savings are driven into more important services locally, such as teaching and learning activities. Meanwhile, another State used an SLDS grant to develop and implement a custom technology tool to provide educators with near real-time data to help inform instruction. Chiefs urge Congress to build on these and similar successes by funding this program at least at the fiscal year 2018 level of \$32,281,000.

CARL D. PERKINS CAREER AND TECHNICAL EDUCATION ACT

Adequately Fund the Carl D. Perkins Career and Technical Education Act

States are leading efforts to ensure that students graduating from high school are prepared to enroll in postsecondary education or enter the workforce with industry-recognized certifications or credentials that can lead them to a well-paying career. In partnership with JPMorgan Chase, Advance CTE and Education Strategy Group, CCSSO is leading the New Skills for Youth Initiative and working with States to increase the number of students who graduate prepared to compete in an evolving job market. To support State leaders in producing graduates who are both college- and career-ready and ensure all students have access to pathways that prepare them for the workplace of tomorrow, Chiefs urge Congress to appropriate at least fiscal year 2018 funding of \$1,192,598,000 for the Perkins Career and Technical Education program.

INDIVIDUALS WITH DISABILITIES EDUCATION ACT

Invest in the Individuals with Disabilities Education Act (IDEA)

IDEA, Part B supports State and local programs for students with special needs, including support for special education teachers, related service providers, and professional development. IDEA funding can also be used to provide more comprehensive supports that benefit all students, such as implementing a universal design for learning curriculum, planning and implementing new learning environments to support all learners in an inclusive setting, or purchasing curriculum-based screening and progress monitoring instruments. While ideally the Federal Government would meet the statutory objective of funding 40 percent of the additional costs of educating students with disabilities, we understand that even with higher spending caps this is a challenging goal under current circumstances. In the fiscal year 2018 Omnibus, Congress appropriated \$12.3 billion for IDEA, a significant increase over previous years, but still far short of the Federal commitment. Therefore, chiefs ask Congress to increase the Federal Government's share of the excess costs of special education services to about 15 percent, or \$12,850,000,000 for IDEA in order to strengthen services for our students with disabilities.

Thank you for considering the appropriations priorities of chief State school officers and the students they serve. As States move to advance equity in the public education system and implement the Every Student Succeeds Act and other key Federal and State programs aligned with this vision, it is imperative that the Fed-

eral Government remain a key partner in supporting the work underway in States to provide the necessary resources to meet the needs of all students, particularly students with disabilities, students from low-income families, English learners, and other students who have been traditionally undeserved by our education system.

We look forward to working with you and your colleagues to ensure that Congress supports educators and students with adequate resources in fiscal year 2019.

Sincerely,

[This statement was submitted by Carissa Moffat Miller, Executive Director, Council of Chief State School Officers.]

PREPARED STATEMENT OF THE COUNCIL ON SOCIAL WORK EDUCATION

On behalf of the Council on Social Work Education (CSWE), I am pleased to offer this written testimony to the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies. CSWE is a nonprofit national association representing more than 2,500 individual members and more than 800 baccalaureate and master’s programs of professional social work education. CSWE requests:

| Agency | Account | Program | Funding Requested |
|--------|---------|--|---|
| HHS | HRSA | HRSA Behavioral Health Workforce Education and Training Grant Program. | \$75 million |
| HHS | HRSA | Scholarships for Disadvantaged Students | \$48.970 million |
| HHS | HRSA | Mental and Behavioral Health Programs | \$38.916 million |
| HHS | HRSA | Geriatrics Programs | \$51 million |
| HHS | HRSA | New authorized demonstration to strengthen mental and substance use disorders workforce. | \$10 million |
| HHS | SAMHSA | Minority Fellowship Program | \$12.669 million |
| ED | N/A | Pell Grant | \$6,230 for the maximum Pell Grant |
| ED | N/A | GAANN | \$41 million |
| ED | N/A | Loan Repayment Programs | Maintain loan forgiveness programs including Public Service Loan Forgiveness (PSLF) program |
| HHS | NIH | Overall Funding for NIH | At least \$39.3 billion |

HRSA TITLE VII HEALTH PROFESSIONS PROGRAMS

CSWE urges the Committee to provide \$424 million in fiscal year 2019 for the health professions education programs authorized under Title VII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA). These programs are designed to provide health-care providers with interdisciplinary training to meet the health-care needs of all Americans, including underserved populations, individuals with special needs, and minority groups that require a culturally competent health-care workforce. Social workers and social work students are eligible for Title VII health professions programs under HRSA, which provide loans, loan guarantees, and scholarships to students, as well as grants to institutions of higher education and non-profit organizations to build and maintain a robust health-care workforce. Within the Title VII program, CSWE specifically urges the Committee to provide:

- \$75 million for HRSA’s Behavioral Health Workforce Education and Training (BHWET) program. CSWE is pleased at the increased investments in the fiscal year 2018 Omnibus for the BHWET program. BHWET supports the recruitment and education of behavioral health-care providers, which is critical as the Nation continues to combat the opioid epidemic. In 2015, the program’s first year, 4,196 social work students participated in the BHWET program and that number continues to grow. In 2018 a new 4-year competition awarded social work programs over \$17 million a year to help develop and expand the behavioral health workforce serving populations across the lifespan, including in rural and medically underserved areas. We hope you will support \$75 million for BHWET in fiscal year 2019; this is the enacted level in the fiscal year 2018 omnibus.
- At least \$48.970 million for Scholarships for Disadvantaged Students. This program helps ensure that the United States has the pipeline of health professionals to meet health needs of underserved individuals and communities. Furthermore, this program provides much needed opportunities for students from disadvantaged backgrounds.

- \$36.916 million for Mental and Behavioral Health programs at HRSA. CSWE was pleased to see new investments in mental and behavioral health programs at HRSA to support, recruit, and train professionals and faculty in the fields of social work, psychology, psychiatry, marriage and family therapy, substance abuse prevention and treatment, and other areas of mental and behavioral health. In addition, given that there was a significant increase in the fiscal year 2018 omnibus for Mental and Behavioral Health programs, CSWE has been made aware that HRSA does not plan to continue to fund the Leadership in Public Health Social Work Education (LPHSWE) Program. CSWE urges the Committee to ensure that funding from this account supports social work either for education and training, or through the LPHSWE Program.
- \$10 million for a demonstration program to strengthen the mental and substance use disorders workforce. CSWE is pleased the 21st Century Cures Act passed Congress with strong bipartisan support. Included in the mental health provisions of this bill, in Section 9022, is a new demonstration program to strengthen the mental and substance use disorders workforce. Specifically, this provision would support training for health professions, including social workers, to provide mental and substance use disorders services in underserved community-based settings that integrate primary care and mental and substance use disorders services.

SAMHSA MINORITY FELLOWSHIP PROGRAM

CSWE urges the Committee to appropriate \$12.669 million for the Minority Fellowship Program (MFP) in fiscal year 2019. The MFP has broad support and was recently authorized in the 21st Century Cures Act for \$12.669 million. For almost 45 years, MFP has been increasing the number of professionals preparing for leadership roles in mental health and substance use fields and working to reduce health disparities and improve behavioral healthcare outcomes for racial and ethnic populations. CSWE appreciates increased investments in the MFP in fiscal year 2018 focused on addiction medicine to address the opioid crisis. However, this funding did not include social work, which is one of the largest substance use and mental health providers in the United States. CSWE urges the committee to include \$12.669 million for the minority fellowship program for postbaccalaureate training for mental and substance use disorder treatment professionals, as authorized in Public Law 114–146, including in the fields of psychiatry, nursing, social work, psychology, marriage and family therapy, mental health counseling, and substance use disorder and addiction counseling.

CSWE urges Congress provide \$12.699 million for MFP in fiscal year 2019, with funding going to support the aforementioned grantees, including social work which has a long record of success and expertise in substance abuse.

DEPARTMENT OF EDUCATION (ED): STUDENT AID PROGRAMS

CSWE supports full funding to bring the maximum individual Pell Grant to \$6,230 in fiscal year 2019. Pell Grants are one of the most important programs to increase access and affordability to ensure that all students, regardless of economic situations, can pursue higher education. CSWE also urges the extension of inflationary adjustment on mandatory funds.

The Graduate Assistance in Areas of National Need (GAANN) program provides graduate traineeships in critical fields of study. Currently, social work is not defined as an area of national need. We encourage ED to include social work in the GAANN program to enhance graduate education opportunities in social work, which will foster a sustainable health professions workforce. CSWE urges you to support a funding level of \$41 million for the GAANN Program and include social work as an area of national need.

Income-driven repayment plans and the Public Service Loan Forgiveness (PSLF) program helps social work graduates serve in high-need communities. CSWE requests your support for the continuation of income-driven loan repayment programs and the support of the PSLF program.

NATIONAL INSTITUTES OF HEALTH: SUPPORT FOR RESEARCH

For fiscal year 2019, CSWE supports \$39.3 billion for the National Institutes of Health (NIH). CSWE thanks Congress for its support of sustained funding increases for NIH. To continue advances in research, CSWE urges Congress to support at least \$39.3 billion for NIH in fiscal year 2019 to continue investments in biomedical and health-related research that incorporates the social and behavioral science research necessary to address the needs of high-risk populations including children, racial and ethnic minorities, and older adults.

Thank you for the opportunity to express these views. Please do not hesitate to call on the Council on Social Work Education should you have any questions or require additional information.

[This statement was submitted by Dr. Darla Spence Coffey, President, Council on Social Work Education.]

PREPARED STATEMENT OF THE COUNCIL ON UNDERGRADUATE RESEARCH

The Council on Undergraduate Research (CUR) urges the Subcommittee to adequately invest in programs at the Department of Education as well as the National Institutes of Health and other programs that support high-quality undergraduate student-faculty collaborative research and scholarship as they consider the fiscal year 2019 Labor, Health and Human Services and Education (LHHS) Appropriations bill.

What is CUR?

CUR is a dynamic and vibrant non-profit organization of more than 13,000 members, representing close to 1000 institutions. CUR identifies undergraduate research as an inquiry or investigation conducted by an undergraduate student that makes an original intellectual or creative contribution to the discipline, in close collaboration with faculty members and other professional mentors. Undergraduate research moves students from passive participants in lecture-based classroom experiences, to independent researchers, with strong critical thinking, communication, organizational, and team work skills. Simply put, undergraduate researchers gain the real-life experience that employers and the research enterprise need and say they can't find in today's novice employee or researcher.

Why Undergraduate Research?

Nearly 2 million students graduate from 4-year colleges each year, suggesting a steady supply of skilled labor to the workforce. Yet employers continue to bemoan the dearth of new employees with the appropriate skills to succeed and advance in the workplace. Hart Research Associates report that over 80 percent of employers expect students to have strong skills in communication, problem solving, and critical thinking; and over 90 percent of employers think these skills are more valued by employers than a student's specific major. Unfortunately, 58 percent of employers do not think recent graduates demonstrate these skills effectively for entry level positions and 64 percent feel recent graduates are not prepared for advancement in a company. Baccalaureate students who have engaged in undergraduate research and creative experiences bring these "skills in demand" with them to their first job and are better prepared to apply them successfully.

In addition to these critical workforce skills, there is a growing demand in the workforce for skilled labor in science and technology. At the same time, there has been a trend toward declining numbers of degrees in science disciplines. Only 40 percent of students who enter college intent on majoring in Science, Technology, Engineering, and Mathematics (STEM) disciplines graduate with STEM degrees and only 20 percent of underrepresented minority students follow through in STEM. Economic projections show the number of STEM degrees graduated annually will not meet our Nation's demand for more skilled workers in the myriad of health-related fields such as practitioners, technicians and manufacturers. As a result, the United States is quickly falling behind on filling the science and technology positions necessary to maintain the mantle of the world's economic leader. The President's Council of Advisors on Science and Technology concluded that we must increase the number of STEM degrees awarded annually by 34 percent to remain competitive. As a means of encouraging and supporting students in STEM disciplines, undergraduate research is a particularly robust tool and student participation in research has been shown to increase retention, persistence, and graduation rates in these areas.

Universities carry the responsibility to produce students ready to meet the demands of the workforce with the necessary broad skills as well as the appropriate degrees. Research is the ultimate form of active learning. Students learn to conceptualize the problem, generate potential solutions, test them, and revise the question. Skills developed include perseverance, communication within groups, and ability to collaborate with others in ways that will help them work confidently with peers and supervisors in the workforce.

This is particularly important for achieving the goal of increasing participation by currently underrepresented populations in STEM fields. These students tend to engage in structured research opportunities in higher percentages than do white, non-

Latino students. The structured programs develop communities that benefit Black, Latino, and Native American students and encourage them in future academic and research pursuits. Assessment of undergraduate research repeatedly points to its positive educational outcomes both in the short term (early-career) and longitudinally (mid- and late-career). As a result, 87 percent of employers stated they were more likely to hire graduates who completed research-based projects. This is because the mentored research process actively engages students, more effectively developing critical thinking, improving motivation and persistence, and building confidence. Students self-report that they feel “better able to think independently and formulate their own ideas”. Research experiences help students clarify their career goals, and they are more likely to apply to graduate school. Finally, getting students involved in research early in their college career helps to keep them in college and persist in STEM majors.

A strong economy and a vibrant society thrive on an engaged and well-trained workforce. The evidence that undergraduate research supports these goals is clear. Thus, to accomplish the goal of increasing undergraduate research opportunities it is essential to support the Federal research agencies that invest in these high-impact practices. This support may take many forms, but ensuring that Federal research agencies have adequate funds to support faculty researchers who are eager to use undergraduate researchers as part of their work is crucial. Interested and committed faculty supported by substantive financial investment can help develop the next generation of creative and critical thinkers. Fostering these resilient and dedicated individuals is critical to maintaining our country’s leadership role in finding and implementing innovative solutions to current and future problems. Augmenting Federal funding streams for these high-impact practices will result in a demonstrated return on the investment of public money as the government seeks to strengthen the economy and American society.

CUR members represent a diverse cross-section of the country. They hail from community colleges to baccalaureate-granting institutions, large public institutions and small private colleges, military and religious institutions, rural and urban settings, and from all fifty States. Additionally, CUR is a founding partner, along with NSF, in the Community College Undergraduate Research Initiative (CCURI), and continues to work with 38 institutional partners to support the practice of undergraduate research at the community college level.

What are CUR’s Funding Priorities?

Undergraduate research is supported by many programs at multiple Federal agencies. In some instances, the program is dedicated to the practice, such as the NSF’s Research Experiences for Undergraduates. In other instances, undergraduate research is supported in a proposal submitted by a prospective principal investigator (PI), or a PI chooses to use undergraduate researchers once they have won an award. As a result, CUR and its members are interested in numerous research opportunities available to them and their institutions. The organization also knows that Federal student aid programs are important to getting undergraduate researchers to campuses that support the practice, keeping them there and ensuring they complete their intended course of study.

With regard to funding of student aid and support programs, please robustly support Federal TRIO programs at the Department of Education. The program should be funded at \$1.07 billion to restore services for the more than 30,000 students who have lost access to the programs over the last 10 years. These are investments aimed at getting more students prepared for, into and through postsecondary education. Further, please reject the White House proposals to transition TRIO to a single State formula grant program and its request to discontinue support for the Student Support Services, McNair Post-baccalaureate and Educational Opportunity Centers programs. We also urge you to reject the Administration’s request to stop funding Gaining Early Awareness Readiness for Undergraduate Programs (GEAR UP), and fund the program at \$375 million, which would bring approximately 70,000 new students into the program. As you know, these programs support activities to help first-generation, low-income and other disadvantaged students progress through the academic pipeline from middle school through college. These investments are crucial as we continue to see the importance of not only getting these students to college campuses, but nurturing their success once there.

CUR also believes that it is important that the Federal Government continue to support the students who need Pell Grants and student loans to advance their academic and professional endeavors. Regarding the Pell Grant program, CUR concurs with the higher education community’s call for an increased maximum award of \$6,230. This increase would help the program to keep pace with inflation and would be crucially important to the 7.5 million students who will use the program in the

coming academic year, according to the Congressional Budget Office. Further, CUR strongly opposes any rescissions from this program or using any surpluses for other programs.

As for campus-based aid programs, CUR opposes the President's proposals for both the Supplemental Educational Opportunity Grants (SEOG) and Federal Work-Study (FWS) programs. SEOG provides targeted, need-based grant aid of up to \$4,000 per student to 1.6 million students, and more than 99 percent of all SEOG recipients are also Pell Grant recipients. This makes the financial need of these students higher, on average, than students receiving only Pell Grants. The FWS program provides Federal and institutional funding to support part-time employment for more than 700,000 students to help them pay their college costs. It also supports undergraduate researchers. Over the last decade, both of these programs have seen level or reduced funding year after year, eroding their ability to serve low- and middle-income students. In order to restore their purchasing power, Congress should fund them at their pre-sequester levels, adjusted for inflation. For SEOG, that would be \$1.028 billion and for FWS it would be \$1.434 billion.

In other areas of the bill, CUR and its members are concerned that cuts or flat funding to research agencies—at a time when other countries are making significant investments in basic research—could lead to the erosion of America's preeminence in innovation and scientific research. We know that the subcommittee is keenly interested in maintaining our Nation's edge in producing the best science and scientists, and we urge you to continue to seek opportunities to maximize investments in the National Institutes of Health, the Institute of Education Sciences and other research programs under your purview.

CUR and its members are also committed to contributing to the fight against our country's opioid epidemic and support calls for increases in spending at HHS and the 21st Century Cures initiatives to address the opioid crisis and serious mental illness. Undergraduate researchers are particularly interested in discovering the causes of opioid addiction and contributing to meaningful and effective strategies for combatting the crisis that touches every college and university community in the country.

Thank You

While CUR's interests are broad, we urge the Subcommittee to develop a bill that invests adequately in the many programs that support undergraduate research and researchers. We thank you for your leadership on these issues and look forward to working with you further as the fiscal year 2019 Labor, Health and Human Services and Education Appropriations bill advances. If you or your staff have any questions about this testimony, the citations therein, CUR, undergraduate research or Federal policies that affect the practice, please contact me at eambos@cur.org. Thank you for your attention to these views.

The mission of the Council on Undergraduate Research is to support and promote high-quality undergraduate student-faculty collaborative research and scholarship. The Council on Undergraduate Research (CUR) and its affiliated colleges, universities, and individuals share a focus on providing undergraduate research opportunities for faculty and students at all institutions serving undergraduate students. CUR believes that faculty members enhance their teaching and contribution to society by remaining active in research and by involving undergraduates in research, and students succeed in their studies and professional advancement through participation in undergraduate research. CUR's leadership works with agencies and foundations to enhance research opportunities for faculty and students. CUR provides support for faculty, administrator, and student development. Our publications and outreach activities are designed to share successful models and strategies for establishing and institutionalizing undergraduate research programs. We assist administrators and faculty members in improving and assessing the research environment at their institutions. CUR also provides information on the importance of undergraduate research to State legislatures, private foundations, government agencies, and the U.S. Congress. CUR welcomes as members faculty, staff, and students from all types of academic institutions.

[This statement was submitted by Elizabeth L. Ambos, Executive Officer, Council on Undergraduate Research.]

PREPARED STATEMENT OF CURE ALZHEIMER'S FUND

Chairman Blunt, Ranking Member Murray, and members of the Senate Labor, Health & Human Services, Education, and Related Agencies Appropriations Subcommittee, I am Tim Armour, President and CEO of Cure Alzheimer's Fund. I appreciate the opportunity to thank Congress for the additional funding for Alzheimer's disease research across the National Institutes of Health (NIH), and to submit this written testimony to request at least an additional \$425 million in fiscal year 2019 above the final enacted amount for fiscal year 2018 for Alzheimer's disease research across the NIH.

Cure Alzheimer's Fund is a national nonprofit, based in Massachusetts that funds research throughout the United States and internationally, investigating genetic and other aspects of Alzheimer's disease. It is the belief of Cure Alzheimer's Fund that we will not be able to cure the disease if we do not know what causes the disease.

Cure Alzheimer's Fund wants to first acknowledge the ongoing support of this Subcommittee for increasing funding for Alzheimer's disease research. With this support, Federal funding for Alzheimer's disease research across NIH is approaching the \$2 billion a year called for by research experts.

The ongoing support from this Subcommittee benefits not only the National Institute on Aging (NIA) which supports the majority of Alzheimer's disease research at NIH, but other institutes including the National Institute on Neurological Disorders and Stroke (NINDS), and the National Institute of Mental Health (NIMH).

Recently, NIH highlighted research into the impact of a lack of sleep on developing Alzheimer's disease. This research, however, was funded by the National Institute on Alcohol Abuse and Alcoholism (NIAAA), with one of the lead researchers, Nora Volkow, being the Director of the National Institute on Drug Abuse (NIDA). This shows that discoveries and unlocking the secrets of the brain generally and with Alzheimer's disease specifically can come from a variety of sources. <https://www.nih.gov/news-events/lack-sleep-may-be-linked-risk-factor-alzheimers-disease>.

Since 2009, Cure Alzheimer's Fund has supported research into the impact of the lack of sleep, primarily at the laboratory of David Holtzman, M.D. at Washington University in St. Louis, MO. This research has led to a potential therapy target, orexin, a neurotransmitter that regulates aspects of sleep.

Dr. Holtzman has also received funding from NINDS for his research on sleep. Cure Alzheimer's Fund supported research, combined with NIH supported research, shows the power and importance of collaboration and public-private partnerships.

Another example of this public private partnership is the development of an amyloid balancing therapy resulting from research sponsored by Cure Alzheimer's Fund and adopted by NIA through its prestigious "Blue Print" program for drug development.

A third example is the growing understanding of the role that the innate immune system plays in the development of Alzheimer's disease. Research that was initially funded by Cure Alzheimer's Fund into the antibiotic role of beta amyloid in developing Alzheimer's disease is being highlighted and supported by NIH. <https://www.nih.gov/news-events/nih-research-matters/alzheimers-protein-may-havenatural-antibiotic-role>.

This innovative and varied research highlights the important roles played by private philanthropic organizations like Cure Alzheimer's Fund and public organizations such as NIH. Without both of these, and others focused on other aspects of therapeutic development, the goal established by the National Alzheimer's Project Act of effectively treating or preventing Alzheimer's disease by 2025 would not be possible. But with a sustained path of increasing investment by both private and public organizations, this goal is achievable.

Collaboration, cooperation, and coalescing within the Alzheimer's disease research community makes the National Alzheimer's Project Act goal achievable. Groups both public and private are working together to further unlock the secrets of Alzheimer's disease pathology.

Without sustained increases in Alzheimer's disease research, collaborative findings such as these would not be possible. Cure Alzheimer's Fund has more than tripled its research funding from 2014 to the end of 2017. This has led to validation of existing theories, as well as the development of new theories.

Because of early stage research funding provided by Cure Alzheimer's Fund, researchers are able to gain proof of concept and initial data. With this, researchers are then able to approach NIH for larger scale funding. Without an increase in NIH funding for Alzheimer's disease research, these new theories would not be able to be further reviewed to determine if they lead to a therapy for Alzheimer's disease.

One important area where collaboration among organizations is focused is the goal to detect Alzheimer's disease pathology earlier in the development of the disease. The Subcommittee is well aware of the numbers of people living with Alzheimer's disease and the cost to the system. The Alzheimer's Association estimates that 6.0 million people are currently living with Alzheimer's disease, and this number is expected to reach 13.8 million by 2050. It is currently costing the United States \$277 billion to care for people living with Alzheimer's disease, and this cost is expected to top \$1 trillion by 2050. Alzheimer's disease has the potential to bankrupt America.

It is believed that Alzheimer's disease pathology begins more than 20 years before symptoms begin to appear. Being able to detect this pathology early and begin to treat it will have enormous positive benefits for the healthcare system in reduced costs, as well as enormous benefits for patients and their families.

NIH is reviewing the 2011 diagnostic guidelines to determine if recent discoveries warrant a redefining of these guidelines. Any redefinition would be focused on helping direct both researchers and clinicians to better detect and diagnose Alzheimer's disease.

Cure Alzheimer's Fund is also working on this issue. The Cure Alzheimer's Fund Research Leadership Group recently heard a presentation from Ron Petersen, M.D. of the Mayo Clinic and former Chair of the National Alzheimer's Project Act Advisory Council on this subject. Cure Alzheimer's Fund is working with NINDS to determine how the two organizations can advance research in this area. Additionally, Cure Alzheimer's Fund will be meeting with NIA to discuss research into the biology of aging and how this can help to lead to a better understanding of Alzheimer's disease pathology. It is hoped that these discussions will lead to collaborative funding opportunities.

This type of collaboration is the path toward a cure. But, to remain on this forward path, there needs to be consistent and sustained funding from both private and public organizations. Cure Alzheimer's Fund is committed to this as evidenced by the tripling of its research budget since 2014. Since its inception in 2004, Cure Alzheimer's Fund has funded close to \$70 million, which has supported more than 100 researchers. These researchers have published more than 200 papers, which have been cited more than 12,000 times. This investment from Cure Alzheimer's Fund has been leveraged to more than \$59 in NIH funding for a total of close to \$130 million for Alzheimer's disease research. This has been possible because of the strong and continuing commitment to Alzheimer's disease research exhibited by this Subcommittee.

Cure Alzheimer's Fund thanks the Subcommittee for its long-standing commitment to increasing funding for Alzheimer's disease. Cure Alzheimer's Fund sees itself as a partner to NIH in Alzheimer's disease research, and the support of this Subcommittee has made that partnership more effective.

Thank you for the opportunity to submit this written testimony and to respectfully request at least an additional \$425 million above the final enacted level in fiscal year 2018 for fiscal year 2019 for Alzheimer's disease research at NIH. 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,

[This statement was submitted by Timothy Armour, President and CEO, Cure Alzheimer's Fund.]

PREPARED STATEMENT OF THE CYSTIC FIBROSIS FOUNDATION

On behalf of the Cystic Fibrosis Foundation and the approximately 30,000 people with cystic fibrosis (CF) in the United States, we submit the following testimony to the Senate Appropriations Committee's Subcommittee on Labor, Health and Human Services, Education, and Related Agencies on our funding requests for fiscal year 2019. We appreciate the successful bipartisan effort by Congress earlier this year to raise the budget caps and hope these higher numbers will allow the Committee to prioritize funding for the vital health programs described below. In particular, the Cystic Fibrosis Foundation requests:

- \$39.3 billion in funding for the National Institutes of Health (NIH) to support basic, translational, and clinical science as well as development of the next generation of researchers;
- \$15.65 million for the Centers for Disease Control and Prevention's (CDC) newborn screening program, in addition to increased support for the CDC's flu activities and antimicrobial resistance activities; and

—\$19.9 million for the Health Resources and Services Administration’s (HRSA) heritable disorders program, a \$2 million increase for the Division of Transplantation, and increased support for HRSA’s newborn screening program.

NATIONAL INSTITUTES OF HEALTH

NIH Supports Advances in CF through Cost-Efficient, Collaborative Research

As the Committee considers its funding priorities for the coming fiscal year, we urge consideration of the critical role that NIH plays in improving the lives of patients with cystic fibrosis and other rare diseases. Cystic fibrosis is a rare genetic disease that causes the body to produce thick mucus that clogs the lungs and other bodily systems, resulting in life-threatening infections, diabetes, malnutrition, and other medical complications. Incredible progress has been made in CF care and drug development over the last five decades. In the 1950’s, children with cystic fibrosis did not live to attend elementary school. Today people with CF are living into their 30’s, 40’s, and beyond. These advancements would not have been possible without the research supported by the NIH, and we request a funding level of at least \$39.3 billion for NIH in fiscal year 2019.

According to the NIH’s RePORT system, NIH devoted \$91 million to cystic fibrosis research in fiscal year 2017, and a strong funding partnership between NIH and the Cystic Fibrosis Foundation has enabled additional groundbreaking research and advances. The CF Foundation collaborates with the NIH to fund and organize initiatives at all stages of scientific investigation from basic and translational research to advancing new CF therapies to evaluation of existing methods of CF care and treatment. Providing funding for the NIH is an effective way to foster collaboration with external stakeholders, advance new treatments for CF, and apply lessons learned from CF drug development to bring new directions to research for other common disorders such as chronic obstructive pulmonary disease (COPD), pancreatic disorders, and infertility.

NIH Supports Vital Basic Research

Basic research funded by the NIH helps build foundational knowledge in cellular and molecular processes to help us improve our knowledge of the underlying cause and progression of diseases like CF. For example, researchers funded by the NIH and CFF at the University of Alabama Birmingham and Columbia University are using cryo-electron microscopy to better understand the structure and function of the cystic fibrosis transmembrane regulator (CFTR) proteins inside the body. Work like this is critical to understanding the underlying cause of CF and may lead in the future to new targeted treatments for this devastating rare disease.

NIH and CFF are also collaborating to tackle basic research on some of the most complex barriers to advancing gene editing technology as a CF therapy. Use of these new tools is especially difficult in cystic fibrosis because the buildup of sticky mucus in the lungs of those with CF can prevent delivery of potential gene editing treatments through traditional methods. Earlier this year the National Heart Lung and Blood Institute held a joint workshop with the CF Foundation to convene researchers for a discussion on the development and evaluation of viable gene delivery technologies in those with CF, and promising research is ongoing in this area.

Advancing Translational Science

NIH funding for translational research tools supports the development of new therapies for rare diseases like cystic fibrosis. Between 2010 and 2016, NIH supported research that contributed to 210 new FDA-approved drugs, vaccines, and new indications for current drugs.¹ To continue this important work, the Foundation requests robust funding for NIH’s National Center for Advancing Translational Sciences (NCATS), which catalyzes innovation by improving the diagnostics and therapeutics development process and removing obstacles to translating basic scientific research into treatments.

The specific programs housed in NCATS are integral to this mission, including the Clinical and Translational Science Awards (CTSA), the Cures Acceleration Network (CAN), and the Therapeutics for Rare and Neglected Diseases (TRND) program. Such initiatives transform the way in which clinical and translational research is conducted and funded. NIH Director Dr. Francis Collins has cited the CF Foundation supported Therapeutics Development Network (TDN), a CF-dedicated clinical trials network, as a model for TRND’s innovative therapeutics development model.

¹Cleary, Ekaterina Galkina, Jennifer M. Beierlein, Navleen Surjit Khanuja, Laura M. McNamee, and Fred D. Ledley. “Contribution of NIH funding to new drug approvals 2010–2016.” *Proceedings of the National Academy of Sciences* 115, no. 10 (2018): 2329–2334.

The Foundation also urges additional funding for the Cystic Fibrosis Research & Translation Centers (CFRTCs), which provide support for basic, preclinical, and clinical research efforts to advance scientific knowledge and new therapies for CF at seven centers across the country. CFRTCs are cost-efficient, providing shared resources and facilities to enhance collaboration and multi-disciplinary work in cystic fibrosis. NIDDK provides funding for the CFRTCs through P30 Center Core grants, which the CF Foundation is able to further support by providing grants for individual CF researchers at the Centers. Funding increases at NIH in recent fiscal years have provided critical support to these programs, and momentum must continue so large centers can continue research programs and maintain their infrastructure and promote funding certainty for small-operation CF research programs, which play an instrumental role in recruiting new investigators into CF research.

Animal models are also an important, NIH-supported tool for understanding disease progression and identifying potential new treatments for CF and other rare diseases. The National Swine Resource and Research Center (NSRRC), funded by the NIH and hosted at the University of Missouri-Columbia, provides services to develop swine models of many genetic conditions, like cystic fibrosis, in order to facilitate research and drug development for these diseases. NIH and the CF Foundation also jointly fund a research program at the University of Iowa to study the effects of CF in a ferret model, and the University of Alabama at Birmingham has used joint funding to develop multiple CF rat models to examine methods for studying basic mechanisms and treatment of the disease. These programs are yielding fundamental new insights to help advance developments in the search for life-changing treatments for CF.

Improving Clinical Care

Research in dissemination and implementation science that focuses on integrating scientific findings and effective clinical practice into real-world settings is crucial to providing the best possible care to those with CF and other conditions. NIH also provides support for advancing optimal care and treatment use for those with CF. The OPTIMIZE study, which receives joint funding from the NIH and the CF Foundation, has brought together hospital systems in nearly 30 States to compare the effectiveness of combining antibiotic treatments for lung infections in those with cystic fibrosis. Findings from this initiative could help advance quality care for those with CF and improve our understanding of effective use of these therapies in specialized CF care centers.

Supporting the Next Generation of Researchers

We strongly urge the Committee to provide robust resources for the NIH to address challenges in recruiting and retaining a strong scientific workforce. It is difficult to recruit scientists into rare disease research, especially in pediatric subspecialties. Robust funding for programs like the K awards, which support early-career investigators, are critical to attracting and retaining a strong scientific workforce. Supporting junior investigators, especially those who specialize in rare diseases and pediatric subspecialties is a crucial element in the fight to find a cure for CF and countless other diseases for which there are not adequate treatment options.

Consistent, Robust Funding for NIH is Critical for American Research

We appreciate the \$3 billion funding increase provided to NIH in fiscal year 2018. However, NIH has not yet overcome the devastating and lasting effects of many years of sequestration and stagnant funding on American research labs both at intramural and extramural research institutions. Funding success rates for all investigators remain below sustainable levels, and promising young investigators struggle to obtain sufficient funding to remain in their respective fields. Recent increases in funding have helped to mitigate the after effects of stagnant funding, but this growth must continue.

Further, NIH is an important driver of the U.S. economy, providing over 400,000 jobs and nearly \$69 billion of economic output in fiscal year 2017.² Increased investment in biomedical research can provide even greater economic benefit and support for the scientific progress that makes the United States the international leader in biomedical research.

²New Data Shows Economic Impact of NIH Research Funding in 50 States DC." United for Medical Research. February 8, 2018. <http://www.unitedformedicalresearch.com/new-data-shows-economic-impact-of-nih-research-funding-in-50-states-dc/#.Ws9WhogbOUk>.

CENTERS FOR DISEASE CONTROL AND PREVENTION

The Centers for Disease Control and Prevention (CDC) plays an important role in helping individuals with CF live longer, healthier lives. Particularly, we ask you to give special consideration to CDC's role in the facilitation of newborn screening to detect congenital disorders, in addition to the CDC's work on antibiotic resistance and flu.

In 2016, 62.4 percent of new CF diagnoses were detected through newborn screening, and there is evidence that individuals diagnosed early-on, prior to the onset of symptoms, have better lung function and nutritional outcomes later in life. The earlier a child is diagnosed with CF, the sooner their families and clinicians can develop a treatment plan that includes airway clearance techniques, nutritional therapies and medicines that may significantly reduce cumulative damage caused by the disease. Funding for newborn screening programs from this committee has done a tremendous amount for State-based programs. However, more can be done to improve this critical public health function.

In particular, the Foundation urges the Committee to provide \$15.65 million (an increase of \$6 million) in funding to the CDC's newborn screening program, which is responsible for strengthening and enhancing laboratory quality assurance programs; enabling public health laboratories to develop and refine screening tests; conducting pilot studies; implementing new methods to improve detection of treatable disorders; and enhancing newborn disorder detection through the Newborn Screening Quality Assurance Program.

The CF Foundation also calls upon the Committee to further support the efforts of the CDC in combating antimicrobial resistance. People with CF are subject to frequent and chronic lung infections, which are the leading cause of morbidity and mortality for the disease. To combat chronic lung infections, many people with CF take antibiotics as part of their daily treatment regimen. Because people with CF are more susceptible to lung infections, the upsurge of antibiotic resistance is of the utmost concern. The work of the CDC to prevent the spread of antibiotic resistant organisms through improving antibiotic prescribing and stewardship, tracking resistance patterns, promoting immunization, and developing new antibiotics is critical in maintaining the health of those with CF. Through a broad agency announcement, the CDC is also funding a project examining how to optimize therapeutic strategies to manage polymicrobial CF lung infections. We hope the Committee will prioritize funding for CDC's activities so this and other important work can continue in fiscal year 2019.

Additionally, the CDC plays an important role in protecting the safety of the public through controlling and preventing infectious diseases. For example, the CDC is a key player in the development and nationwide distribution of flu vaccinations as well as in flu surveillance. People with CF are especially susceptible to contracting the flu and, in some cases, the virus can become life-threatening and lead to lengthy hospital stays. Because of the severity of the flu in the CF community, we appreciate the collaborative work of the Department of Health and Human Services, including at NIH, CDC, ASPR and FDA to prepare for and seek to minimize the morbidity and mortality of the flu virus every year. It is also imperative that HHS receives the funding necessary to develop a more effective and modern universal flu vaccine.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

We also encourage the Committee to provide \$19.9 million (an increase of \$6 million) for HRSA's heritable disorders program, which evaluates the effectiveness of newborn screening and follow-up programs and provides grants for programs to support other critical aspects of newborn screening. Additionally, within HRSA, we encourage strong support for the Title V Maternal and Child Health Services Block Grants program, which provides flexible funding for States to support programs that provide access to quality care for low-income and underserved people and create systems of coordinated care for children with special healthcare needs. In many States, these grants enable the provision of comprehensive newborn screening education, services, and follow up.

Additionally, the CF Foundation appreciates the \$2 million increase in funding for the Division of Transplantation within HRSA in fiscal year 2018 and urges the Committee to continue robust funding for the program in fiscal year 2019. Cystic fibrosis is a degenerative disease that can cause severe damage and ultimately failure of the lungs. Those with CF who experience extensive lung damage may consider transplant as a way to regain critical lung function and continue living full, productive lives. In 2016, 1,642 individuals in the CF patient registry identified as

receiving a lung, kidney, heart, or liver transplant with an additional 151 individuals who are approved candidates for transplant but are on the waiting list.

The oversight HRSA provides to the transplant network through operation of the United Network for Organ Sharing (UNOS) is crucial in promoting the safety and efficacy of organ transplantation. In recent years, the CF Foundation has seen a marked increase in the need for donor lungs in our patient community. To address this need, we created a lung transplant initiative in 2016 which offers education and support services for CF patients seeking a lung transplant. However, we believe that permanent changes to the geographic allocation of donor lungs are needed to deliver lungs to the patients who need transplants the most. To support this and other critical work at UNOS, we ask the Committee to provide robust funding for the Division of Transplantation in fiscal year 2019.

This is a time of great hope and optimism for the CF community and those with other rare diseases, as more research is being conducted to treat these life-threatening conditions. We urge you to provide at least \$39.3 billion for the National Institutes of Health as well as robust funding for other relevant agencies to support healthcare quality research and newborn screening. We stand ready to work with the Committee and Congressional leaders on the challenges ahead. Thank you for your consideration.

Sincerely,

[This statement was submitted by Preston W. Campbell, III, MD., President and CEO, Cystic Fibrosis Foundation.]

PREPARED STATEMENT OF THE DAVE THOMAS FOUNDATION FOR ADOPTION

The Dave Thomas Foundation for Adoption offers the following testimony requesting increased funds for the following six programs under the supervision of the Administration for Children and Families (ACF): Child Welfare Services (CWS), Promoting Safe and Stable Families, the Adoption and Kinship Incentives Fund, the Adoption Opportunities Act, the Child Abuse Prevention Treatment Act State grants and the Community-Based Child Abuse Prevention program.

In February, Congress passed the Family First Prevention Services Act (P.L. 115–123). The legislation has potential to expand services that can prevent the placement of children into foster care. It challenges States to reduce the number of children and youth in congregate placements. It will be a challenge to States to build the capacity and access to services (mental health, substance use, and in-home services) and to build the infrastructure of services and providers.

The challenge is against a backdrop of ever increasing foster care numbers driven by the opioid epidemic in parts of the country. Since 2012, the number of children in foster care has increased by 10 percent to 437,000 in 2016. Dave Thomas Foundation for Adoption believes it is critical for Congress to fully fund six programs to both build capacity to effectively implement the Family First Act, and help address the crisis many communities are facing as foster care placement demands explode.

The Family First Act provides funding for services to prevent the placement of children in foster care but does not fund services to prevent child abuse and neglect. Child welfare strategy must significantly increase funding for child abuse prevention. We urge appropriators to focus more attention on primary prevention through the Child Abuse Prevention and Treatment Act (CAPTA) and the Community-Based Child Abuse and Neglect Prevention (CB–CAP) program.

Dave Thomas Foundation for Adoption calls on Congress to fully fund Child Welfare Services from \$269 million to \$325 million and Promoting Safe and Stable Families from \$99 million in discretionary funding to \$200 million; increase funding to the Adoption Opportunities Act to \$60 million; fully fund the Adoption and Kinship Incentives Fund at \$75 million; fund the Child Abuse Prevention and Treatment Act (CAPTA) at \$120 million in State grants and double the funding of Community-Based Grants for the Prevention of Child Abuse and Neglect/CB–CAP at \$80 million.

Impact of Opioids on Child Abuse and Neglect and Foster Care

Earlier this year HHS, through the Secretary of Planning and Evaluation, conducted an analysis of child welfare data and supplemented that work with field level research. Some of the key findings included:

—A 10 percent increase in overdose death rates correspond to a 4.4 percent increase in the foster care entry rate and a 10 percent increase in the hospitaliza-

tion rate due to drug use corresponds to a 3.3 percent increase in the foster care entry rate.

- While during past drug epidemics family and communities could fill some of the gaps, today agencies report that family members across generations may be experiencing substance use problems, forcing greater reliance on State custody and non-relative care.
- Parents using substances have multiple problems including domestic violence, mental illness, trauma history; addressing substance abuse alone is unlikely to be effective.
- Substance use assessment is haphazard and there is a lack of “family-friendly” treatment that includes family therapy, child care, parenting classes and developmental services.
- There is a shortage of foster homes and this is exacerbated by the need to keep children in care longer, which keeps existing homes full and unable to accept new placements.

PREVENTING CHILD MALTREATMENT

The Child Abuse Prevention and Treatment Act (CAPTA) State Grants

Investing in prevention is less costly to society and the government than trying to treat problems later. Successful prevention of child maltreatment means better outcomes for children and can prevent the need for future intervention services or foster care.

We are pleased with the 2018 \$60 million increase for CAPTA to \$85 million. As Congress looks to implement CAPTA provisions for plans of safe care, we ask the Committee to appropriate a full \$120 million for CAPTA State grants. The Family First Act provides important intervention services to prevent foster care placements. It is the role of CAPTA and CB-CAP to fund the prevention of child abuse.

The 1974 Child Abuse Prevention and Treatment Act (CAPTA) has helped establish national standards for reporting and response practices for States to include in their child protection laws. CAPTA is the only Federal legislation exclusively dedicated to preventing, assessing, identifying, and treating child abuse and neglect. Successful prevention means better outcomes for children and can prevent the need for intervention services such as foster care.

According to Prevent Child Abuse America (PCA), child abuse and neglect affects over one million children each year. Child abuse and neglect costs our Nation \$220 million every day through increased investigations, foster care, healthcare costs, and behavioral health costs and treatment. Additional costs may include special education, juvenile and adult crime, chronic health problems, and other costs in a life span. According to PCA, we paid \$80 billion to address child abuse and neglect in 2012. Funding CAPTA State grants beyond the small allocation of \$25 million in recent years can help develop greater accountability and a stronger continuum of child prevention and child protection.

The Community-Based Grants for the Prevention of Child Abuse and Neglect (CB-CAP)

Another key prevention program is the Community-Based Grants for the Prevention of Child Abuse and Neglect (CB-CAP), which provides funds to States to support, develop, operate, and expand a network of community-based, prevention-focused family support programs. Funds coordinate family resources among a range of local public and private organizations.

Dave Thomas Foundation for Adoption asks for a doubling of funds from \$40 million to \$80 million. The advantage of this increase is that it is community-based, it is targeted to prevention and it is designed to leverage outside sources of funding. 70 percent of funding is allocated to States based on child population and 30 percent is based on leveraged State, Federal and private funds. The minimum grant award is \$200,000 and States must meet minimum 20 percent cash match (not in-kind).

In 2016, the National Resource Center for CB-CAP funded activities covered more than 295,000 adults and caregivers as well as 289,000 children and 200,000 families, including those with disabilities. Over 29.4 million families were reached through public awareness activities funded by CB-CAP. These services included 21,697 parents and 19,710 children with disabilities.

Each State application must describe actions the lead agency (frequently a Children’s Prevention Trust Fund) will take to advocate systemic changes in State policies, practices, procedures and regulations to improve the delivery of community-based child abuse and neglect prevention programs and activities designed to strengthen and support families to prevent child abuse. Some of the recent work includes: 22 States working with tribes or tribal organizations, 14 States working on

human trafficking initiatives, 43 States providing outreach and/or local programs to rural populations, and 33 States using CB-CAP funds for fatherhood initiatives and programs.

A doubling of funding will support a significant expansion in the number of children and families served. More States might be able to move toward a comprehensive service system, particularly where family needs are more challenging, complex and complicated. Small States that have low child populations and, as a result, receiving the lowest amounts from CB-CAP, would likely be able to increase their ability to provide services that would show greater impact.

This doubling of funding could also assist in addressing a need for CB-CAP State lead agencies to evaluate their efforts to know what is working, to refine and adjust services as needed and to ensure their services are the best fit for their population. In addition to supporting proven effective strategies, it has always been the role of CB-CAP lead agencies to identify, assess and fund emerging, innovative ideas and to evaluate them to determine whether continued funding is warranted. This will help in the development of programs to be replicated in Family First.

FAMILY FIRST ACT

In fiscal year 2020, Families First will allow States to draw funds for children and families at risk of foster care. States taking the optional services will be limited to evidence-based services for families that need intervention, post-adoption, and reunification services. States must engage in and coordinate public-private agencies experienced with providing child and family community-based services, including mental health, substance use, and public health providers. There is a limited supply of foster homes and family-based aftercare support that can provide for post-discharge services for children leaving institutional care. Child welfare agencies need to find and support more family-based foster care homes. These four funds can help States develop evidence-based services that will meet the “well-supported,” “supported,” and “promising” standards of the law and can assist in the coordination of community-based behavioral health and human services.

Child Welfare Services (CWS), Title IV-B part 1

We ask for \$325 million for Child Welfare Services, the full authorization and above the current total of \$269 million. Starting in fiscal year 2020, the Families First Act will allow States to draw funds for children and families at risk of foster care. CWS is flexible enough to allow States to test out and develop these services and provide the research required to meet the evidence standards.

Promoting Safe and Stable Families (PSSF), Title IV-B part 2

We also asking for full funding of \$200 million for Promoting Safe and Stable Families. Currently this appropriations is set at \$99 million despite being authorized at \$200 million. These funds supplement \$345 million in mandatory funds divided between services, the courts, substance use treatment grants and workforce development. Appropriations to \$200 million could be used for the four key services under PSSF: family reunification, adoption support, family preservation and family support. There are limited services for reunification services for children who return to their families and the same is true of post adoption services. These will all be eligible services under Family First but there are few models now eligible for funding.

The Adoption Opportunities Act

The Adoption Opportunities program is the Nation’s oldest adoption program created to develop adoption promotion, post adoption services and strategies. It has funded grants to reduce barriers to adoption, reduce disproportionality, and more recently to promote adoptions of older youth in foster care and develop post-adoption services. It is funded at \$39 million. We ask for funding at \$60 million to develop evidence-based models for post-adoption services to families.

The Adoption and Kinship Incentive Fund

We ask for a continued funding level of \$75 million for the adoption incentive fund. The fund was created in the Adoption and Safe Families Act (ASFA). In 2014, it became the Adoption and Legal Guardianship Incentive Payments Program. We thank the Appropriations Committee for partially addressing a recent shortfall in this incentive fund with the 2018 appropriations of \$75 million. In recent years HHS has been not been able to fully award States because of a reduced appropriation. As a result, HHS has made up the previous year’s shortfall with the following year’s appropriations. The \$75 million for fiscal year 2018 was a significant step in addressing the shortfall of 2017. In the beginning years Congress would recognize

this and provide an extra amount of appropriation. The 2018 appropriation reestablished this practice. When HHS issues the latest awards for fiscal year 2018 in September, there will be \$25 million remaining. That will likely fall short to fully fund the incentives, so we would ask for an appropriation of \$75 million to fully fund 2018 awards and have enough in place for fiscal year 2019.

These funds are reinvested by States into adoption services and can be used to build evidence-based adoption services and include post-adoption counseling and services that can prevent and reduce adoption disruption.

Thank you for your consideration of this testimony; the Dave Thomas Foundation for Adoption stands ready to respond to your questions and concerns.

[This statement was submitted by Rita Soronen, President & CEO, Dave Thomas Foundation for Adoption.]

PREPARED STATEMENT OF THE DEADLIEST CANCERS COALITION

The Deadliest Cancers Coalition is a collaboration of national nonprofit organizations focused on addressing issues related to our Nation’s most lethal cancers, which were defined in the Recalcitrant Cancer Research Act (Public Law 112–239) as those with a 5-year relative survival rate below 50 percent. While any cancer with a survival rate below 50 percent is considered part of this group, it is notable that the definition currently includes seven site-specific cancers: brain, esophageal, liver, lung, ovarian, pancreatic, and stomach. We appreciate the opportunity to submit this statement in support of strengthening the Federal investment in deadliest cancers research conducted and supported by the National Institutes of Health (NIH) and the National Cancer Institute (NCI).

We deeply appreciate the Subcommittee’s leadership in securing the \$3 billion increase for the NIH in the fiscal year 2018 Omnibus Appropriations bill, which brought their funding level to \$37.084 billion and provided \$5.965 billion for the NCI. For fiscal year 2019, the Deadliest Cancers Coalition respectfully requests that NIH receives \$39.3 billion, including funding provided through the 21st Century Cures Act, and \$6.375 billion for the NCI.

The deadliest cancers offer a powerful example of the need for continuing the path you started in fiscal year 2016 of providing significant increases for the NIH and NCI. Critical progress has been made, thanks in part to the funding increases, and yet we are still far short of our goal of significantly improving survival.

This year, the coalition is marking the 10th anniversary of our founding. We have made some important progress in the last 10 years, most notably, the 5-year survival rates have increased at least slightly for most of the deadliest cancers. While the increases have been relatively small (in the range of 2 to 7 percent), they represent important progress as each percentage point increase represents thousands of patients who get to live longer than they would have 10 years ago. Further, myeloma, which was considered one of the deadliest cancers in 2008 with a 5-year survival rate of 34 percent, “graduated” out of the deadliest cancers definition in 2016 and now has a 5-year survival rate of 51 percent. These are successes worth celebrating, but it is critical to remember that the 5-year survival rate for all of these cancers is far below average as the 5-year survival rate for all cancers combined is now 67 percent.

Five Year Survival Rates for the Deadliest Cancers Compared to the Overall Cancer Survival Rate (2008–2018):

| | Est. 2018 5-year Survival Rates | Est. 2008 5-year Survival Rates |
|-------------------|---------------------------------|---------------------------------|
| Brain | 35% | 35% |
| Esophageal | 19% | 16% |
| Liver | 18% | 11% |
| Lung | 18% | 15% |
| Myeloma | 51% | 34% |
| Ovarian | 47% | 45% |
| Pancreas | 9% | 5% |
| Stomach | 31% | 24% |
| ALL CANCERS | 67% | 66% |

It is worth noting that over the last decade, NCI funding has also increased for most of the deadliest cancers. There has been a 33 percent increase in overall funding for the deadliest cancers since fiscal year 2007, from \$634 million to \$841 million in fiscal year 2016, the latest year that is available on NCI’s Funded Research

Portfolio (NFRP). While we applaud the upward trend of funding, the low survival rates show that continued partnership between NCI and the research/patient community is critical to developing the new treatments and early detection tools that are so desperately needed by patients with one of the deadliest cancers.

NCI has taken important steps to address some of these cancers since the passage of the Recalcitrant Cancer Research Act in 2012. However, there is still a great deal of advancement that needs to be made. It is therefore vital that Congress not only provide sufficient funding for the NCI, but also continue to shine a light on these cancers so that they do not slip back into the shadows. The Deadliest Cancers Coalition has submitted report language to Subcommittee that we believe will help our members have more productive conversations and collaboration with NCI to determine ways in which we can work together to improve survival.

In addition to the need to continue the fight on the Nation's deadliest cancers, robust increases for NCI are also needed to fill the gap left after many years of flat funding. Even with the recent increases, NCI purchasing power is still 16 percent below 2003 levels. Further, while we know that NIH research supports more than 400,000 jobs and nearly \$69 billion in economic activity across the United States, the NIH budget currently represents less than 1 percent of the Federal budget. We encourage you to continue the robust increases for NIH and NCI so that we can not only increase the number of lives that are saved, but also continue to reap the economic rewards that NIH supported research offers to our communities.

The Deadliest Cancers Coalition was founded because we believe that every patient diagnosed with cancer should have at least a 50 percent chance shot at survival. Unfortunately, in 2018, nearly half of all cancer-related deaths will be due to one of the deadliest cancers—a statistic that is largely unchanged since we were founded. We clearly still have a long road ahead of us to see more cancers “graduate” out of being considered a recalcitrant cancer. We therefore urge the Subcommittee to continue its leadership to ensure that NIH receives \$39.3 billion for fiscal year 2019, including funding provided through the 21st Century Cures Act, and \$6.375 billion for the NCI and that you continue to shine a light on these cancers through report language.

The Deadliest Cancers Coalition:

| | |
|--|--|
| American Association for the Study of Liver Diseases | Digestive Disease National Coalition |
| American Gastroenterological Association | Esophageal Cancer Action Network |
| American Liver Foundation | Hepatitis B Foundation |
| American Society for Gastrointestinal Endoscopy | Lung Cancer Alliance |
| Asbestos Disease Awareness Organization | Mesothelioma Applied Research Foundation |
| Blue Faery: The Adrienne Wilson Liver Cancer Association | National Brain Tumor Society |
| Debbie's Dream Foundation: Curing Stomach Cancer | National Pancreas Foundation |
| | Ovarian Cancer Research Fund Alliance |
| | Pancreatic Cancer Action Network |
| | Society of Gynecologic Oncology |
| | TargetCancer Foundation |

PREPARED STATEMENT OF THE DIGESTIVE DISEASE NATIONAL COALITION

THE COALITION'S FISCAL YEAR 2019 L-HHS APPROPRIATIONS RECOMMENDATIONS

-
- \$8.445 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.
 - \$50 million for Colorectal Cancer Prevention.
 - \$1 million for Inflammatory Bowel Disease.
 - \$134 million for the Division of Viral Hepatitis.
 - At least \$39.3 billion in program level funding for the National Institutes of Health (NIH).
 - \$2.28 billion for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

Chairman Blunt, Ranking Member Murray, and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of

the digestive disease community. As you work to craft the fiscal year 2019 L–HHS Appropriations Bill, we hope you will support proportional funding increases for the National Institutes of Health and the Centers for Disease Control and Prevention.

ABOUT THE COALITION

The Digestive Disease National Coalition (DDNC) is an advocacy organization comprised of the major national voluntary and professional societies concerned with digestive diseases. DDNC focuses on improving public policy and increasing public awareness with respect to diseases of the digestive system. DDNC's mission is to work cooperatively to improve access to and the quality of digestive disease healthcare in order to promote the best possible medical outcome and quality of life for current and future patients.

ABOUT DIGESTIVE DISEASES

Digestive diseases are disorders of the digestive tract, which includes the esophagus, stomach, small and large intestines, liver, pancreas, and the gallbladder; as such, these diseases range from digestive cancers to functional GI and motility disorders, and everything in between. Some of these diseases are classified as acute, as they occur over a short period of time, while others are chronic, life-long conditions. 60 to 70 million Americans are affected by these diseases, accounting for 21.7 million hospitalizations and \$141.8 billion in healthcare costs.

CENTERS FOR DISEASE CONTROL AND PREVENTION

DDNC joins the public health community in asking Congress to provide the Centers for Disease Control and Prevention (CDC) with \$8.445 billion through fiscal year 2019, which includes budget authority, the Prevention and Public Health Fund, Public Health and Social Services Emergency Fund, and PHS Evaluation transfers. The CDC houses several important programs related to digestive diseases, including colorectal cancer, inflammatory bowel disease (IBD), and viral hepatitis.

The Colorectal Cancer Control Program (CRCCP) helps States and tribes across the United States increase colorectal cancer screening rates among men and women aged 50 years and older, and an increase in these screenings will reduce illness and death from this cancer. Currently, the CRCCP funds 23 States, 6 universities, and one American Indian tribe. A proportional increase in funding will ensure that more vulnerable communities across the U.S. will gain the resources necessary to adhere to regular colorectal cancer screening.

The CDC has led an epidemiological study of IBD to understand incidence, prevalence, demographics, and healthcare utilization. The study's goal is to learn more about the causes of IBD in order to improve care and target interventions. A modest increase in funding will allow CDC to improve treatments and diagnostics for patients with IBD, including Crohn's disease and ulcerative colitis.

The Division of Viral Hepatitis (DVH), in collaboration with domestic and global partners, provides the scientific and programmatic foundation and leadership for the prevention and control of hepatitis virus infections and their manifestations. Its three branches, Epidemiology and Surveillance, Prevention, and Laboratory, work to prevent viral hepatitis infections and associated liver disease. Increases in funding for DVH will allow the Division to achieve the imperatives, objectives, and strategies outlined in its 5-year strategic plan to decrease disease incidence, morbidity and mortality, and health disparities.

NATIONAL INSTITUTES OF HEALTH

DDNC joins the broader medical research community in thanking Congress for providing a \$3 billion funding increase for NIH for fiscal year 2018 and in requesting at least a subsequent \$2 billion funding increase for fiscal year 2019 to bring NIH's budget up to \$39.3 billion, which is consistent with the necessary level of funding identified through the 21st Century Cures Act. 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. In this regard, please also provide a proportional increase of \$2.28 billion for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) for fiscal year 2019. NIDDK supports basic, translational, and clinical research into various diseases such as inflammatory bowel disease (IBD), pancreatic cancer, gastroparesis, and others. This federally-funded research often serves as a catalyst with industry turning medical breakthroughs and scientific advancements into innovative therapies and cutting-edge diagnostic tools.

Thank you for the opportunity to testify before your committee and for your time and consideration of our requests.

[This statement was submitted by Dr. Ralph Mckibbin, MD, President, Digestive Disease National Coalition.]

PREPARED STATEMENT OF THE DYSTONIA MEDICAL RESEARCH FOUNDATION
SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2019

- Provide \$39.3 billion for the National Institutes of Health (NIH) and proportional increases across its Institutes and Centers
 - Continue dystonia research supported by NIH through the National Institute on Neurological Disorders and Stroke (NINDS), the National Institute on Deafness and other Communication Disorders (NIDCD), and the National Eye Institute (NEI).
-

Dystonia is a neurological movement disorder characterized by involuntary muscle spasms that cause the body to twist, repetitively jerk, and sustain postural deformities. Focal dystonia affects specific parts of the body, while generalized dystonia affects multiple parts of the body at the same time. Some forms of dystonia are genetic but dystonia can also be caused by injury or illness. Although dystonia is a chronic and progressive disease, it does not impact cognition, intelligence, or shorten a person's life span. Conservative estimates indicate that between 300,000 and 500,000 individuals suffer from some form of dystonia in North America alone. Dystonia does not discriminate, affecting all demographic groups. There is no known cure for dystonia and treatment options remain limited.

Although little is known regarding the causes and onset of dystonia, two therapies have been developed that have demonstrated a great benefit to patients and have been particularly useful for controlling patient symptoms. Botulinum toxin (e.g., Botox, Xeomin, Disport and Myobloc) injections and deep brain stimulation have shown varying degrees of success alleviating dystonia symptoms. Until a cure is discovered, the development of management therapies such as these remains vital, and more research is needed to fully understand the onset and progression of the disease in order to better treat patients.

DYSTONIA RESEARCH AT THE NATIONAL INSTITUTES OF HEALTH

The Dystonia Medical Research Foundation urges the Subcommittee to continue its support for natural history studies on dystonia that will advance the pace of clinical and translational research to find better treatments and a cure. In addition, we encourage Congress to continue supporting NINDS, NIDCD, and NEI in conducting and expanding critical research on dystonia.

Currently, dystonia research at NIH is supported by the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute on Deafness and Other Communication Disorders (NIDCD), and the National Eye Institute (NEI).

The majority of dystonia research at NIH is supported by NINDS. NINDS has utilized a number of funding mechanisms in recent years to study the causes and mechanisms of dystonia. These grants cover a wide range of research including the genetics and genomics of dystonia, the development of animal models of primary and secondary dystonia, molecular and cellular studies in inherited forms of dystonia, epidemiology studies, and brain imaging. We are continuing our conversations with the leadership of NINDS regarding a State of the Science conference that will bring together researchers and stakeholders from around the country to discuss the critical needs in researching dystonia. We were pleased to see Congress has directed NINDS to continue discussions about this important opportunity to advance research and we look forward to continuing our discussions with NINDS to facilitate a conference.

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 \$3 billion increase for NIH in fiscal year 2018. We know firsthand that this will further NIH's ability to fund meaningful research that benefits our patients.

Patient Perspectives

My dystonia first presented when I was about 8 years old and my parents took me to many, many doctors. My foot and leg would turn in when I tried to walk—making walking very difficult. The kids at school would tease me and called me names like “mental foot”. When I couldn't explain it, they teased me more. Finally, at the age of 12 the diagnosis of dystonia was made. I have the genetic form of dystonia—DYT1 dystonia that is generalized and commonly affects children between the ages of 8 to 15. For me, dystonia spread from my left foot to both legs, my arms and my back. When I walked, my back would arch and put a lot of pressure on the bottom of my spine which was pretty painful. My legs were very tight. My right foot started to turn in and that put pressure on my ankle when I walked. My right arm was very tight, so when I had to write it was painful. I decided to pursue Deep Brain Stimulation for my dystonia when it became too painful to walk with my son to the park that was around the corner from our house. The results have been life-changing. My wife and sons now have a husband and father who, despite having dystonia, is physically able to be active and a part of their lives. It isn't a cure but a treatment that really worked for me. We need NIH to support dystonia research so we can advance our understanding of dystonia and have all affected by dystonia have the chance for a full and productive life.

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.

Dystonia has no cure. Botox injections offer temporary relief for some, but limited insurance coverage after deductibles is an enormous financial burden, costing thousands of dollars. Health Care reform that denies pre-existing conditions will force me to discontinue treatment. As one of hundreds of thousands of Dystonia sufferers, I ask Congress to fund NIH research.

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 I am having trouble with my voice, it is difficult for others to understand me. As a middle school math teacher, students and parents depend on me to speak loudly and clearly. I have had to step down and enlist a substitute to take my place when I cannot communicate well. During these periods, I even have trouble with everyday tasks and interactions and have to write notes and use gestures when I talk with others. I receive injections of botulinum toxin into my vocal cords every 3 months for temporary relief of symptoms. This has worked well for me for over a decade. At the start of this year, my insurance coverage changed when my husband's company changed providers. As a result, I had to undergo an extensive review process and change methods for obtaining my medicine. The review lasted for four weeks. Multiple times during this time period, my doctor and I were told that I had been denied coverage. We had to make numerous phone calls to encourage the company and specialty pharmacy to review my case again and again. These phone calls were extremely difficult as my voice deteriorated from the delay in treatment. The automated phone systems were the worst, but the representatives also had trouble understanding my broken voice and I had to repeat my information over and over. Finally, the company determined my treatment is medically necessary and has approved it for 1 year. After a seven week delay, I am scheduled for my injection and am looking forward to a period of spasm-free speaking.

DMRF was founded in 1976. Since its inception, the goals of DMRF have remained to advance research for more effective treatments of dystonia and ultimately find a cure; to promote awareness and education; and support the needs and wellbeing of affected individuals and their families.

Thank you for the opportunity to present the views of the dystonia community, we look forward to providing any additional information.

[This statement was submitted by Janet Hieshetter, Executive Director, Dystonia Medical Research Foundation.]

PREPARED STATEMENT OF THE EDUCATION TRUST

On behalf of The Education Trust, an organization dedicated to closing long-standing gaps in opportunity and achievement separating low-income students and students of color from their peers, thank you for the opportunity to present testimony on the fiscal year 2019 Labor, Health and Human Services, Education and Related Agencies Appropriations bill. While there are many programs under your jurisdiction that are critical to advancing equity, for fiscal year 2019, The Education Trust is focused on two: strengthening the Pell Grant program by increasing the maximum award to at least \$6,230 and lifting the ban on Pell eligibility for students who are incarcerated; and supporting teachers and school leaders by level funding ESSA's Title II–A (\$2.055B), the Teacher and School Leader Incentive Program (\$200 million), the Supporting Effective Educator Development Program (\$75 million) and restoring funding to the School Leader Recruitment and Support Program (\$14.5M).

STRENGTHENING THE PELL GRANT PROGRAM

The Pell Grant program is the cornerstone of Federal financial aid. Created in 1972 as the Basic Educational Opportunity Grant, the program now benefits over 7.5 million students and continues to serve as the primary Federal effort to open the door to college for low-income students. Over one-third of White students, two-thirds of Black students, and half of Latino students rely on Pell Grants every year.¹ Pell Grant dollars are well-targeted to those in need: 83 percent of Pell recipients come from families with annual incomes at or below \$40,000, including 44 percent with annual family incomes at or below \$15,000.²

Increasing the Maximum Award

The Pell Grant program's impact is shrinking as the maximum award has failed to keep pace with the rapidly rising cost of college. The purchasing power of the Pell Grant has dropped dramatically since the program's inception. In 1980, the maximum Pell Grant award covered 76 percent of the cost of attendance at a public university. Today, it covers just over 29 percent, the lowest portion in over 40 years. The purchasing power of Pell will further decrease with the expiration of automatic inflation adjustments at the end of the 2017–18 award year. If the maximum award continues to be frozen at its current level, the grant will cover just one-fifth of college costs in 10 years.

We very much appreciate the \$175 increase in the maximum award in the fiscal year 2018 omnibus appropriations bill, and we respectfully request that you continue to increase the maximum award amount. For fiscal year 2019, the maximum award should be increased to at least \$6,230 to continue to keep pace with inflation. We also ask Congress to restore the mandatory adjustment for inflation and set an ambitious plan to reverse the downward trend of Pell's purchasing power.

Restoring Pell Eligibility to Students Who Are Incarcerated

The evidence on the impact of providing higher education opportunities for individuals who are incarcerated is clear. Research shows that correctional education programs reduce the rate of recidivism by 43 percent, increase the rate of employment after release by 13 percent, and are associated with fewer violent incidents in participating prisons. These programs result in net savings to taxpayers and are significantly more cost efficient than incarceration alone. They also represent an essential strategy for breaking the cycles of incarceration and poverty and helping formerly incarcerated individuals reintegrate into society. There are also significant intergenerational benefits for the more than 5 million children in our country with one or more parent who is or has been incarcerated.

But despite the significant and positive impacts of prison education programs, Congress instituted a ban on the use of Federal Pell Grants by incarcerated students in the 1994 Violent Crime Control and Law Enforcement Act. The number of postsecondary education programs in prisons subsequently dropped from over 350 in 1990 to only a dozen in 2005. The percentage of incarcerated individuals participating in postsecondary education programs also dropped from 14 percent in 1991 to 7 percent in 2004. Restoring Pell eligibility for incarcerated individuals would support the expansion of such programs and yield significant benefits for participating students and society as a whole, advancing justice while making our communities safer and saving taxpayers money. Further, before the ban, the percentage

¹ Congressional Budget Office (CBO), January 2017 baseline projections for the Pell Grant program, <http://bit.ly/2mLy0nk>, Table 2; and Ed Trust calculation NPSAS:12 using PowerStats.

² <https://www2.ed.gov/finaid/prof/resources/data/pell-2014-15/pell-eoy-2014-15.html>.

of Pell Grant recipients who were incarcerated was less than 1 percent of the entire Pell Grant population; thus, this policy change can have great social benefits that should not come at the expense of providing opportunities for other low-income students.

For fiscal year 2019, Congress should strike paragraph 6 of section 401(b) in the Higher Education Act and restore Pell eligibility to students who are incarcerated and in high-quality programs that support students toward a degree.

SUPPORTING TEACHERS AND SCHOOL LEADERS

Research and experience show the powerful impact that teachers and school leaders have on student learning. ESSA's Title II program provides grants to States and districts that can be used to invest in the education profession. These funds can be used to, among other things, address inequities in access to effective teachers and school leaders, provide professional development, and improve teacher recruitment and retention. States and districts can also apply for additional competitive grant dollars for programs targeted at specific, evidence-based strategies for improving teacher and school leader effectiveness and increasing educator diversity.

Maintain funding for Title II–A (Supporting Effective Instruction), the Teacher and School Leader Incentive Program (TSLIP), and the Supporting Effective Educator Development (SEED) program

Despite the nationwide attention to the need to invest in educators, the President's fiscal year 2019 budget request again called for the elimination of the Title II–A grant, the TSLIP, and the SEED program. We appreciate Congress' rejection of these requests in the fiscal year 2018 omnibus appropriations bill. For fiscal year 2019, Congress should continue funding Title II–A, TSLIP, and SEED at their fiscal year 2018 levels: \$2.055B, \$200 million and \$75 million, respectively.

Restore Funding for the School Leader Recruitment and Support Program

Landmark research funded by the Wallace Foundation has found “virtually no documented instances of troubled schools being turned around without intervention by a powerful leader,” and the School Leader Recruitment and Support Program is the only Federal program specifically focused on investing in evidence-based, locally driven strategies to strengthen school leadership in high-need schools.

During the past decade, we have learned a lot about what works in education leadership -lessons made possible, in part, by Federal investments in the School Leader Program (the previous iteration of the SLRSP). There is still a great deal of work to do, especially when it comes to identifying and efficiently preparing effective turnaround leaders, as well as sustainably supporting them to accelerate academic achievement, close gaps, and maintain improvement over time for all students and in every community. The SLRSP is a key lever for seeding the next generation of effective school leader development programs, promoting equity, advancing ongoing innovation, and sharing cutting-edge lessons on transformational leadership with the broader field.

For fiscal year 2019, Congress should fund the School Leader Recruitment and Support Program at \$14.5M, its fiscal year 2017 appropriation level.

[This statement was submitted by John B. King Jr., President and CEO, The Education Trust.]

PREPARED STATEMENT OF THE ENDOCRINE SOCIETY

The Endocrine Society thanks the Subcommittee for the opportunity to submit the following testimony regarding fiscal year 2019 Federal appropriations for biomedical research.

The Endocrine Society is the world's largest and most active professional organization of endocrinologists representing more than 18,000 members worldwide. Our organization is dedicated to promoting excellence in research, education, and clinical practice in the field of endocrinology. The Society's membership includes basic and clinical scientists who receive Federal support from the National Institutes of Health (NIH) to fund endocrine-related research on diseases that affect millions of Americans, such as diabetes, cancer, fertility, aging, obesity and bone disease. Our membership also includes clinicians who depend on new scientific advances to better treat and cure these diseases. To support necessary advances in biomedical research to improve health, the Endocrine Society asks that the NIH receive total funding of least \$39.3 billion for fiscal year 2019.

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 disease. 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. Consequently, endocrinologists contribute an important understanding of how the various systems of the human body communicate and interact to maintain health. The areas governed by the endocrine system are broad and essential to overall wellbeing: endocrine functions include reproduction, the body's response to stress and injury, sexual development, energy balance and metabolism, bone and muscle strength, and others. Endocrinologists also study interrelated systems, for example how hormones produced by fat can influence the development of bone disease.

ENDOCRINE RESEARCH IS SUPPORTED BY NUMEROUS NIH INSTITUTES

Endocrine society members are funded by and contribute to the scientific missions of many of the NIH Institutes and Centers (ICs), reflecting the cross-cutting nature of endocrinology. For example:

- Endocrine researchers funded by the National Institute of Aging help us understand how hormonal treatment for menopause might improve stress responses in women;¹
- Scientists funded by the National Institute of Diabetes and Digestive and Kidney Diseases, and the National Center for Advancing Translational Sciences are helping us understand the association between levels of thyroid-stimulating hormone (TSH) and unexplained infertility.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 developed a new drug with a unique mechanism that could inhibit the growth of drug-resistant prostate cancer.⁴
- Diabetologists funded by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) are exploring new genes and biological pathways that could prevent or reverse the development of diabetes.⁵
- Endocrinologists funded by NIDDK are also studying hormones that influence eating behavior and metabolism might be potential therapeutic targets for weight loss.⁶

An effective biomedical research enterprise requires a strong base appropriation for the NIH and sustained support for all institutes and centers. Many endocrine diseases and disorders are addressed by the missions of multiple NIH ICs, therefore fundamental research on all biological systems and disease states is necessary to advance effective therapies for these diseases.

¹ <https://www.endocrine.org/news-room/press-release-archives/2017/treating-menopausal-symptoms-can-protect-against-stress-negative-effects> Accessed March 11, 2018.

² Orouji Jokar, T, et al., "Higher TSH Levels Within the Normal Range Are Associated With Unexplained Infertility" *The Journal of Clinical Endocrinology & Metabolism*. Volume 103, Issue 2, 1 February 2018, Pages 632–639.

³ Torres, PJ, et al., "Gut Microbial Diversity in Women with Polycystic Ovary Syndrome Correlates with Hyperandrogenism" *The Journal of Clinical Endocrinology & Metabolism*, jc.2017–02153.

⁴ <https://www.endocrine.org/news-room/press-release-archives/2013/new-medication-treats-drug-resistant-prostate-cancer-in-the-laboratory>. Accessed March 11, 2018.

⁵ Cinti, F, et al., "Evidence of β -Cell Dedifferentiation in Human Type 2 Diabetes." *The Journal of Clinical Endocrinology & Metabolism*, Volume 101, Issue 3, 1 March 2016, Pages 1044–1054.

⁶ Lawson, EA., "The effects of oxytocin on eating behaviour and metabolism in humans." *Nat Rev Endocrinol*. 2017 Dec;13(12):700–709.7

CONTINUING RESOLUTIONS THREATEN SCIENTIFIC MOMENTUM

The Endocrine Society appreciates the \$7 billion in total increases NIH has received in the fiscal year 2016, fiscal year 2017, and fiscal year 2018 Omnibus Appropriations bills. This funding will help address the erosion in buying power from appropriations not keeping pace with biomedical research inflation. However, the NIH and other Federal agencies have dealt with Continuing Resolutions (CRs) in each of these years and in many years prior. Extended CRs, like those required in fiscal year 2018, threaten to derail the significant progress gained through recent funding increases; without a final appropriation, the NIH cannot make decisions on many worthwhile grant applications, and the overall pace of scientific discovery is severely diminished by fiscal uncertainty. Well-regarded research projects are therefore left waiting for confirmation of the status of their grant application, and highly-qualified research staff are unable to put their expertise to productive use. Or worse, labs are forced to reduce staff, putting longstanding research programs in jeopardy. We urge you to support the NIH on a more predictable funding schedule that allows the agency to engage in more strategic and long-term planning.

RESEARCHERS FACE INCREASING ADMINISTRATIVE BURDENS

The Endocrine Society recognizes that certain administrative tasks are critical to the research process and we applaud NIH's efforts to identify and reduce sources of administrative burden for researchers. It is important to ensure that researchers spend more productive time working on science, rather than applying for and reporting on grants. We note that the modular budget cap has not increased with inflation, and that grant applications with necessary costs above the modular budget cap incur additional administrative responsibilities. The Endocrine Society encourages the Committee to include report language requesting an update from NIH in fiscal year 2020 regarding the effect of modular budget cap increases on reducing administrative burdens while maintaining appropriate fiscal oversight of grant costs.

NIH REQUIRES STEADY, SUSTAINABLE FUNDING INCREASES

The biomedical research community requires steady, sustainable increases in funding to ensure that the promise of scientific discovery can efficiently be translated into new cures. NIH grant success rates are predicted to remain at historically low averages, meaning that highly skilled scientists will continue to spend more time writing highly meritorious grants that will not be funded. Young scientists will also continue to be driven out of biomedical research careers due to the lack of funding.

We may never be able to quantify the opportunities we have missed to improve the health and economic status of the United States due to persistent underinvestment in research. We do know however, that when "laboratories lose financing; they lose people, ideas, innovations and patient treatments."⁷ Based on the personal stories of researchers who have been forced to curtail research programs, we know that research programs to understand how genetics can influence heart disease, develop therapeutic treatments for Parkinson's disease, and evaluate the effect of metal contaminants on reproductive health, among many others, are delayed or terminated.⁸

FISCAL YEAR 2019 NIH FUNDING REQUEST

The Endocrine Society recommends that the Subcommittee provide at least \$39.3 billion, representing further steady, sustainable, increases in funding for NIH through the fiscal year 2019 Labor-HHS-Education Appropriations bill. This funding recommendation represents the minimum investment necessary to avoid further loss of promising research and at the same time allows the NIH's budget to keep pace with biomedical inflation.

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 arthropod-borne disease research at the U.S. Department of Health and Human Services (HHS).

⁷ Teresa K. Woodruff "Budget Woes and Research." The New York Times. September 10, 2013.

⁸ Sequester Profiles: How Vast Budget Cuts to NIH are Plaguing U.S. Research Labs. United for Medical Research. http://www.unitedformedicalresearch.com/advocacy_reports/sequestration-profiles/ Accessed March 20, 2014.

ESA requests \$39.3 billion in fiscal year 2019 for the National Institutes of Health (NIH). This should include increased support for arthropod-borne disease research at the National Institute of Allergy and Infectious Diseases (NIAID). The Society also supports increased investment in the core infectious diseases budget and the global health budget within the Centers for Disease Control and Prevention (CDC) to fund scientific activities related to vector-borne diseases for a total of \$8.445 billion in fiscal year 2019.

Cutting-edge research in the biological sciences, including the field of entomology, is essential for addressing societal needs related to environmental and human health. Many species of insects and arachnid (including ticks and mites) serve as vectors for an array of infectious diseases that threaten the health and well-being of people across the globe. This includes populations in every State and territory of the United States and U.S. military personnel serving at home and abroad. Vector-borne diseases can be particularly challenging to control; effective vaccines are not available for many of these diseases, and controlling the vectors is complicated by their mobility and their propensity for developing pesticide resistance.

The risk of emerging infectious diseases grows as global travel increases in speed and frequency and as environmental conditions conducive to vector population growth continue to expand globally. Entomological research aimed at understanding the relationships between arthropod vectors and the diseases they transmit is essential for reliable monitoring and prediction of outbreaks, effective prevention of disease transmission, and rapid diagnosis and treatment of diseases. The magnitude of the challenges presented by vector-borne diseases cannot be overstated. Mosquitoes alone are considered responsible for the deaths of more people than all other animal species combined, including humans.

Given the enormous impact of arthropod vectors on human health, ESA urges the subcommittee to support vector-borne disease research programs that incorporate the entomological sciences as part of a comprehensive approach to addressing infectious diseases.

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. More than 80 percent of NIH funding is competitively awarded to scientists at approximately 2,500 universities, medical schools, and other research institutions across the Nation. As one of NIH's 27 institutes and centers, NIAID conducts and supports fundamental and applied research related to the understanding, prevention, and treatment of infectious, immunologic, and allergic diseases.

The necessity of investments in basic and translational research in vector-borne diseases is exemplified by the dramatic spread of Zika virus, a disease transmitted by the *Aedes aegypti* mosquito, across the south western hemisphere starting in 2015. While scientists have been aware of Zika for more than 40 years, it previously posed minimal threat beyond contained regions. Epidemiologists identified the emergence of this threat, and scientists quickly began working on a vaccine, but validating safety and efficacy, once a potentially successful therapeutic is created, takes time. In 2017, NIH began an efficacy trial against Zika in North, Central, and South America. While the preliminary results are promising, it will take time to confirm how effective it is at eliciting an immune response and preventing transmission.¹ Furthermore, studies of the Zika pandemic continue not only because it hasn't fully disappeared from the U.S., but also because it can help us better respond to the next infectious disease outbreak transmitted by arthropods.²

NIAID has also funded research for a new model system, announced in August 2017, to study the relationship between ticks and a type of virus known as flaviviruses, which can be transmitted to humans. These types of viruses include dengue fever and West Nile virus, which are transmitted by mosquitoes, as well as Powassan virus disease and tick-borne encephalitis, which are spread by ticks. However, the mechanism by which these viruses infect the ticks is still poorly understood, and researchers hope that this system will create a better and more efficient way to support the development of countermeasures to tick-borne viruses.³

To ensure funding for future groundbreaking projects of great utility for public health, ESA supports increased funding for NIAID and encourages the committee to support vector-borne disease research at NIH.

¹M Gaudinski et al. Zika Virus DNA Vaccine Candidates are Safe and Immunogenic in Healthy Adults. *The Lancet* DOI: 10.1016/S0140-6736(17)33105-7 (2017).

²Morens, DM and Fauci, AS. Pandemic Zika: A formidable challenge to medicine and public health. *The Journal of Infectious Diseases* DOI: 10.1093/infdis/jix383 (2017).

³J Grabowski et al. Flavivirus infection of *Ixodes scapularis* (black-legged tick) ex vivo organotypic cultures and application for control. *mBio* DOI: 10.1128/mBio.01255-17 (2017).

CDC, serving as the Nation's leading health protection agency, conducts scientific research and provides health information to prevent and respond to infectious diseases and other global health threats, irrespective of whether they arise naturally or via acts of bioterrorism. Within the core infectious diseases budget of CDC, the Division of Vector-Borne Diseases (DVBD) aims to protect the Nation from the threat of viruses and bacteria 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 critical role in surveillance systems for vector-borne diseases and identifying emerging threats. The growing incidence of the generally rare Bourbon virus, first discovered in Kansas in 2014 and transmitted by *Amblyomma americanum*, better known as Lone Star ticks, is being monitored in the Midwestern and southern States. However, very little is known about this disease and there are currently no medicines, so DVBD plays a central role in surveilling the threat and disseminating information about how people can reduce their potential exposure to ticks possibly carrying this disease.⁴

Another component of CDC's global health budget supports activities on malaria and other parasitic diseases, which include maintaining a global reference insectary that houses colonies of mosquitoes from around the world to be used by the agency for studies on malaria transmission.

Given that the contributions of the CDC are vital for the health security of the Nation, ESA requests that the committee provide robust support for CDC programs addressing vector-borne diseases.

ESA, headquartered in Annapolis, Maryland, is the largest organization in the world serving the professional and scientific needs of entomologists and individuals in related disciplines. As the largest and one of the oldest insect science organizations in the world, ESA has over 7,000 members affiliated with educational institutions, health agencies, private industry, and government. Members are researchers, teachers, extension service personnel, administrators, marketing representatives, research technicians, consultants, students, pest management professionals, and hobbyists.

Thank you for the opportunity to offer the Entomological Society of America's support for HHS research programs. For more information about the Entomological Society of America, please see <http://www.entsoc.org/>.

[This statement was submitted by Michael Parrella, PhD, President, Entomological Society of America.]

PREPARED STATEMENT OF THE FAMILIES AND FRIENDS OF CARE FACILITY RESIDENTS

Chairman Blunt, Ranking Member Murray and Subcommittee Members, thank you for the opportunity to testify.

I represent Families and Friends of Care Facility Residents (FF-CFR), Arkansas' statewide parent-guardian association, an all-volunteer 501 (c) 3 organization. Most FF-CFR members have loved ones with life-long cognitive and other developmental disabilities and most of our family members with disabilities receive residential treatment services at Arkansas' specialized intermediate care facilities (ICFs), which are licensed by the office of long term care.

To understand my personal interest in the subcommittee's work, you must understand my son, John, age 49, who suffered severe brain injuries at birth. Mentally, he functions as a young toddler but he is otherwise a non-verbal, physically strong and mobile middle-aged man. John has the judgment of a one and a half year old. Our son's care is beyond our family's capacities and for many years his safe home has been a Medicaid-certified congregate care facility in Arkansas, which sits in a protected park—like setting. To be federally certified through CMS, his center must meet 8 major criteria on: management, client protections, facility staffing, active treatment, client behavior and facility practices, healthcare services, physical environment and dietetic services. The center has many "eyes on the ground," with built-in safeguards to protect residents. These staff members are important, because like a toddler, John is unable to report if something were wrong; and like a toddler, he depends totally on others for his health and safety.

The Protection and Advocacy System for Persons with Developmental Disabilities (PADD) and three other programs (State Councils on Developmental Disabilities, University Centers for Excellence in Developmental Disabilities and Projects of National Significance) were originally established by the Developmental Disabilities

⁴ <https://www.cdc.gov/nceid/dvbd/bourbon/index.html>

and Bill of Rights Act of 1975 (“DD Act”). The programs were last reauthorized for a period of 7 years in 2000 (Public Law 106–402- October 30, 2000).

Congressional appropriations to HHS have funded the P&As systems and other DD Act programs since 1976 making them “quasi-Federal entities” but with insufficient oversight and accountability. There have been no public hearings on the DD Act and the activities of its grantees and sub-grantees in over 20 years. The last reauthorization of the DD Act was in 2000 and despite families’ requests, there were no Congressional hearings at the time nor have there been in the intervening years. ACL/A Administration on Intellectual and Developmental Disabilities (AIDD) has not held public hearings since 2010 when I traveled with two other FF–CFR members to Dallas, Texas to attend one of the agency’s “listening” sessions. Those of us who supported the option of congregate care facilities were screened out of Day—Two of the meeting and despite our request, we were not included in the follow-up strategic planning meetings held by ACL/AIDD.

I am familiar with the DD Act programs, which operate in every State. I served on the Arkansas State DD Council over 35 years ago and I also have endured with other Arkansas families the aggressive attacks by the Arkansas PADD program, now called Disability Rights Arkansas (DRA), on the state’s licensed intermediate care facilities (ICFs). The extensive list of partisan actions by DRA aimed at undermining and eliminating Arkansas’ intermediate care facilities (ICFs) include litigation, using named plaintiffs in litigation without consent or notice to their families, testifying before legislative hearings against appropriations for capital expenditures for the ICFs, smearing a licensed facility in an inaccurate report and calling for its closure in the media; lobbying other organizations to join in its work to close the center; distributing and promoting false information about the Supreme Court decision in *Olmstead*; and working in favor of one Medicaid program (home and community programs) over another Medicaid program (ICF programs).

People who lack the cognitive ability to report their hurts and needs are particularly in need of specialized services and protection. In 2010, the American Medical Association’s Resolution 805–I–10 called for the AMA to “lobby Congress to work with the appropriate Federal agencies, such as Department of Health and Human Services to classify intellectually disabled persons as a medically underserved population.” “People with developmental disabilities are significantly more likely than others to be victims of violence .. Odds of experiencing violence are two to three times higher for people with disabilities as compared to those without.” (Disability Scoop, Feb. 26, 2013). The DD Act PADD program is failing to comply with the DD Act in protecting persons with developmental disabilities by not reporting deaths of and serious injuries to the population. Last year in an e-mail request, I asked the national association representing the protection and advocacy systems (National Disability Rights Network—NDRN): “Do the DD Act P&A programs submit narrative reports to ACL/AIDD on these (abuse, neglect, exploitation and mortality) subjects? If so, please send me reports submitted to ACL/AIDD from the Georgia Protection and Advocacy program on outcomes following the Georgia Settlement Agreement with Department of Justice (October, 2010).” On 02/13/2017, I received this reply from NDRN:

Finally, there were no mortality studies following GA–DOJ settlement/transitions from State facilities-2012-present.

Media reports of the many unexpected deaths of persons with developmental disabilities in the State of Georgia after deinstitutionalization transfers required by the DOJ class action suit are horrific.

Almost 10 percent of the 480 people with developmental disabilities who have moved out of State hospitals since July 2010 have died after their placement in community residences.—*Georgia Health News, January, 2014*.

Christen Shermaine Hope Gordon was one of 500 patients in 2013 who died in community care while under the auspices of the Georgia Department of Behavioral Health and Developmental Disabilities. The 12-year-old was one of 82 classified as unexpected deaths, including 68 who, like her, were developmentally disabled. In 2014, an additional 498 patients who were receiving community care died, including 141 considered unexpected.—*Augusta Chronicle, March, 2015*

Of the estimated 503 residents with developmental disabilities who have moved from State facilities into community-based care, 79 have died, according to court documents filed by the Federal Government in its request to hold the State in contempt. Even more disturbing, according to an independent consultant specializing in the transition of people from institutions to community settings, Georgia only investigated 38 of those 79 deaths, and the cause

of death for 29 patients was listed as “unknown.”—*Augusta Chronicle, January, 2016*

Where were the federally funded protection and advocacy services for those vulnerable people in Georgia? The DD Act requires the Secretary of Health and Human Services “to prepare and submit to the President, Congress and the National Council on Disability, a report that describes the goals and outcomes of the [DD Act] programs,” including “reports of deaths of and serious injuries to individuals with developmental disabilities.” 42 USC 15005 SEC.105 REPORTS OF THE SECRETARY. Where are the Secretary’s reports on outcomes for people with developmental disabilities in Georgia?

DD Act programs are not held accountable for use of their Federal appropriations. There is insufficient oversight of their partisan activities. There are no repercussions when P&As bring class action lawsuits against facilities which are in good standing, or when State DD Councils adopt 5 Year Plans of shifting funds away from ICFs and goals of closing ICFs. There are no consequences when State Councils’ sub-grantees work to smear ICFs and engage in advocacy for closures of ICFs. The use of funds by Projects of National Significance (PNS) grantees and sub-grantees to undermine and eliminate ICFs for persons with developmental disabilities goes unchallenged. *Note: Examples provided upon request.*

There is something terribly wrong with government when public funds are used to fund groups engaged in ideological pursuits. It should not be acceptable that a public agency (HHS|ACL) charged with protecting at-risk people cannot or will not provide the reforms required for the DD Act programs which have used and are using grant funds to promote across-the-board deinstitutionalization of persons with cognitive deficits and to eliminate specialized long-term care programs for persons unable to care for themselves.

REQUESTS FOR FISCAL YEAR 2019

- Please discontinue funding for P&A class action lawsuits against Intermediate Care Facilities (ICFs);
- Please discontinue funding for activities of DD Act programs, their sub-grantees and their national organizations to undermine and eliminate Intermediate Care Facilities (ICFs), and
- Please insert Legislative text and Report Language in the fiscal year 2019 Labor, Health and Human Services, Education and Related Agencies Appropriations bill as follows:

Proposed Bill Language:

“ . . . *Provided further*, That none of the funds made available under this heading may be used by a Protection and Advocacy system (as defined in the Developmental Disabilities and Assistance and Bill of Rights Act of 2000 (Public Law 106–401) in class action litigation against an Intermediate Care Facility (ICF) for people with intellectual or developmental disabilities when the facility is in good standing with its licensure requirements and funding authority.”

Proposed Report Language:

The Committee notes that in *Olmstead v. L.C.* (1999), a majority of the Supreme Court held that the Americans with Disabilities Act does not condone or require removing individuals from institutional settings when they are unable to handle or benefit from a community-based setting, and that Federal law does not require the imposition of community-based treatment on patients who do not desire it.

Respectfully submitted.

[This statement was submitted by Carole L. Sherman, Public Affairs Chair, Families and Friends of Care Facility Residents.]

PREPARED STATEMENT OF THE FAMILY FOCUSED TREATMENT ASSOCIATION

The Family Focused Treatment Association (FFTA) offers the following testimony requesting increased funds for the following programs under the supervision of the Administration for Children and Families (ACF): Child Welfare Services (CWS), Promoting Safe and Stable Families, the Adoption and Kinship Incentives Fund, and the Adoption Opportunities Act and to pass and fund S1357, the Family Based Care Services Act, for safe facilitation of the Family First Prevention Services Act (Public Law 115–123).

In February, Congress passed the Family First Prevention Services Act (FFPSA). The legislation has potential to expand services that can prevent the placement of

children into foster care. It also challenges States to reduce the number of children and youth in congregate placements unless evidence clearly demonstrates that a family home is insufficient treatment for their unique needs.

It will be a challenge to States to build the capacity and access to services (mental health, substance use, and family-based services) especially for children and youth with significant mental and behavioral health conditions. However, Therapeutic Family/Foster Care (TFC) is an evidence-informed and trauma-specific clinical intervention to serve such youth in specially trained and supported families in their community.

S1357/HR2290, the Family-based Care Services Act, requires the same accreditation standard for TFC providers that FFPSA requires for congregate care. The legislation offers a list of core services required to meet the needs of these youth, all of which are presently reimbursed by CMS when appropriately authorized by a State's Medicaid plan.

Without passage of S1357/HR2290, the concerns of "appropriateness of placement" and "quality of provider" that Congress addressed in FFPSA can reappear in family, community settings. This challenge to successful implementation of FFPSA can be remedied by inclusion of S1357/HR2290 now in proposed SUD legislation.

I. THE FAMILY FIRST ACT

Our Nation faces these challenges against a backdrop of ever increasing foster care numbers driven by the opioid epidemic in parts of the country. Since 2012 the number of children in foster care has increased by 10 percent to 437,000 in 2016. FFTA believes it is critical for Congress to fully fund programs to both build capacity to effectively implement the Family First Act and help address the crisis many communities are facing as foster care placement demands explode.

The Family First Act provides funding for services to prevent the placement of children in foster care but does not fund services to prevent child abuse and neglect, nor are there protections and requirements offered for services to youth with high behavioral or mental health conditions.

In fiscal year 2020, Families First will allow States to draw funds for children and families at risk of foster care. States taking the optional services will be limited to evidence-based services for families that need intervention, post-adoption, and reunification services. States must engage in and coordinate public-private agencies experienced with providing child and family community-based services, including mental health, substance use, and public health providers. There is a limited supply of foster homes and family-based aftercare support that can provide for post-discharge services for children leaving institutional care. It is the opinion of FFTA that Congress must include the protections and requirements outlined in S1357.

II. CHILD ABUSE PREVENTION AND TREATMENT SERVICES

In addition to needed prevention services, Child welfare agencies need to find and support more family-based foster care homes, including kinship homes and non-relative homes for youth with high needs.

Child welfare strategy must significantly increase funding for child abuse prevention. FFTA calls on Congress to fully fund Child Welfare Services from \$269 million to \$325 million and Promoting Safe and Stable Families from \$99 million in discretionary funding to \$200 million; increase funding to the Adoption Opportunities Act to \$60 million; fully fund the Adoption and Kinship Incentives Fund at \$75 million.

We support increased funding for these four funds that can help States develop evidence-based services that will meet "well-supported," "supported," and "promising" standards of FFPSA and can assist the coordination of community and/or family-based behavioral health and human services.

Child Welfare Services (CWS), Title IV-B part 1:

We ask for \$325 million for Child Welfare Services, the full authorization and above the current total of \$269 million. Starting in fiscal year 2020, the Families First Act will allow States to draw funds for children and families at risk of foster care. CWS is flexible enough to allow States to test out and develop these services and provide the research required to meet these evidence standards.

Promoting Safe and Stable Families (PSSF), Title IV-B part 2:

We also asking for full funding of \$200 million for Promoting Safe and Stable Families. Currently this appropriations is set at \$99 million despite being authorized at \$200 million. These funds supplement \$345 million in mandatory funds divided between services, the courts, substance use treatment grants and workforce development. Appropriations to \$200 million could be used for the four key services under PSSF: family reunification, adoption support, family preservation and family

support. There are limited services for reunification services for children who return to their families and the same is true of post adoption services. These will all be eligible services under Family First but there are few models now eligible for funding.

The Adoption Opportunities Act:

The Adoption Opportunities program is the Nation's oldest adoption program created to develop adoption promotion, post adoption services and strategies. It has funded grants to reduce barriers to adoption, reduce disproportionality, and more recently to promote adoptions of older youth in foster care and develop post-adoption services. It is funded at \$39 million. We ask for funding at \$60 million to develop evidence-based models for post adoption services to families.

The Adoption and Kinship Incentive Fund:

We ask for a continued funding level of \$75 million for the adoption incentive fund. The fund was created in the Adoption and Safe Families Act (ASFA). In 2014 it became the Adoption and Legal Guardianship Incentive Payments Program. We thank the Appropriations Committee for partially addressing a recent shortfall in this incentive fund with the 2018 appropriations of \$75 million. In recent years HHS has been not been able to fully award States because of a reduced appropriation. As a result, HHS has made up the previous year's shortfall with the following year's appropriations. The \$75 million for fiscal year 2018 was a significant step in addressing the shortfall of 2017. In the beginning years Congress would recognize this and provide an extra amount of appropriation. Your 2018 appropriation reestablished this practice. When HHS issues the latest awards for fiscal year 2018, this September, there will have \$25 million remaining. That will likely fall short to fully fund the incentives. And we again ask for an appropriation of \$75 million to fully fund 2018 awards and have enough in place for fiscal year 2019.

These funds are reinvested by States into adoption services. These funds can be used by States to build both the evidence-based adoption services include post-adoption counseling and services that can prevent and reduce adoption disruption. VFA thanks you for this consideration and stands ready to respond to your questions and concerns.

III. IMPACT OF OPIOIDS ON CHILD ABUSE AND NEGLECT AND FOSTER CARE

Earlier this year HHS through the Secretary of Planning and Evaluation conducted an analysis of child welfare data and supplemented that work with field level research. Some of the key findings included:

- A 10 percent increase in overdose death rates correspond to a 4.4 percent increase in the foster care entry rate and a 10 percent increase in the hospitalization rate due to drug use corresponds to a 3.3 percent increase in the foster care entry rate.
- While in past drug epidemics family and communities could fill some of the gaps, today agencies report that family members across generations may be experiencing substance use problems forcing greater reliance on State custody and non-relative care.
- Parents using substances have multiple problems including domestic violence, mental illness, trauma history, and addressing substance abuse alone is unlikely to be effective.
- Substance use assessment is haphazard and there is a lack of “family-friendly” treatment that includes family therapy, child care, parenting classes and developmental services.
- There is a shortage of foster homes and this is exacerbated by the need to keep children longer in care which keeps existing homes full and unable to accept new placements.

Children and infants ages 5 and under are the largest cohort of youth newly entering out-of-home care. Their developmental, and often physical, needs are severely impacted by their parents' addictions. Older children struggle with increased trauma due to years of neglect and/or separation from known parents and caregivers. Too many children must face the death of a parent.

FFTA believes it is imperative that Congress fully fund:

- Implementation of FFPSA, including protections and requirements for youth with significant mental and behavioral health issues as outlined in S1357, the Family Based Services Act of 2017,
- Child abuse prevention services and treatment programs as outlined above, and
- Training and support of the professional workforce who will deliver this care.

[This statement was submitted by Laura Boyd, Ph.D., National Director of Public Policy, Family Focused Treatment Association.]

PREPARED STATEMENT OF THE FAMILY PLANNING COALITION

Chairman Blunt, Ranking Member Murray, and Subcommittee Members:

The undersigned organizations collectively represent millions of providers, patients, administrators, researchers, and advocates who support Federal funds for the Title X family planning program, which helps ensure that millions of individuals can access high-quality family planning and sexual health services. We share the approach of former President George H.W. Bush, who, as the lead congressional sponsor of the legislation that created the Title X program, said in 1969 about public funding for family planning:

We need to take sensationalism out of this topic so that it can no longer be used by militants who have no real knowledge of the voluntary nature of the program but, rather are using it as a political stepping stone. If family planning is anything, it is a public health matter.¹

As you develop the fiscal year 2019 funding framework for the Labor, Health and Human Services, Education, and Related Agencies appropriations bill, we respectfully request that you similarly recognize the essential role of publicly funded family planning and sexual healthcare services by funding Title X at \$327 million in fiscal year 2019.

Title X helps more than 4 million people access family planning and related services at nearly 4,000 health centers around the country annually.² 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, complete and medically accurate information about their sexual health and family planning options, and other basic care. Six in ten women seen at a Title X-supported healthcare center have reported that the center was their usual source of medical care.³ In 2015 alone, the contraceptive services supported by Title X helped women avoid 822,000 unintended pregnancies, which would have resulted in 387,000 unplanned births and 278,000 abortions.⁴

In addition to direct clinical care, Title X supports critical needs, such as staff training, that are not reimbursable under Medicaid or private insurance. Notably, research has shown that Title X-supported services save the Federal and State Governments approximately \$7 billion a year,⁵ and 75 percent of American adults—including 66 percent of Republicans, 75 percent of Independents, and 84 percent of Democrats—support the program.⁶

In spite of the increasing need for publicly funded family planning services and the demonstrated public health and fiscal benefits of the program, Title X investments have been substantially cut in recent years. From 2010 to 2014 the number of women who needed publicly funded family planning services increased by 1 million,⁷ but Congress cut Title X's funding by \$31 million over that period. That decrease unfortunately corresponds to dramatic decreases in the number of patients served at Title X-funded sites; the numbers dropped from 5.22 million in 2010⁸ to just over 4 million in 2016.⁹

¹ Clare Coleman and Kirtly Jones, "Title X: a proud past, an uncertain future," *Contraception* 84 (2011): 209–211. <http://www.arhp.org/UploadDocs/journaleditorialsept2011.pdf>.

² Christina Fowler et al, "Family Planning Annual Report: 2016 National Summary," RTI International (August 2017). <https://www.hhs.gov/opa/sites/default/files/title-x-fpar-2016-national.pdf>.

³ Adam Sonfield, Kinsey Hasstedt, and Rachel Gold, "Moving Forward: Family Planning in the Era of Health Reform," Guttmacher Institute (March 2014). <https://www.guttmacher.org/report/moving-forward-family-planning-era-health-reform>.

⁴ Jennifer Frost et al, "Publicly Funded Contraceptive Services at U.S. Clinics, 2015," Guttmacher Institute (April 2017). <https://www.guttmacher.org/report/publicly-funded-contraceptive-services-us-clinics-2015>.

⁵ Adam Sonfield, "Beyond Preventing Unplanned Pregnancy: The Broader Benefits of Publicly Funded Family Planning Services," Guttmacher Policy Review (December 2014). <https://www.guttmacher.org/gpr/2014/12/beyond-preventing-unplanned-pregnancy-broader-benefits-publicly-funded-family-planning>.

⁶ Survey Says: Birth Control Support, The National Campaign to Prevent Teen and Unplanned Pregnancy (2017). <https://thenationalcampaign.org/resource/survey-says-january-2017>.

⁷ Jennifer Frost, Lori Frohwirth and Mia Zolna, "Contraceptive Needs and Services, 2014 Update," Guttmacher Institute (September 2016). <https://www.guttmacher.org/report/contraceptive-needs-and-services-2014-update>.

⁸ Christina Fowler et al, "Family Planning Annual Report: 2010 National Summary," RTI International (August 2011). <https://www.hhs.gov/opa/sites/default/files/fpar-2010-national-summary.pdf>.

⁹ Fowler et al, "Family Planning Annual Report: 2016 National Summary."

Congress has yet to restore the program's funding to \$317 million, its peak investment (which was the appropriation in fiscal year 2010).¹⁰ The reduced program investment is counter to research published in the *American Journal of Public Health* stating that Title X would need at least \$737 million to support all women in need of publicly funded family planning services.¹¹ We are deeply concerned about diminishing access to high-quality family planning and sexual health services and urge Congress to increase funding for Title X to \$327 million in fiscal year 2019 to reverse this devastating trend.

Beyond these fiscal challenges, Title X is facing administrative threats to the integrity of the program and the provider network.¹² For example, in the recently released fiscal year 2018 Funding Opportunity Announcement (FOA), the administration removed all references to and requirements for Title-X funded providers to follow the nationally recognized clinical standards for family planning care, known as the Quality Family Planning guidelines, which were jointly developed by the Office of Population Affairs and the CDC in 2014.¹³ It also eliminated all mentions of contraception, the provision of which is central to the mission of Title X. On top of these noteworthy changes, the administration made a number of troubling amendments to the FOA's selection criteria aimed at making it more difficult for reproductive health-focused providers to participate in the program while potentially opening the door for the participation of ideologically-motivated organizations with little or no experience in providing healthcare.¹⁴ The administration's approach, in short, threatens access to basic, preventive healthcare for millions of individuals in communities across the country.

Supporting and strengthening the program is a smart investment in public health—a fact that has been recognized by members of both parties for over 45 years. Now a renewed commitment is needed to allow this critical component of our Nation's safety net to continue its mission and deliver the health, social, and economic benefits that have made such a difference in the lives of so many.

If you have any questions or would like additional information, please contact Lauren Weiss at the National Family Planning & Reproductive Health Association at lweiss@nfrpha.org.

Thank you for considering these requests.

Sincerely,

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| AIDS Action Baltimore | Association of Women's Health, Obstetric and Neonatal Nurses |
| AIDS Alabama | Black Women's Health Imperative |
| AIDS Alliance for Women, Infants, Children, Youth & Families | Cascade AIDS Project |
| AIDS Foundation of Chicago | Catholics for Choice |
| American Academy of HIV Medicine | Center for Reproductive Rights |
| American Academy of Pediatrics | Equality California |
| American Atheists | Equality North Carolina |
| American Civil Liberties Union | Feminist Majority Foundation |
| American College of Nurse-Midwives | Girls Inc. |
| American College of Obstetricians and Gynecologists | Hadassah, The Women's Zionist Organization of America, Inc. |
| American Psychological Association | Healthy Teen Network |
| American Public Health Association | HIV Medicine Association |
| American Sexual Health Association | Human Rights Campaign |
| American Society for Reproductive Medicine | In Our Own Voice: National Black Women's Reproductive Justice Agenda |
| Association of Nurses in AIDS Care | Los Angeles LGBT Center |
| Association of Reproductive Health Professionals (ARHP) | March of Dimes |
| Association of Schools and Programs of Public Health | NARAL Pro-Choice America |
| | NASTAD |
| | National Abortion Federation |

¹⁰Title X (Public Health Service Act) Family Planning Program, Congressional Research Service (2017).

¹¹Euna 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.

¹²Note that we do not address the draft NPRM released on HHS' website on May 22, 2018, as the rule has not been published.

¹³Loretta Gavin et al, "Providing Quality Family Planning Services: Recommendations of the CDC and the U.S. Office of Population Affairs," *Morbidity and Mortality Weekly Report* 63.4 (2014).

¹⁴Office of Population Affairs, "Announcement of Anticipated Availability of Funds for Family Planning Services Grants," Funding Opportunity PA-FPH-18-001. (2018).

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| National Asian Pacific American Women's Forum (NAPAWF) | National Women's Law Center |
| National Association of County and City Health Officials | National Working Positive Coalition |
| National Center for Lesbian Rights | PAI |
| National Coalition of STD Directors | People For the American Way |
| National Council of Jewish Women | Physicians for Reproductive Health |
| National Family Planning & Reproductive Health Association | Planned Parenthood Federation of America |
| National Health Law Program | Population Connection Action Fund |
| National Institute for Reproductive Health (NIRH) | Population Institute |
| National Latina Institute for Reproductive Health | Power to Decide |
| National Organization for Women | Sexuality Information and Education Council of the United States (SIECUS) |
| National Partnership for Women & Families | Society for Adolescent Health and Medicine |
| National Women's Health Network | Society for Maternal-Fetal Medicine |
| | The AIDS Institute |
| | Treatment Action Group |
| | Unite for Reproductive & Gender Equity |

PREPARED STATEMENT OF THE FEDERATION OF AMERICAN SOCIETIES FOR
EXPERIMENTAL BIOLOGY

The Federation of American Societies for Experimental Biology (FASEB) respectfully requests a minimum of \$39.3 billion in fiscal year 2019 for the National Institutes of Health (NIH) within the Department of Health and Human Services.

FASEB, a federation of 30 scientific societies, represents over 130,000 life scientists and engineers, making it the largest coalition of biomedical research associations in the United States. Our mission is to advance health and welfare by promoting progress and education in biological and biomedical sciences.

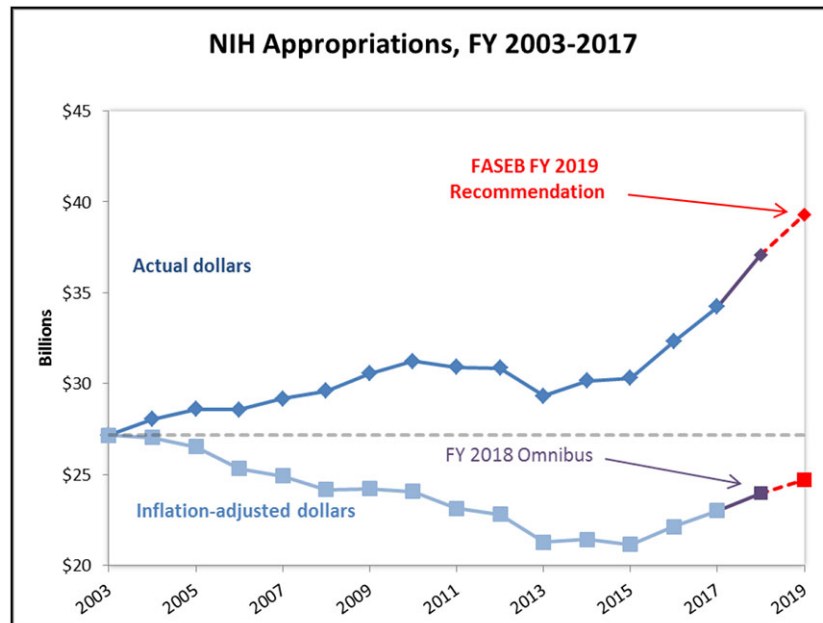
The National Institutes of Health (NIH) is the Nation's largest funder of basic biomedical research, providing competitive grants to more than 300,000 scientists at universities, medical schools, independent research institutions, and biotechnology companies in nearly every State and congressional district.

Increased longevity, a reduced number of deaths from heart disease and stroke, the development of the first hepatitis A and Ebola vaccines, and research that led to treatments for rare autoimmune diseases—all are part of NIH's outstanding legacy.¹

Today, new breakthroughs in biomedical research are transforming medicine. Cancer immunotherapy harnesses a patient's own immune system to fight cancer and is giving new hope to patients who once faced dire prognoses. Groundbreaking discoveries are enabled by a renewed congressional commitment to NIH, including new funding authorized through the 21st Century Cures Act. But there is much work to be done; in real dollars, the NIH budget is approximately 12 percent below the fiscal year 2003 level (Figure 1). Congress must marshal additional resources.

¹ <https://www.nih.gov/about-nih>.

Figure 1: NIH Appropriations



Continued progress towards new cures and better therapies also requires support for the best and brightest young scientists. The current funding environment makes it more difficult for younger scientists to establish and maintain independent research careers, and to pursue innovative scientific directions.² NIH must be able to provide sufficient support for these essential members of the biomedical workforce.

FASEB Fiscal Year 2019 Recommendation: at least \$39.3 billion for NIH

A \$39.3 billion budget (a \$2 billion increase in addition to 21st Century Cures funding³) would allow NIH to accelerate progress in all areas of biomedical science. This funding level could support about 400 additional early career and early established investigators; provide \$700 million already authorized through the 21st Century Cures Act for key research initiatives in cancer, precision medicine, neuroscience, and regenerative medicine; and bolster other areas in urgent need of additional resources, including raising the NIH grant modular budget limit (not increased since its inception in 2000). This funding means NIH could keep pace with the increased cost and sophistication of biomedical research.

PREPARED STATEMENT OF FOSTERADOPT CONNECT

FosterAdopt Connect offers the following testimony requesting increased funds for the following five programs under the supervision of the Administration for Children and Families (ACF): Child Welfare Services (CWS), Promoting Safe and Stable Families, the Adoption and Kinship Incentives Fund, and the Adoption Opportunities Act.

In February, Congress passed the Family First Prevention Services Act (PL 115-123). The legislation has potential to expand services that can prevent the placement of children into foster care. It challenges States to reduce the number of children and youth in congregate placements. It will be a challenge to States to build the capacity and access to services (mental health, substance use, and in-home services) and to build the infrastructure of services and providers.

²Sustaining Discovery in the Biological and Biomedical Sciences: A Framework for Discussion. Federation of American Societies for Experimental Biology, Bethesda, MD.

³H.R. 1625—Consolidated Appropriations Act, 2018.

The challenge is against a backdrop of ever increasing foster care numbers driven by the opioid epidemic in parts of the country. Since 2012 the number of children in foster care has increased by 10 percent to 437,000 in 2016. FosterAdopt Connect believes it is critical for Congress to fully fund six programs to both build capacity to effectively implement the Family First Act and help address the crisis many communities are facing as foster care placement demands explode.

The Family First Act provides funding for services to prevent the placement of children in foster care but does not fund services to prevent child abuse and neglect. Child welfare strategy must significantly increase funding for child abuse prevention.

FosterAdopt Connect calls on Congress to fully fund Child Welfare Services from \$269 million to \$325 million and Promoting Safe and Stable Families from \$99 million in discretionary funding to \$200 million; increase funding to the Adoption Opportunities Act to \$60 million; fully fund the Adoption and Kinship Incentives Fund at \$75 million.

IMPACT OF OPIOIDS ON CHILD ABUSE AND NEGLECT AND FOSTER CARE

Earlier this year HHS through the Secretary of Planning and Evaluation conducted an analysis of child welfare data and supplemented that work with field level research. Some of the key findings included:

- A 10 percent increase in overdose death rates correspond to a 4.4 percent increase in the foster care entry rate and a 10 percent increase in the hospitalization rate due to drug use corresponds to a 3.3 percent increase in the foster care entry rate.
- While in past drug epidemics family and communities could fill some of the gaps, today agencies report that family members across generations may be experiencing substance use problems forcing greater reliance on State custody and non-relative care.
- Parents using substances have multiple problems including domestic violence, mental illness, trauma history, and addressing substance abuse alone is unlikely to be effective.
- Substance use assessment is haphazard and there is a lack of “family-friendly” treatment that includes family therapy, child care, parenting classes and developmental services.
- There is a shortage of foster homes and this is exacerbated by the need to keep children longer in care which keeps existing homes full and unable to accept new placements.

Family First Act

In fiscal year 2020, Families First will allow States to draw funds for children and families at risk of foster care. States taking the optional services will be limited to evidence-based services for families that need intervention, post-adoption, and reunification services. States must engage in and coordinate public-private agencies experienced with providing child and family community-based services, including mental health, substance use, and public health providers. There is a limited supply of foster homes and family-based aftercare support that can provide for post-discharge services for children leaving institutional care. Child welfare agencies need to find and support more family-based foster care homes. These four funds can help States develop evidence-based services that will meet the laws “well-supported,” “supported,” and “promising” standards and can assist the coordination of community based behavioral health and human services.

CHILD WELFARE SERVICES, TITLE IV–B PART 1

We ask for \$325 million for Child Welfare Services (CWS), the full authorization and above the current total of \$269 million. Starting in fiscal year 2020, the Families First Act will allow States to draw funds for children and families at risk of foster care. CWS is flexible enough to allow States to test out and develop these services and provide the research required to meet these evidence standards.

PROMOTING SAFE AND STABLE FAMILIES, TITLE IV–B PART 2

We also asking for full funding of \$200 million for Promoting Safe and Stable Families (PSSF). Currently this appropriations is set at \$99 million despite being authorized at \$200 million. These funds supplement \$345 million in mandatory funds divided between services, the courts, substance use treatment grants and workforce development. Appropriations to \$200 million could be used for the four key services under PSSF: family reunification, adoption support, family preservation and family support. There are limited services for reunification services for children

who return to their families and the same is true of post adoption services. These will all be eligible services under Family First but there are few models now eligible for funding.

THE ADOPTION OPPORTUNITIES ACT

The Adoption Opportunities program is the Nation's oldest adoption program created to develop adoption promotion, post adoption services and strategies. It has funded grants to reduce barriers to adoption, reduce disproportionality, and more recently to promote adoptions of older youth in foster care and develop post-adoption services. It is funded at \$39 million. We ask for funding at \$60 million to develop evidence-based models for post adoption services to families.

THE ADOPTION AND KINSHIP INCENTIVE FUND

We ask for a continued funding level of \$75 million for the adoption incentive fund. The fund was created in the Adoption and Safe Families Act (ASFA). In 2014 it became the Adoption and Legal Guardianship Incentive Payments Program. We thank the Appropriations Committee for partially addressing a recent shortfall in this incentive fund with the 2018 appropriations of \$75 million. In recent years HHS has been not been able to fully award States because of a reduced appropriation. As a result, HHS has made up the previous year's shortfall with the following year's appropriations. The \$75 million for fiscal year 2018 was a significant step in addressing the shortfall of 2017. In the beginning years Congress would recognize this and provide an extra amount of appropriation. Your 2018 appropriation reestablished this practice. When HHS issues the latest awards for fiscal year 2018, this September, there will have \$25 million remaining. That will likely fall short to fully fund the incentives. And we again ask for an appropriation of \$75 million to fully fund 2018 awards and have enough in place for fiscal year 2019.

These funds are reinvested by States into adoption services. These funds can be used by States to build both the evidence-based adoption services include post-adoption counseling and services that can prevent and reduce adoption disruption. FosterAdopt Connect thanks you for this consideration and stands ready to respond to your questions and concerns.

PREPARED STATEMENT OF FRED HUTCHINSON CANCER RESEARCH CENTER

Fred Hutchinson Cancer Research Center (Fred Hutch) is grateful to Congress for providing strong, reliable funding for the National Institutes of Health (NIH), which is a key national priority. The Nation's investment in NIH research pays a lifetime of dividends in better health and quality of life for all Americans. In fiscal year 2019, Fred Hutch recommends at least \$39.3 billion for the NIH, including funds provided to the agency through the 21st Century Cures Act (Public Law 114-255) for targeted initiatives. Fred Hutch also recommends the Beau Biden Cancer Moonshot program be funded at \$400 million in fiscal year 2019 through the NIH Innovation Account created by the 21st Century Cures Act. These funding levels would continue the momentum of recent increases by enabling meaningful base budget growth above inflation, while ensuring that the NIH Innovation Account supplements the agency's base budget, as intended, through dedicated funding for specific programs.

Through the strong, bipartisan leadership of this Subcommittee's leaders, Chairman Roy Blunt and Ranking Member Patty Murray, who has been a consistent champion for biomedical research and a leader in the fight to end cancer, Congress is helping the agency regain lost ground after years of effectively flat budgets. In the fiscal year 2018 omnibus, the Subcommittee's leadership ensured continued progress by providing a substantial increase to all NIH institutes and centers, in addition to dedicated funding through the 21st Century Cures Act and other funding devoted to specific priorities.

The Federal investment in biomedical research has yielded a significant number of scientific advances that help improve health outcomes of patients suffering from disease. With its NIH funding, Fred Hutch has been redefining what is possible across the full spectrum of research into cancer and related diseases. Fred Hutch is committed to working with Congress and the Administration to further the longstanding, bipartisan tradition of enhancing the Federal investment in medical discovery and ensuring NIH remains a top priority in fiscal year 2019 and beyond.

ABOUT FRED HUTCH

Fred Hutchinson Cancer Research Center, founded in 1975, is an NCI-designated Comprehensive Cancer Center that seeks to eliminate cancer and related diseases as causes of human suffering and death. Fred Hutch's interdisciplinary team of world-renowned scientists and humanitarians work together to prevent, diagnose, and treat cancer, HIV/AIDS, and other diseases. Our groundbreaking 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.

Today, Fred Hutch continues to pave the way in research to understand the fundamental biological mechanisms of cancer, develop new methods to diagnose and treat cancer, and generate new knowledge to help individuals and communities reduce the incidence and death rate from cancer. Below are examples of how NIH funding drives Fred Hutch innovation and accelerates research advancements in cancer and other diseases.

- Fred Hutch is spearheading a revolutionary approach, called immunotherapy, which is yielding cancer treatments that can be more effective than conventional drugs, radiation, or surgery. Fred Hutch has led the way in developing cellular immunotherapies, as our researchers were the first to use a melanoma patient's own cloned T cells as the sole treatment to put his cancer into long-term remission.
- NCI-funded research at Fred Hutch showed strains of the human papillomavirus (HPV) cause nearly all cervical cancers. The team also found a way to produce virus-like particles that could trigger an immune response, paving the way for today's cancer-preventing HPV vaccines.
- Launched in 1991 with an NIH grant, the Women's Health Initiative is one of the largest U.S. prevention studies of its kind and the largest, most ethnically and geographically diverse study of older women. A single study from the Fred Hutch Women's Health Initiative showing the health risks of combined hormone therapy led to tens of thousands fewer cases of breast cancer, heart disease and stroke, and venous thromboembolism between 2003 and 2012, generating a net return of \$37.1 billion—or roughly \$140 on every dollar invested in the trial.
- Fred Hutch research also extends to infectious diseases, reflecting a growing understanding that eradicating certain infectious diseases can reduce the world's cancer burden. Fred Hutch began researching HIV in 1988, and today is home to the HIV Vaccine Trials Network supported by the National Institute of Allergy and Infectious Diseases (NIAID)—one of the largest HIV research networks in the world, focused on developing and testing a successful preventive HIV vaccine.

THE VALUE OF FEDERALLY-FUNDED MEDICAL RESEARCH

The Federal Government has an 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 research necessary to yield new innovations and technologies of the future. The partnership between NIH and America's scientists and research institutions is a unique and highly productive relationship, leveraging the full strength of our Nation's research enterprise to foster discovery, improve our understanding of the underlying causes of disease, and develop the next generation of medical innovations—and innovators—that deliver better treatments and cures to patients.

As an independent research institute with its sole mission to pursue lifesaving discoveries, Fred Hutch depends on NIH funding to focus exclusively on basic, translational, and clinical scientific research and to respond quickly to the research needs of the country. In addition to supporting robust funding, Fred Hutch opposes provisions—such as directives to reduce the salary limit for extramural researchers—which would harm the integrity of the research enterprise and disproportionately affect independent research institutes. Policies to cut salary support hinder the center's research mission and ability to recruit and retain the talented researchers who make U.S. institutions global leaders in advancing the biomedical sciences and improving and saving lives.

The NIH initiatives focusing on career development and recruitment of a diverse scientific workforce are important to innovation in biomedical research and public health. Robust increases to the NIH budget are critical to fostering the next generation of scientists, as training funds work to attract the brightest minds to pursue a career in research. Fred Hutch is committed to training the current and next generation of scientific leaders from diverse backgrounds and supports NIH efforts to

address challenges faced by investigators seeking to launch and sustain their research careers.

CONCLUSION

Fred Hutch thanks the Subcommittee for its important work dedicated to ensuring the health of the Nation and for its strong support for NIH funding in fiscal year 2018. We appreciate the opportunity to urge the Subcommittee to provide at least \$39.3 billion in fiscal year 2019 for NIH, including funds provided to the agency through the 21st Century Cures Act for targeted initiatives, as the next step toward a multi-year increase in our Nation's investment in medical research. Advances in bioscience, technology and data science have brought us to an inflection point. This is not a time to pull back. Given the abundance of scientific opportunity, this recommendation represents a minimum investment to sustain progress that only would be amplified through an even more robust commitment.

[This statement was submitted by Gary Gilliland, MD, PhD, President and Director, Fred Hutchinson Cancer Research Center.]

PREPARED STATEMENT OF THE FRIENDS OF THE HEALTH RESOURCES AND SERVICES ADMINISTRATION COALITION

Friends of HRSA is a nonpartisan coalition of 170 national organizations representing tens of millions of public health and healthcare professionals, academicians and consumers invested in the Health Resources and Services Administration's mission to improve health and achieve health equity. HRSA is the primary Federal agency responsible for improving health, and does so by supporting access to quality health services, a skilled workforce and innovative programs. We are grateful for the increases provided for HRSA programs in the fiscal year 2018 omnibus, but HRSA's discretionary budget authority is far too low to effectively address the Nation's current healthcare needs. Additional funding will allow HRSA to fill preventive and primary healthcare gaps and to build upon the achievements of HRSA's 90-plus programs and more than 3,000 grantees. We urge Congress to continue their support for these important programs and we recommend providing \$8.56 billion for HRSA's total discretionary budget authority in fiscal year 2019.

Our Nation's ability to deliver services that meet the pressing health challenges of the 21st century is essential for a healthy and thriving population. The Nation faces a shortage of health professionals, and a growing and aging population which will demand more healthcare. We must make deliberate investments in robust systems of care, and a high-performing workforce ready to respond to the Nation's current health demands and prepared to take on unexpected health needs as they arise. Providing additional funding to HRSA's discretionary budget will allow the agency to address these challenges. The agency is continuously exploring and supporting efforts that drive quality care, better leverage existing investments and achieve improved health outcomes at a lower cost. HRSA's programs have been successful in improving the health of people with complex health, behavioral and social needs who traditionally have poor health outcomes.

HRSA operates programs in every State and U.S. territory. 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 quality health services. HRSA programs work in coordination with each other to maximize resources and leverage efficiencies. For example, Area Health Education Centers, a health professions training program, was originally authorized at the same time as the National Health Service Corps to increase the number of primary care providers at health centers and other direct providers of healthcare services for underserved areas and populations. AHECs play an integral role to recruit providers into primary healthcareers, diversify the workforce and develop a passion for service to the underserved among future providers.

HRSA's programs also work synergistically across the Federal Government to enhance health outcomes. Through maternal and child health programs, HRSA has contributed to the decrease in infant mortality rates, a widely used indicator of the Nation's health. While HRSA has contributed to driving down the national rate, which is now at a historic low of 5.8 deaths per 1,000 live births, it would not have been possible without the effort of other Federal public health programs, including those that address perinatal care, preventive health screenings, cessation programs for tobacco and other substances, healthy eating and physical activity programs, among other efforts.

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 the health emergencies such as the Zika virus and the opioid epidemic. However, much of this work required emergency supplemental funding to increase capacity in health centers, support additional National Health Service Corps providers to deliver care and expand maternal and child 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.

Our recommendation is based on the need to continue improving the health of Americans and to provide HRSA with the resources needed to pave the way for new achievements by supporting critical HRSA programs, including:

- Primary care programs support more than 10,400 health center sites in every State and territory, improving access to preventive and primary care for more than 27 million people in geographic areas with few healthcare providers. Health centers coordinate a full spectrum of health services including medical, dental, vision, behavioral and social services. Close to half of all health centers serve rural populations. For over 50 years, health centers have delivered comprehensive, cost-effective care for people who otherwise may not have obtained care and have demonstrated their ability to reduce the use of costlier providers of care.
- Health workforce programs support the education, training, scholarship and loan repayment of primary care physicians, nurses, oral health professionals, optometrists, physician assistants, nurse practitioners, clinical nurse specialists, public health personnel, mental and behavioral health professionals, pharmacists and other allied health providers. With an emphasis on primary care and training in interdisciplinary, community-based settings, these are the only Federal programs focused on filling the gaps in the supply of health professionals, as well as improving the geographic distribution and diversity of the workforce so that health professionals are well-equipped to care for the Nation's changing needs and demographics.
- Maternal and child health programs, including the Title V Maternal and Child Health Block Grant, Leadership Education in Neurodevelopmental and Related Disabilities, Healthy Start and others support initiatives designed to promote optimal health, reduce disparities, combat infant mortality, prevent chronic conditions and improve access to quality healthcare. 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.
- 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 550,000 people impacted by HIV/AIDS. Additionally, the program provides education and training for health professionals treating people with HIV/AIDS and works toward addressing the disproportionate impact of HIV/AIDS on racial and ethnic minorities. People receiving care through the Ryan White HIV/AIDS Program achieve significantly higher viral suppression compared to the national average, which is central to preventing new HIV infections.
- Title X ensures access to a broad range of reproductive, sexual and related preventive health services for more than 4 million women, men and adolescents, with priority given to low-income individuals. Services include patient education and counseling for family planning; provision of contraceptive methods; cervical and breast cancer screenings; sexually transmitted disease prevention education, testing and referral; and pregnancy diagnosis. This program helps improve maternal and child health outcomes and promotes healthy families.
- Rural health programs improve access to care for people living in rural areas. The Office of Rural Health Policy serves as the Nation's primary advisor on rural policy issues, conducts and oversees research on rural health issues and administers grants to support healthcare delivery in rural communities. Rural health programs are designed to support community-based disease prevention and health promotion projects, help rural hospitals and clinics implement new technologies and strategies and build health system capacity in rural and frontier areas.
- Special programs include the Organ Procurement and Transplantation Network, the National Marrow Donor Program, the C.W. Bill Young Cell Trans-

plantation Program and National Cord Blood Inventory. These programs maintain and facilitate organ marrow and cord blood donation, transplantation and research, along with efforts to promote awareness and increase organ donation rates. Special programs also include the Poison Control Program, the Nation's primary defense against injury and death from poisoning for over 50 years. Poison control centers contribute to significantly decreasing a patient's length of stay in a hospital and save the Federal Government \$662.8 billion each year in medical costs and lost productivity.

We urge you to consider HRSA's central role in strengthening the Nation's health and advise you to adopt our fiscal year 2019 request of \$8.56 billion for HRSA's discretionary budget authority. Thank you for the opportunity to submit our recommendation to the subcommittee.

[This statement was submitted by Gaby Witte, Senior Manager of Government Relations, American Public Health Association.]

PREPARED STATEMENT OF FRIENDS OF THE INSTITUTE OF EDUCATION SCIENCES

Dear Chairman Shelby, Vice Chairman Leahy, Chairman Blunt and Ranking Member Murray:

On behalf of the Friends of IES—a consortium of scientific societies, research universities and independent research organizations—we urge you to include \$670 million for the Institute of Education Science (IES) in the fiscal year 2019 Labor, Health and Human Services, and Education Appropriations bill.

As you know, 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 education policy and practice, as well as rigorous analysis of educational programs and initiatives.

Our member organizations rely on IES to support vital research that probes many of the most important questions confronting American education—from literacy and numeracy at the elementary level, to the integration of technology in teaching and learning, to advancing STEM education, to closing achievement gaps at every level of our educational systems. The National Center for Education Statistics compiles and disseminates important, scientifically valid data that is essential to the research being conducted across the nation. Moreover, IES helps inform policymakers, practitioners, and State and local governments about the most effective strategies, interventions, curricula and teacher training, through the What Works Clearinghouse powered by IES.

Given that public education expenditures generally account for a significant share of State and local budgets, and with the implementation of Every Student Succeeds Act (ESSA)'s new requirements, including those that seek to promote evidence based innovative educational practices, it is more important than ever for the Federal Government to provide robust funding to the agency charged with compiling and disseminating evidence-based educational research and data. To this end, we urge the Committee to support funding IES at \$670 million in fiscal year 2019. 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.

Thank you for your thoughtful consideration of this request,
The Friends of IES

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 of over 150 scientific and professional societies, patient groups, and other organizations committed to preventing and treating substance use disorders as well as understanding their causes through the research agenda of NIDA. In the fiscal year 2019 Labor-HHS Appropriations bill, we request that the subcommittee provide at least \$2 billion above the fiscal year 2018 level for the National Institutes of Health, and within that amount a proportionate increase for the National Institute on Drug Abuse using the Institute's conferenced level of \$1,383,603,000 as NIDA's base budget for Fiscal 2019. We also respectfully request the inclusion of the following NIDA specific report language.

Opioid Initiative.—With additional funding for NIDA targeted at addressing the opioid epidemic, the Institute's opioid specific allocation should be targeted for the following areas: development of safe and effective medications and new formulations and combinations to treat opioid use disorders and to prevent and reverse overdose; conduct demonstration studies to create a comprehensive care model in communities nationwide to prevent opioid misuse, expand treatment capacity, enhance access to overdose reversal medications, and enhance prescriber practice; test interventions in justice system settings to expand the uptake of medication assisted treatment and methods to scale up these interventions for population-based impact; and develop evidence-based strategies to integrate screening and treatment for opioid use disorders in emergency department and primary care settings.

Opioid Misuse and Addiction.—The Committee continues to be extremely concerned about the epidemic of prescription opioid, heroin, and illicit synthetic opioid use, addiction and overdose in the U.S. Approximately 174 people die each day in this country from drug overdose (over 100 of those are directly from opioids), making it one of the most common causes of non-disease-related deaths for adolescents and young adults. This crisis has been exacerbated by the availability of illicit fentanyl and its analogs in many communities. The Committee appreciates the important role that research can and should play in the various Federal initiatives aimed at this crisis. The Committee urges NIDA to 1) continue funding research on medication development to alleviate pain and to treat addiction, especially the development of medications with reduced abuse liability; 2) as appropriate, work with private companies to fund innovative research into such medications; and 3) report on what we know regarding the transition from opioid analgesics to heroin and synthetic opioid use and addiction within affected populations.

Alcohol's Role in Opioid Overdose.—The Committee is concerned that the role of alcohol in opioid and other drug overdoses is not receiving the attention it should. The CDC estimates that alcohol contributes to over 8000 annual overdose deaths that are primarily attributed to other substances, and that data suggest alcohol is commonly omitted from death certificates leading to underreporting. In order to address the opioid crisis, all avenues of investigation must be addressed. The Committee directs NIDA to work with NIAAA and any other appropriate agencies to better understand these linkages and to support research that will help to address this aspect of the problem.

Barriers to Research.—The Committee is concerned that restrictions associated with Schedule 1 of the Controlled Substance Act effectively limit the amount and type of research that can be conducted on certain Schedule 1 drugs, especially marijuana or its component chemicals and certain synthetic drugs. At a time when we need as much information as possible about these drugs, we should be lowering regulatory and other barriers to conducting this research. The Committee directs NIDA to provide a short report on the barriers to research that result from the classification of drugs and compounds as Schedule 1 substances.

Raising Awareness and Engaging the Medical Community in Drug Abuse and Addiction Prevention and Treatment.—Education is a critical component of any effort to curb drug use and addiction, and it must target every segment of society, including healthcare providers (doctors, nurses, dentists, and pharmacists), patients, and families. Medical professionals must be in the forefront of efforts to curb the opioid crisis. The Committee continues to be pleased with the NIDAMeD initiative, targeting physicians-in-training, including medical students and resident physicians in primary care specialties (e.g., internal medicine, family practice, and pediatrics). NIDA should continue its efforts in this space, providing physicians and other medical professionals with the tools and skills needed to incorporate drug abuse screening and treatment into their clinical practices.

Marijuana Research.—The Committee is concerned that marijuana public policies in the States (medical marijuana, recreational use, etc.) are being changed without the benefit of scientific research to help guide those decisions. NIDA is encouraged to continue supporting a full range of research on the health effects of marijuana and its components, including policy research focused on policy change and implementation across the country.

Adolescent Brain Development.—The Committee recognizes and supports the NIH Adolescent Brain and Cognitive Development (ABCD) Study. We know that the brain continues to develop into the mid-twenties. However, we do not yet know enough about the dramatic brain development that takes place during adolescence and how the various experiences people are exposed to during this time interact with each other and their biology to affect brain development and, ultimately, social, behavioral, health and other outcomes. The ABCD study addresses this knowledge gap. The committee also recommends and recognizes that the cost of this comprehensive study should not inhibit investigator-initiated studies or any potential

special appropriation for its ongoing support. The Committee understands that recruitment and data development efforts are proceeding well, and requests a summary report detailing activity and progress to date.

Drug Treatment in Justice System Settings.—The Committee understands that providing evidence-based treatment for substance use disorders offers the best alternative for interrupting the drug use/justice system cycle for offenders with drug problems. Untreated substance using offenders are more likely to relapse into drug use and criminal behavior, jeopardizing public health and safety and taxing criminal justice system resources. Treatment has consistently been shown to reduce the costs associated with lost productivity, crime, and incarceration caused by drug use. The Committee applauds NIDA's focus on adult and juvenile justice populations in its research, supports this important work and asks for a progress report in the next appropriations cycle.

Electronic Cigarettes.—The Committee understands that electronic cigarettes (e-cigarettes)/other vaporizing equipment are increasingly popular among adolescents. Lack of regulation, easy availability, and a wide array of cartridge flavors may make them particularly appealing to this age group. In addition to the unknown health effects, evidence continues to suggest that e-cigarette use may serve as an introductory product for youth who then go on to use other tobacco products, including conventional cigarettes, which are known to cause disease and lead to premature death. Evidence also reveals that these devices are widely used as tools for smoking derivatives of marijuana (hash oil, "shatter," etc.) The Committee requests that NIDA fund research on the use and consequences of these devices.

Drug abuse is costly to Americans; it ruins lives, while tearing at the fabric of our society and taking a financial toll on our resources. Beyond the unacceptably high rates of morbidity and mortality, drug abuse is often implicated in family disintegration, loss of employment, failure in school, domestic violence, child abuse, and other crimes. We know that many of these problems can be prevented entirely, and that the longer we can delay initiation of any use, the more successfully we mitigate future morbidity, mortality and economic burdens.

Over the past three decades, NIDA-supported research has revolutionized our understanding of addiction as a chronic, often-relapsing brain disease -this new knowledge has helped to correctly emphasize the fact that drug addiction is a serious public health issue that demands strategic solutions. By supporting research that reveals how drugs affect the brain and behavior and how multiple factors influence drug abuse and its consequences, scholars supported by NIDA continue to advance effective strategies to prevent people from ever using drugs and to treat them when they cannot stop. 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, however areas of significant concern include the recent increase in lethality due to heroin and synthetic fentanyl, as well as the continued abuse of prescription opioids and the recent increase in availability of designer drugs and their deleterious effects. The need to increase our knowledge about the effects of marijuana is most important now that decisions are being made about its approval for medical use and/or its legalization. We support NIDA in its efforts to find successful approaches to these difficult problems.

The Nation's previous investment in scientific research to further understand the effects of abused drugs on the body has increased our ability to prevent and treat addiction. An obvious significant result of this type of research is the discovery and development of naloxone and other drugs to reduce deaths due to opioid overdose. This one success has saved many lives. As with other diseases, much more needs to be done to improve prevention and treatment of these dangerous and costly diseases. Our knowledge of how drugs work in the brain, their health consequences, how to treat people already addicted, and what constitutes effective prevention strategies has increased dramatically due to support of this research. However, since the number of individuals continuing to be affected is still rising, we need to continue the work until this disease is both prevented and eliminated from society.

We understand that the fiscal year 2019 budget cycle will involve setting priorities and accepting compromise, however, in the current climate we believe a focus on substance abuse and addiction deserves to be prioritized accordingly. Thank you for your support for the National Institute on Drug Abuse.

PREPARED STATEMENT OF FSH SOCIETY

Agency: National Institutes of Health (NIH).

Account: National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), National Institute of Neurological Disorders and Stroke (NINDS), Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), National Heart, Lung and Blood (NHLBI) and other Institutes as appropriate.

Fiscal Year 2019 Program/Amount Language: Scientific opportunities and recent breakthroughs alongside community defined research priorities in facioscapulohumeral disease (FSHD) call for more funding on the disorder. The Committee strongly encourages the NIH to significantly increase funds to \$29 million on basic and exploratory research efforts and to accelerate clinical trials readiness funding to foster access to treatment of facioscapulohumeral muscular dystrophy (FSHD) and other FSHD-related-epigenetic diseases.

Honorable Chairman Blunt, Ranking Member Murray and distinguished members of the Subcommittee, thank you for the opportunity to submit testimony. We kindly request \$29 million for fiscal year 2019 of NIH funding for research on facioscapulohumeral disease (FSHD).

FSHD, a heritable disease, is the most common form of muscular dystrophy with a prevalence of 1:8,000.¹ It affects 934,000 children and adults of both sexes worldwide. FSHD is characterized by progressive loss of muscle strength that is asymmetric and widely variable. Muscle weakness typically starts at the face, shoulder girdle and upper arms, often progressing to the legs, torso and other muscles. FSHD can cause significant disability and, in severely affected individuals, premature death that is mainly through respiratory failure. In addition to affecting muscle, it can bring with it hearing loss, eye problems, asymptomatic cardiac arrhythmias and respiratory insufficiency.

I started my journey in 1989 to raise the understanding and visibility of FSHD. I naively believed in those years that if you had a chronic and debilitating disease that someone somewhere would be funding research and working on a cure. We had not yet discovered that it would happen ever so gradually and that it would take years of personal endeavor and self-advocacy by people directly concerned with the disease to advocate for funding and research. I co-founded the FSH Society in 1991, we are a small group of affected, dedicated and talented individuals working to alter the course of a disease. We testify each year and are still here working hard for a sense of agency and survival against extraordinary odds.

At any age an individual with FSHD should be recognized as a lifelong survivor of severe trauma and tension. Patients and their families deal with the continuing, unrelenting and unending loss caused by FSHD from birth, over the months and through the years. Not for a moment is there a reprieve from continual loss of physical ability; not for a moment is there a time to mourn the loss; not for a moment is there relief from the physical and mental pain that is a result of this disease. There is no known treatment for this disease.

FSHD insidiously and systematically deprives patients and their families of the full range of choices in life. FSHD affects the way you walk, the way you dress, the way you work, the way you wash, the way you sleep, the way you relate, the way you parent, the way you love, how and where you live, and the way people perceive and treat you. Individuals manifesting signs of the FSHD disorder cannot smile; or hold a baby in their arms; cannot close their eyes fully either when awake or when asleep; can no longer run or walk on the beach or climb stairs. Every day they are keenly aware of the things that they may not be able to do tomorrow. This is the reality for the near 41,000 people living with FSHD in the United States of America.

Meticulous scientific efforts by world-class FSHD researchers and clinicians working with partial seed funding from the FSH Society, the NIH and others have yielded significant scientific discoveries advancing epigenetic and human disease knowledge. FSHD is the only human disease known to be caused by the contraction of repetitive “junk’ DNA. Its cause is found within a stretch of ‘junk DNA’ thought previously to have no biological function. A contraction of this array of macrosatellite repeats called ‘D4Z4’ located near the chromosome 4q telomere causes the production of a transcription factor called DUX4. This transcription factor is a gene which when overexpressed makes a protein product DUX4 that causes skeletal muscle death and degeneration. FSHD-patients’ ‘junk’ DNA contains a gene DUX4 that is

¹Deenen JC, et al, Population-based incidence and prevalence of FSHD. *Neurology*. 2014 Sep 16;83(12):1056–9. Epub 2014 Aug 13.

normally turned on in initial stage embryonic development and shuts off before the embryo even implants in the uterus, and as an adult it is packed away in the 'junk'. In FSHD, when this 'junk' array of DNA is shortened, contracted or modified, the gene DUX4 is made accessible, and is toxic to skeletal muscle.^{2,3,4,5}

The fact that reanimated 'junk' DNA can cause disease in a Mendelian fashion is so astounding NIH Director Dr. Francis Collins emphasized its significance on the front page of the New York Times, saying "If we were thinking of a collection of the genome's greatest hits, this [FSHD] would go on the list."⁶ This past March, NIH funded extramural researchers highlighted groups of proteins that normally turn DUX4 off and on (NuRD^{Dux4off}, CAF^{Dux4off} and MBD3L2^{Dux4on}) in development. Researchers found that when MBD3L2 turns DUX4 on in a muscle cell it spreads down the muscle fiber from nucleus to nucleus in culture.⁷ Though in actual muscle tissue these cells may not be as close to one another or touching one another—it might perhaps explain why only muscles are affected in FSHD, as muscle-cell nuclei unlike other cells do not have walls between them. It helps us rationalize a mechanism whereby when at any given time we only view under the microscope one in 1,000 cells expressing DUX4. Controlling MBD3L2 theoretically may affect spreading and progression. Last month, a paper came out in Molecular Therapy on FSHD screens and FSHD candidate targets showing that FSHD causing targets can be repressed by different methods in skeletal myocytes without major effects on certain critical muscle genes. Both small molecules and CRISPR gene editing techniques were independently used. This project funded by NIH NIAMS and industry provides data demonstrating that expression of DUX4-fl toxic variant is regulated by multiple epigenetic pathways, and highlights multiple viable, druggable candidates for therapeutic target development.⁸

The National Institutes of Health (NIH) is the principal worldwide source of funding of research on FSHD. Currently active projects are \$13.654 million fiscal year 2018 (actual), a portion of the estimated \$85 million spent on all muscular dystrophies.

This 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. Congress is responsible for this success by its sustaining support of the overall NIH budget, and enacting the Muscular Dystrophy Community Assistance, Research and Education Amendments of 2001 (MD-CARE Act, Public Law 107-84). Several years past, NIH leadership and staff published the '2015 NIH Action Plan for the Muscular Dystrophies'—a research plan—written by the Federal advisory committee mandated by MD CARE Act, called the MDCC, along with working groups of outside scientific experts in the field. It specifies eighty-one objectives, in six sections (mechanism, screening, treatments, trial readiness, access to care, infrastructure including workforce) in need of funding and further development.⁹

Since inception, the FSH Society has provided approximately \$9.834 million in seed funds and grants to pioneering FSHD researchers and created an international network of patients and researchers. Recent papers have emerged with findings on potential FSHD targets, validated candidate targets, cell and animal models, bio-

²Whiddon JL, Langford AT, Wong CJ, Zhong JW, Tapscott SJ. Conservation and innovation in the DUX4-family gene network. *Nat Genet.* 2017 Jun;49(6):935-940. doi: 10.1038/ng.3846. Epub 2017 May 1.

³Hendrickson PG, Dorá is JA, Grow EJ, Whiddon JL, Lim JW, Wike CL, Weaver BD, Pflueger C, Emery BR, Wilcox AL, Nix DA, Peterson CM, Tapscott SJ, Carrell DT, Cairns BR. Conserved roles of mouse DUX and human DUX4 in activating cleavage-stage genes and MERVL/HERVL retrotransposons. *Nat Genet.* 2017 Jun;49(6):925-934. doi: 10.1038/ng.3844. Epub 2017 May 1.

⁴De Iaco A, Planet E, Coluccio A, Verp S, Duc J, Trono D. DUX-family transcription factors regulate zygotic genome activation in placental mammals. *Nat Genet.* 2017 Jun;49(6):941-945. doi: 10.1038/ng.3858. 2017 May 1.

⁵Töhönen V, Katayama S, Vesterlund L, Sheikhi M, Antonsson L, Filippini-Cattaneo G, Jaconi M, Johnsson A, Linnarsson S, Hovatta O, Kere J. Transcription activation of early human development suggests DUX4 as an embryonic regulator. *bioRxiv.* 2017: 123208.

⁶Kolata, 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>.

⁷Campbell 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.

⁸Himeda 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.* 2018 Apr 26. pii: S1525-0016(18)30192-8. doi: 10.1016/j.ymthe.2018.04.019. [Epub ahead of print].

⁹Rieff 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].

markers, muscle pathophysiology and cell biology, genetics of FSHD, FSHD stem cell biology, MRI, surrogate outcome measures, drug discovery and development work—therapeutic studies using small molecules, studies in gene therapy, genetic engineering, CRISPR, antisense oligonucleotide (ASO), morpholino, and LNA gapmers to name a crowd of exciting priorities and concepts. FSH Society funded researchers have shown through peer review publications proof-of-concept in-vivo and in-vitro studies that the DUX4 gene and protein can be turned off!^{10,11,12}

With more grant applications the NIH can increase the amount of research funding on FSHD without having to increase the NIH budget or take money from other promising areas of research. Better data, higher quality science, and focus allows for more efficiency out of a slowly increasing budget, while achieving the goals of the NIH Action Plan for muscular dystrophy.

We must keep moving forward. At the FSH Society's most recent annual International Research Consortium meeting in Boston, Massachusetts (a meeting funded in part by the NIH NICHD University of Massachusetts Medical School Wellstone Center for FSHD) over 110 researchers from around the world gathered to present the latest data and discuss research strategies. The FSHD clinical and research community listed 2016–2018 priorities in the following Table I as:

TABLE I.

2017/2018 RESEARCH PRIORITIES

Molecular Mechanisms

Priority 1: Understanding genetic toxicity in FSHD.
 Priority 2: Understanding DUX4/Dux4 and how to silence it. How to silence the DUX4 RNA.
 Priority 3: Understanding what real pathophysiology is in FSHD.
 Priority 4: Studying relationship to other markers and correlation between the expression and activity, transcriptional activity of DUX4.

Genetics and Epigenetic

Priority 5: Studies that focus on the uniformity in genetic testing and subgrouping of patients.
 Priority 6: Understanding epigenetic regulation of the repeats to help better understand the disease process and the disease mechanism.
 Priority 7: Research on modifiers of the disease mechanism.

Clinical and Therapeutic Studies

Priority 8: Generating and identifying surrogate outcome biomarkers.
 Priority 9: Establishing validated outcome measures.
 Priority 10: More research with natural history studies.
 Priority 11: Studies to identify, validate, and determine the best standard measurements critical for trial preparedness in FSHD.

Models

Priority 12: Research to ensure clinician-researchers are measuring the same kinds of things which translate into usable tools for our therapeutic industry.
 Priority 13: Development, characterization and use of animal models: whole animal; mice; fish; pig mammal.
 Priority 14: Emphasis on development, characterization and use of FSHD human cellular models.
 Priority 15: Research on models to develop how to deliver, how to formulate, how to turn the conceptual entity into an effective therapeutic use of the entity, all require something that you can test.

(Source: <http://www.fshsociety.org/>).

¹⁰Himeda 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.* 2016 Mar;24(3):527–35. epub 2015 Nov 3.

¹¹Chen JC, King OD, Zhang Y, et al. Morpholino-mediated Knockdown of DUX4 Toward Facioscapulohumeral Muscular Dystrophy Therapeutics. *Molecular Therapy.* 2016;24(8):1405–1411. doi:10.1038/mt.2016.111.

¹²Balog J, Thijssen PE, Shadle S, et al. Increased DUX4 expression during muscle differentiation correlates with decreased SMCHD1 protein levels at D4Z4. *Epigenetics.* 2015;10(12):1133–1142. doi:10.1080/15592294.2015.

NIH funding for muscular dystrophy. Mr. Chairman, these major advances in scientific understanding and epidemiological surveillance are not free. They come at a significant cost. Since passing the MD CARE Act in 2001, funding at NIH for FSHD muscular dystrophy has remained far too level given the remarkable and exponential rate of discoveries in the past 3 years.

FSHD RESEARCH DOLLARS & FSHD AS A PERCENTAGE OF TOTAL NIH MUSCULAR DYSTROPHY FUNDING

[Dollars in millions]

| Fiscal Year | 2006 | 2007 | 2008 | 2009 | 2010 | 2011 | 2012 | 2013 | 2014 | 2015 | 2016 | 2017e | 2018e |
|----------------------------|--------|--------|------|------|------|------|------|------|------|------|------|-------|---------|
| All MD (\$ millions) | \$39.9 | \$47.2 | \$56 | \$83 | \$86 | \$75 | \$75 | \$76 | \$78 | \$77 | \$79 | \$81 | \$85ee |
| FSHD (\$ millions) | \$1.7 | \$3 | \$3 | \$5 | \$6 | \$6 | \$5 | \$5 | \$7 | \$8 | \$9 | \$11 | \$13.7a |
| FSHD (% total MD) | 4% | 5% | 5% | 6% | 7% | 8% | 7% | 7% | 9% | 10% | 11% | 14% | 16% |

Sources: NIH/OD Budget Office & NIH OCPL & NIH RePORT RCDC (a=actual, e=estimate, ee=estimate enacted).

There are 28 active projects NIH-wide totaling \$13.654 million as of April 18, 2018, versus 28 active projects NIH-wide totaling \$12.751 million as of March 3, 2017, and 32 active projects NIH-wide totaling \$12.616 million on April 14, 2016 (source: NIH Research Portfolio Online Reporting Tools (RePORT) <http://report.nih.gov> keyword 'FSHD or facioscapulohumeral or landouzy-dejerine'). NIH's 28 projects cover 2 F31, 1 K22, 1 K23, 12 R01, 1 R13, 4 R21, 1 R56, 1 P01, 1 P50, 2 U01, and 2 U54 grants.

What we need. Specifically, NIH needs to increase its current portfolio by funding substantial additional R01 and R21 style grants. The engine of Federal research runs on the basic building blocks of workforce training, exploratory/developmental research grants (parent R21) and research project grants (parent R01). NIH can help by issuing targeted funding announcements covering FSHD such as Program Announcement (PA) and similar calls for applications. A request for applications (RFA) on FSHD for R01 and R21 grants will yield results in FSHD and illustrate to NIH leadership the pent up demand for funding and let us know that leadership has listened to our concerns. These types of efforts help convey to FSHD and allied researchers that NIH has an elevated interest.

What we are asking for. We request for fiscal year 2019, a doubling of the NIH FSHD research portfolio to \$29 million. We are very appreciative of the slow but steady year-to-year increases and thank NIH and Congress. This year FSHD needs an investment in centers, collaborative research grants—and, most importantly, a rapid ramp up of basic grants and exploratory research awards along with the expansion of post-doctoral and clinical training fellowships. The NIH research plan for FSHD calls for and needs these additional funds to succeed. The opportunities before us in FSHD are quite significant at all levels—the time to move forward with purpose and expeditiously is now. Mr. Chairman, thank you for this opportunity to testify before your committee. Thank you as always for your kind consideration and help.

[This statement was submitted by Daniel Paul Perez, co-Founder & CSO, FSH Society.]

PREPARED STATEMENT OF THE GBS|CIDP Foundation International

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2018

-
- Provide \$39.3 billion for the National Institutes of Health (NIH) and proportional increases across its Institutes and Centers
 - Continue expanding GBS research supported by NIH with proportional funding increases for the National Institute of Neurological Disorders and Stroke (NINDS), and the National Institute of Allergy and Infectious Diseases (NIAID)
-

Chairman Blunt, Ranking Member Murray and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the community of individuals impacted by Guillain-Barré Syndrome (GBS), Chronic Inflammatory Demyelinating Polyneuropathy (CIDP), and related conditions as you work to craft the fiscal year 2019 L–HHS Appropriations Bill.

ABOUT GBS, CIDP, VARIANTS AND RELATED CONDITIONS

Guillain-Barré Syndrome

GBS is an inflammatory disorder of the peripheral nerves outside the brain and spinal cord. It's also known as Acute Inflammatory Demyelinating Polyneuropathy and Landry's Ascending Paralysis. The cause of GBS is unknown. We do know that about 50% of cases occur shortly after a microbial infection (viral or bacterial), some as simple and common as the flu or food poisoning.

We do know that about 50% of cases occur shortly after a microbial infection (viral or bacterial), some as simple and common as the flu or food poisoning. Some theories suggest an autoimmune trigger, in which the patient's defense system of antibodies and white blood cells are called into action against the body, damaging myelin (nerve covering or insulation), and leading to numbness and weakness.

GBS in its early stages is unpredictable, so except in very mild cases, most newly diagnosed patients are hospitalized. 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, with over 90 percent of patients moving into the rehabilitative phase within four weeks. 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. Some patients require speech therapy if speech muscles have been affected.

Recovery may occur over 6 months to 2 years or longer. A particularly frustrating consequence of GBS is long-term recurrences of fatigue and/or exhaustion as well as abnormal sensations including pain and muscle aches. These can be aggravated by 'normal' activity and can be alleviated by pacing activity and rest.

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. Fortunately, CIDP is even rarer than GBS. The incidence of new cases is estimated to be between 1.5 and 3.6 in a million people (compare to GBS: 1-2 in 100,000).

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 not self-limiting (with an end to the acute phase). Left untreated, 30 percent of CIDP patients will progress to wheelchair dependence. Early recognition and treatment can avoid a significant amount of disability.

Post-treatment life depends on whether the disease was caught early enough to benefit from treatment options. Patients respond in various ways. 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 CIDP and related conditions. In order to initiate new, potentially cost-saving programs, CDC requires meaningful funding increases to support crucial activities. CIDP is a progressive condition with serious health impacts. Patients can end up almost completely paralyzed and on a ventilator. The key to limiting serious health impacts is an early and accurate diagnosis. The time it takes for a CIDP patient to begin therapy is linked to the length of therapy and the seriousness of the health impacts. An early diagnosis can mean the difference between a 3 month or 18 month hospital stay, or no hospitalization at all. For the Federal healthcare system, there is an economic incentive to ensure early and accurate diagnosis as longer hospitalizations equate to higher costs.

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. The Zika virus has been linked to the onset of GBS, and it continues to remain critical that NIAID and NINDS receive meaningful increase to support their ongoing efforts into researching, understanding and combatting the virus and associated conditions. We ask that resources continue to be used to support a State of the Science Conference between NIAID, NINDS and the GBS|CIDP community. This conference would allow intramural and extramural researchers to develop a roadmap that would lead research into these conditions into the next decade and encourage younger investigators to apply for grants, leading to sustained research activities. We are continuing to have conversations with the leadership of both institutes to facilitate a robust agenda and goals for the Conference. In our meetings with the leadership we also spoke about the possibilities of cross-institute work between NINDS and NIAID to expand the research and understanding of the link between Zika and GBS. While such a conference would not require additional appropriations, the Foundation urges you to provide NIH with meaningful funding increases to facilitate growth in the GBS, CIDP, and related conditions research portfolio.

PATIENT ACCESS

As we have seen from communities that currently have access to home infusion, such as primary immunodeficiency diseases, the cost 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 and long hours to cities in order to receive treatment and are often forced to choose between paying a bill and incurring the cost to travel for their infusion. Through our work, the Foundation has seen that when there are obstacles to receiving regular infusions, medical management becomes complicated, and 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 sub-optimal circumstances when seeking to manage their condition. Further, when 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 their next infusion. Most importantly patients and physicians should be able to choose their preferred site of care. We hope that members of this subcommittee and Congress as a whole support the Medicare IVIG Access Enhancement Act (H.R.4724).

[This statement was submitted by Lisa Butler, Executive Director, GBS|CIDP Foundation International.]

PREPARED STATEMENT OF THE GLOBAL HEALTH COUNCIL

Global Health Council (GHC), the leading alliance of non-profits, businesses, universities, and individuals dedicated to saving lives and improving the health of people worldwide, thanks the Subcommittee for the opportunity to submit this testimony in support for the Center for Global Health (CGH) within the Centers for Disease Control and Prevention (CDC). For fiscal year 2019, GHC encourages continued robust support for CGH at a minimum of \$488.6 million which maintains funding

that reflects the fiscal year 2018 enacted level. Recognizing that the need is greater, GHC believes that \$642 million is the ideal level to support the work in CGH.

The role of CDC in responding to the current outbreak of Ebola in the Democratic Republic of Congo (DRC), demonstrates the crucial role that the Center for Global Health has in building the capacity of countries to monitor and control infectious disease outbreaks, and ultimately, in protecting the health of Americans. During the Ebola outbreak in West Africa in 2014–2015, the CDC ultimately deployed more than 1,400 epidemiologists, contact tracers, and virus hunters to the affected countries. These experts were critical to ending the epidemic.

CDC serves a critical role in gathering and sharing public health data and evidence, and one of its greatest assets is the level of expertise it brings to both the domestic and global health spheres. Within the CDC, the Center for Global Health protects the health of Americans by monitoring 24/7 disease outbreaks around the world. CGH works in over 60 countries and partners with ministries of health, international organizations, and other global health partners to foster local ownership and strengthen countries' capacity to prevent, detect, and respond to outbreaks.

The Global Disease Detection program monitors 30–40 public health threats each day. Between March 2014 and May 2016, the Global Disease Detection Operations Center tracked over 269 outbreaks in 145 countries, keeping Americans and the global community safe from infectious disease threats. In addition, CGH works with partner countries to improve capacity of local emergency response centers (EOC) to respond to disease outbreaks. And impact is already being seen: as just one example, in Cameroon, work by CDC decreased the response time to stopping outbreaks from 8 weeks to just 24 hours. This rapid response can mean the difference between an isolated incident and a global catastrophe.

Additionally, the CGH is leading the administration's engagement on the Global Health Security Agenda (GHSA), an international effort to accelerate progress toward a world safe and secure from infectious disease threats. In this effort, CDC is collaborating with national governments, international organizations, and civil society to prevent and reduce the likelihood of disease outbreaks, detect potential and emerging threats, and coordinate a rapid, effective response. As demonstrated by the recent outbreaks of Ebola and Zika, prioritizing funding and implementation of global health security objectives are critical to protecting the health and security of citizens around the world.

However, the Center for Global Health is about more than just global health security. It is also home to the Global HIV/AIDS, Global Immunization, Parasitic Disease and Malaria, and Global Public Health Capacity Development programs. These programs position CGH as a leader in global immunization, disease eradication, and public health capacity building, and are critical to CDC's global health mission.

Through these programs CGH works to strengthen foreign government's research and laboratory infrastructure, train new health professionals, foster resilient health systems, and conduct research to develop new technologies to combat diseases around the world. Accomplishments as a result of these programs include:

- CGH is a key partner in the President's Emergency Plan for AIDS Relief (PEPFAR). Working in over 75 partner countries, CGH provides technical assistance on how to implement the latest science, such as scaling up HIV treatment and preventing mother-to-child transmission.
- Immunization programs have helped reduce the number of new polio cases globally by more than 99 percent between 1988 and 2010, and the CDC-led global campaign to eradicate Guinea worm disease has helped reduce the disease burden from 3.5 million cases per year in 1986 to near-eradication today.
- Malaria and Parasitic Disease programs play a key role in developing new tools and diagnostics for malaria and neglected tropical diseases, including conducting research to refine the use of proven interventions to maximize effectiveness and overcome lingering challenges.
- The Field Epidemiology Training Program (FETP) through the Public Health Capacity Building program has trained over 3,100 epidemiologists in 72 countries on how to detect and rapidly respond to infectious disease outbreaks, which greatly contributed to Nigeria's ability to contain the 2014 Ebola outbreak.

Sustained funding the Center for Global Health at CDC will ensure that CGH continues to build strong health systems that ensure security and improvement of health of those around the world, and also of Americans. Moreover, we encourage you to maintain robust investments in global health programs at CDC, while also maintaining funding for other critical humanitarian and development programs that enable the United States to reach its goal of ending extreme poverty and creating a more stable, prosperous world.

Global Health Council thanks the Subcommittee for the opportunity to submit written testimony in support of the Global Health Programs Account. For more information on U.S. investments in global health, visit <http://ghbb.globalhealth.org>.

[This statement submitted by Loyce Pace, MPH, President and Executive Director, Global Health Council.]

PREPARED STATEMENT OF GLOBAL HEALTH TECHNOLOGIES COALITION

Chairman Blunt, Ranking Member Murray, and members of the Committee, thank you for the opportunity to provide testimony on the fiscal year 2019 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). We appreciate your leadership in promoting the value of global health, particularly continued research and development (R&D) to advance new drugs, vaccines, diagnostics, and other tools for longstanding and emerging health challenges.

I am submitting this testimony on behalf of the Global Health Technologies Coalition (GHTC), a group of more than 25 organizations working together to advance policies that can accelerate the development of global health innovations that combat global health diseases and conditions and save lives at home and around the world.

To achieve this goal, we respectfully request maintaining robust funding for NIH, providing funding to match CDC's increased responsibilities in global health and global health security—at minimum level funding of \$488.62 million for the CDC Center for Global Health (CGH) and \$614.57 million for the CDC National Center for Emerging Zoonotic and Infectious Diseases (NCEZID)—and supporting new, dedicated funding for BARDA's critical work in emerging infectious diseases, at a minimum of \$300 million.

We also strongly urge the Committee to continue its established support for global health R&D by urging leaders at the NIH, CDC, the Food and Drug Administration, and other entities within the U.S. Department of Health and Human Services, like the Office of Global Affairs, BARDA, and the NIH Fogarty International Center, to join leaders of other U.S. agencies to develop a cross-government global health R&D strategy to ensure that U.S. investments in global health research are efficient, coordinated, and streamlined.

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. My testimony reflects the needs expressed by our members, which work with a wide variety of partners to develop new and improved technologies for the world's most pressing health issues.

Critical Need for New Global Health Tools

While we have made tremendous gains in global health over the past 15 years, millions of people around the world are still threatened by HIV/AIDS, tuberculosis (TB), malaria, and other neglected diseases and conditions. In 2014, TB killed 1.5 million, surpassing HIV/AIDS deaths. Sub-Saharan Africa saw 1.4 million new HIV infections. Half the global population remains at risk for malaria with drug-resistance growing. One out of 12 children in sub-Saharan Africa dies before the age of five, often from preventable diseases. These figures highlight the tremendous global health challenges that remain and the need for sustained investment in global health R&D to deliver new tools to combat endemic and emerging threats.

New technologies are critical to address unmet global health needs and new challenges like drug resistance, replace outdated or toxic treatments, and overcome barriers in administering current technologies in remote settings. Particularly in our era of globalization where diseases know no borders, investments today in global health innovations will mean millions of future lives saved—at home and around the world.

RESEARCH AND U.S. GLOBAL HEALTH EFFORTS

The United States is at the forefront of innovation in global health, with NIH, CDC, and BARDA leading much of our global health research.

NIH

The groundbreaking science conducted at the NIH has long upheld U.S. leadership in medical research. Within the NIH, the National Institute of Allergy and Infectious Diseases, the Office of AIDS Research, and the Fogarty International Cen-

ter all play critical roles in developing new health technologies that save lives at home and around the world. Recent activities have led to the creation of new tools to combat neglected diseases, including vaccines for dengue and trachoma, new drugs to treat malaria and TB, and multiple projects to develop diagnostics, vaccines, and treatments for Ebola. Leadership at NIH has long recognized the vital role the agency plays in global health R&D and has named global health as one of the agency's top five priorities.

We recognize and are grateful for Congress' work to bolster funding for NIH, including through the 21st Century Cures Act. It remains critical that support for NIH considers all pressing areas of research—including research in neglected diseases. To deliver on the remarkable progress being made across the institutes, it is vital that we renew our commitment to health research and maintain steady support for the NIH.

CDC

The CDC also makes significant contributions to global health research, particularly through CGH and NCEZID. CDC's ability to respond to disease outbreaks, like recent episodes of Zika and Ebola, is essential to protecting the health of citizens both at home and abroad, and the work of its scientists is vital to advancing the development of tools, technologies, and techniques to detect, prevent, and respond to urgent public health threats. Important work at NCEZID includes the development of innovative technologies to provide a rapid diagnostic test for the Ebola virus, a new vaccine to improve rabies control, and a new and more accurate diagnostic test for dengue virus. The center also plays a leading role in the National Strategy for Combating Antibiotic-Resistant Bacteria, to prevent, detect, and control outbreaks of antibiotic resistant pathogens, such as drug-resistant TB.

Programs at CDC's CGH—including the Global HIV/AIDS, Global Immunization, Parasitic Diseases and Malaria, Global Disease Detection and Emergency Response, and Global Public Health Capacity Development programs—have also yielded tremendous results in the development and refinement of vaccines, drugs, microbicides, and other tools to combat HIV/AIDS, TB, malaria, and neglected tropical diseases like leishmaniasis and dengue fever. In addition, the CGH plays a critical role in disease detection and response, working to monitor and respond to outbreaks, develop new tools to help detection efforts, train epidemiologists in high-burden regions, and build capacity of health systems.

CDC's work in novel technology development and global health security has significantly expanded due to the increasing frequency of global disease epidemics and engagement with the international community on a coordinated Global Health Security Agenda (GHSA). This increased responsibility has only been supported with one-time supplemental funding, not sustainable appropriations. As threats multiply, this will jeopardize CGH operations, scale-back important programming, and ultimately put American health security at risk.

GHTC urges the Committee to dedicate new, targeted resources to continue the GHSA work and maintain all global health security activities. This funding should not come at the expense of other vital global health activities at CDC, and we support appropriations for CDC CGH and NCEZID at no less than fiscal year 2018 levels.

BARDA

BARDA plays an unmatched role in global health R&D by providing an integrated, systematic approach to the development and purchase of critical medical technologies for public health emergencies. By leveraging unique contracting authorities and targeted incentive mechanisms, BARDA partners with diverse stakeholders from industry, academia, and nonprofits to bridge the "valley of death" between basic research and advanced-stage product development for medical countermeasures—an area where more traditional U.S. Government research enterprises do not operate.

With these unique assets, BARDA has played a vital role in the development of urgently needed countermeasures for emerging infectious diseases (EIDs) like Ebola and Zika, developing at least three Ebola vaccine candidates, at least six diagnostics for Zika, and at least five Zika vaccine candidates in under 2 years. To date, BARDA's work in advancing tools to protect against the threat of EIDs has been funded through emergency funding. To ensure the continuation of this critical work and forward-looking investments, GHTC supports the creation of a separate line item for EIDs within BARDA, with an authorization at a minimum of \$300 million.

Innovation as a Smart Economic Choice

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.

\$0.89 cents of every U.S. dollar invested in global health R&D goes directly to U.S.-based researchers. U.S. Government investment in global health R&D between 2007 and 2015 generated an estimated 200,000 new jobs and \$33 billion in economic growth. Furthermore, investments in global health R&D today can help achieve significant cost-savings in the future. New therapies to treat drug-resistant TB, for example, have the potential to reduce the price of TB treatment by 90 percent and cut health system costs significantly.

Now more than ever, Congress must make smart budget decisions. Global health research that improves the lives of people around the world—while at the same time supporting U.S. interests, creating jobs, and spurring economic growth at home—is a win-win. On behalf of the members of the GHTC, I would like to extend my gratitude to the Committee for the opportunity to submit written testimony for the record.

[This statement was submitted by Jamie Bay Nishi, Director, Global Health Technologies Coalition.]

PREPARED STATEMENT OF THE HIV MEDICINE ASSOCIATION

The HIV Medicine Association (HIVMA) of the Infectious Diseases Society of America (IDSA) represents more than 6,000 clinicians and researchers working on the frontlines of the HIV epidemic. Our members provide medical care and treatment to people living with HIV in the U.S. and globally, lead HIV prevention programs, and conduct research that has led to the development of effective HIV prevention and treatment options. As you work on the fiscal year 2019 appropriations process, we urge you to increase funding for the Ryan White HIV/AIDS Program at the Health Resources and Services Administration (HRSA); increase funding for the Centers for Disease Control and Prevention's (CDC) HIV, viral hepatitis and STD prevention programs; increase investments in HIV/AIDS research supported by the National Institutes of Health (NIH), including maintaining the Fogarty International Center; and heighten our response to the opioid epidemic including its infectious diseases consequences and the need for workforce expansion.

Three decades of American investment in evidence-based public health approaches to HIV prevention, treatment, care, and research have brought the fight against HIV to a tipping point, both domestically and globally, allowing us to speak cautiously about ending the HIV epidemic, while knowing that our progress is fragile, with implementation of our most effective programs beginning to suffer as funding does not keep pace with demand. U.S. investments have resulted in groundbreaking scientific discovery, saved millions of lives, and realized tremendous cost savings to the healthcare system by preventing new infections and hospitalizations. We now know that early diagnosis and continuous access to HIV treatment allows persons with HIV to live long, healthy, and productive lives; is cost effective; and directly benefits public health by stopping HIV transmission when people with HIV achieve durable viral suppression by taking HIV medications without interruption. Despite progress including a 14.8 percent reduction in new infections between 2008 and 2015,¹ just 50 percent of people living with HIV are optimally benefiting from treatment.² Moreover, our progress is not uniform. The South, now the epicenter of the epidemic with over half of new HIV diagnoses annually, lags behind other regions in care and treatment outcomes. 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, and are estimated to be the amounts necessary to mount an effective response to the HIV epidemic.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

HIV/AIDS Bureau

HRSA's (Health Resources and Services Administration) Ryan White HIV/AIDS Program (RWP), conceived in 1990 as a public health response to AIDS, stands today as the most effective and cost-effective comprehensive care model in the U.S. As people with HIV live longer due to effective treatment, more people need ongoing access to care. At the same time, 37,600 new infections occur annually, straining

¹ Singh S, Song R, Johnson AS, McCray E, Hall HI. HIV Incidence, HIV Prevalence, and Undiagnosed HIV Infections in Men Who Have Sex With Men, United States. *Annals of Internal Medicine*, 2018 Mar 20. doi: 10.7326/M17-2082.

² Centers for Disease Control and Prevention. HIV Continuum of Care, U.S., 2014, Overall and by Age, Race/Ethnicity, Transmission Route and Sex. <https://www.cdc.gov/nchstp/newsroom/2017/HIV-Continuum-of-Care.html>.

the ability of clinics to serve an ever-increasing patient load with flat and increasingly inadequate funding. To continue providing comprehensive, life-saving treatment and care for over 550,000 people with HIV, as well as people newly coming into care, we request a \$145 million increase over fiscal year 2018 omnibus levels for the RWP for a total of \$2.465 billion. It is essential to expand overall funding levels for the Ryan White Program at this critical time.

In particular, HIVMA urges an allocation of \$225.1 million, or a \$24 million increase over current funding, for Ryan White Part C programs. Part C-funded HIV medical clinics currently struggle to meet the demand of increasing patient case-loads. The team-based and patient-centered Ryan White care model has been highly successful at improving clinical outcomes in a population with complex healthcare needs. Those who receive Ryan White services are more likely to be prescribed HIV treatment and to be virally suppressed. Between 2010 and 2016, the viral suppression rate for all Ryan White clients increased from 70 to 85 percent.³ Annual healthcare costs for HIV patients whose virus is not suppressed (often due to delayed diagnosis and care) are nearly 2.5 times that of healthier HIV patients.⁴

As a key component of the opioid response, we recommend leveraging the expertise of Ryan White clinics nationwide in treating individuals with a complex condition in addition to substance use disorder (SUD) and mental health disorders. Increased Ryan White Part C funding is urgently needed to meet demand for SUD and mental health treatment for people with HIV receiving care at these clinical sites. Additional non-Ryan White funding for SUD treatment and supportive services such as case management, would allow clinics to provide SUD treatment to patients with other infectious diseases such as hepatitis C and SUD.

The RWP has always had bipartisan support and now reaches over half of all people with HIV in the U.S. With instability in the individual healthcare insurance market, new State restrictions on Medicaid eligibility, increases in infectious diseases associated due to the opioid crisis, and the rising number of people living with HIV, the program's ability to meet demand for services including HIV treatment, primary care and SUD treatment must be expanded with new resources.

CENTERS FOR DISEASE CONTROL AND PREVENTION

National Center for HIV/AIDS, Viral Hepatitis, Sexually Transmitted Diseases, and Tuberculosis Prevention

To meaningfully address the syndemic HIV, viral hepatitis, and STDs epidemics, as well as the co-occurring crisis of addiction and injection drug use associated with the opioid epidemic, we request a \$303 million overall increase above fiscal year 2018 levels for a total of \$1.430 billion.

For the Division of HIV/AIDS Prevention (DHAP), we request a total of \$872.7 million, which is an \$84 million increase over fiscal year 2018 omnibus levels. DHAP conducts national HIV surveillance and funds State and local health departments and community based organizations to conduct evidence-based HIV prevention activities. In 2015, new infections fell below 40,000 for the first time in decades. CDC's high impact prevention strategies, grounded in the latest evidence-based HIV prevention and treatment, are working but require new resources for scale up. We appreciate the Administration's attention to the infectious disease consequences of the opioid epidemic through an "Elimination Initiative" at CDC, but strongly oppose its short-sighted proposal to cut \$40 million from DHAP to fund it. This is not a cost-effective way to approach the HIV epidemic. Now is a vital time to invest new funding in all the divisions to prevent a worsening of current epidemics. We will effectively address these overlapping threats to individual and public health by building local and State capacity to respond on multiple fronts.

For the Division of Viral Hepatitis (DVH), we request a total of \$134.0 million, which is a \$95 million increase over fiscal year 2018 omnibus levels. On April 18, 2018, CDC announced that in 2016, there were over 41,000 new cases of hepatitis C (HCV), a 21 percent increase over 2015 and a 350 percent increase since 2010. New HCV and hepatitis B (HBV) infections are being driven by injection drug use throughout the country, and especially in regions hardest hit by the opioid epidemic.⁵ A significant increase in resources is needed so that CDC can adequately fund and support viral hepatitis education, prevention, testing, and surveillance ac-

³Health Resources and Services Administration. Ryan White HIV/AIDS Program Annual Client-Level Data Report 2016. <https://hab.hrsa.gov/sites/default/files/hab/data/datareports/RWHAP-annual-client-level-data-report-2016.pdf>.

⁴Gilman BH, Green, JC. Understanding the variation in costs among HIV primary care providers. *AIDS Care*, 2008;20:1050-6. doi: 10.1080/09540120701854626.

⁵Centers for Disease Control and Prevention. Viral Hepatitis Surveillance Report 2016. <https://www.cdc.gov/hepatitis/statistics/2016surveillance/pdfs/2016HepSurveillanceRpt.pdf>.

tivities. With existing resources, the U.S. is not equipped to monitor viral hepatitis cases and the impact of these infections, much less appropriately cure and sufficiently prevent new infections.

For the Division of STD Prevention (DSTDP), we request a total of \$227.3 million, which is a \$70 million increase over fiscal year 2018 omnibus levels. Last year, CDC reported the greatest ever number of new STD cases, with over 1.6 million cases of chlamydia, 468,000 cases of gonorrhea, and 28,000 cases of syphilis, including 628 cases of congenital syphilis. This is a national public health emergency, and should be declared as such. CDC and jurisdictional health departments need a significant investment of new resources to expand local public health capacity to conduct screening, linkage to treatment, and partner services.

NATIONAL INSTITUTES OF HEALTH

Office of AIDS Research

To continue funding 21st century discoveries, such as an effective vaccine, functional cure, and improved HIV prevention and treatment options, HIVMA requests an overall fiscal year 2019 budget level of at least \$2 billion above the fiscal year 2018 omnibus for the National Institutes of Health (NIH). Consistent with the most recent Trans-NIH HIV/AIDS Research Professional Judgment Budget for fiscal year 2018, we ask that at least \$3.450 billion be allocated for HIV research at the NIH in fiscal year 2019, an increase of \$450 million. This level of funding is vital to sustain the pace of research that will improve the health and quality of life for millions of people in the U.S. and in the developing world. Flat funding of HIV/AIDS research since fiscal year 2015 threatens to slow progress toward a vaccine and a cure, erode our Nation's historic worldwide leadership in HIV/AIDS research and innovation, and discourage the next generation of scientists from entering the field.

INFECTIOUS DISEASES AND THE OPIOID EPIDEMIC

The ongoing opioid epidemic means we must prevent its infectious diseases complications and bring those with addictive disease into comprehensive treatment, medical care, and recovery services. Federal fiscal year 2019 resources should support CDC's interventions to prevent, track, and treat infectious diseases. Funding should support collaboration with SAMHSA, CDC, and HRSA to support education and training for medical providers on the frontlines of the epidemic to expand access to coordinated care. NIH and CDC funding is needed to expand research on opioid-related infectious diseases to include endocarditis, and bone, skin and soft tissue infections, in addition to HIV, and hepatitis B and C, and to address the unique barriers to care for justice-involved individuals and rural populations.

EVIDENCE-BASED HEALTH POLICY—SYRINGE SERVICE PROGRAMS

HIVMA applauds the subcommittee's work in advancing report language that allows for the judicious use of Federal funding for syringe services programs as an important prevention and public health intervention. We support the continuation of this policy.

CONCLUSION

We will lose ground against the HIV epidemic if we fail to prioritize HIV public health, treatment and research programs. Already, many Ryan White clinics are underfunded to serve those with HIV who need access to care and medications. The growing opioid crisis and associated rise in infectious diseases, including HIV, calls for increased investment in infectious diseases prevention, treatment, care, and research. We will not end the HIV epidemic at home or abroad with current levels of funding. Increasing funding for these successful programs will save the lives of millions living with, or at risk for, HIV, and will restore our progress toward ending HIV as a public health crisis.

[This statement was submitted by Melanie Thompson, MD, Chair, HIV Medicine Association.]

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 \$454 million for the Agency for Healthcare Qual-

ity and Research (AHRQ) and \$339.121 million for the National Institute for Occupational Safety and Health (NIOSH), in fiscal year 2019.

AHRQ funds research to protect and promote patient safety and care, while identifying and evaluating efficiencies to save lives and reduce costs. HFES requests \$454 million, which is consistent with the fiscal year 2010 level adjusted for inflation. This funding level will allow AHRQ to rebuild portfolios terminated after the last 7 years of cuts and will help the agency avoid a funding cliff that will result in more than a 25 percent cut to its program level budget when the Patient-Centered Outcomes Research (PCOR) Trust Fund is at risk of expiring at the end of fiscal year 2019. HFES also urges the Subcommittee to continue to fund AHRQ as its own agency, rather than integrating it into the National Institutes of Health (NIH), as proposed in the President's fiscal year 2019 budget request.

Additionally, HFES requests \$339.121 million for NIOSH, including funding for the Education and Research Centers (ERCs). The fiscal year 2019 President's budget request proposes reducing the NIOSH budget and eliminating many NIOSH programs, which would limit the ability of workers to avoid exposures that can result in injury or illnesses, push back improved working conditions, eliminate occupational safety and health educational services to U.S. businesses, and ultimately raise healthcare costs. Further, support keeping NIOSH within the Centers for Disease Control and Prevention and oppose moving it to the NIH, as proposed in the President's fiscal year 2019 budget request.

HFES and its members recognize and appreciate the challenging fiscal environment in which we as a nation currently find ourselves; however, we believe strongly that investment in scientific research serves as an important driver for innovation and the economy and for protecting and promoting the health, safety, and wellbeing of Americans. We thank the Subcommittee for its longtime recognition of the value of scientific and engineering research and its contribution to innovation and public health in the U.S.

THE VALUE OF HUMAN FACTORS AND ERGONOMICS SCIENCE

HFES is a multidisciplinary professional association with over 4,500 individual members worldwide, comprised of scientists and practitioners, all with a common interest in enhancing the performance, effectiveness and safety of systems with which humans interact through the design of those systems' user interfaces to optimally fit humans' physical and cognitive 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 decisionmaking, 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 decisionmaking, engineering, design, technology, and the world around us. The reach of HF/E is profound, touching nearly all aspects of human life from the healthcare sector, to the ways we travel, to the hand-held devices we use every day.

CONCLUSION

HFES urges the Subcommittee to provide \$454 million for AHRQ and \$339.121 million for NIOSH. 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 Valerie Rice, PhD, President and Julie Freeman, Interim Executive Director, Human Factors and Ergonomics Society.]

PREPARED STATEMENT OF THE INFECTIOUS DISEASES SOCIETY OF AMERICA

On behalf of the Infectious Diseases Society of America (IDSA), which represents more than 11,000 physicians and scientists involved in infectious disease prevention, care, research and education, I urge the Subcommittee to reject the Trump administration's proposed budget cuts for fiscal year 2019 and to provide robust fiscal year 2019 funding for public health and biomedical research activities that save lives, contain healthcare costs and promote economic growth. IDSA asks the Subcommittee to provide \$8.445 billion for the Centers for Disease Control and Prevention (CDC), \$39.3 billion for the National Institutes of Health (NIH), and \$700 million for the Biomedical Advanced Research and Development Authority (BARDA).

CENTERS FOR DISEASE CONTROL AND PREVENTION

National Center for Emerging and Zoonotic Infectious Diseases (NCEZID)

The NCEZID leads CDC efforts against antibiotic resistance as well as serves to confront public health threats, including emerging and vector-borne diseases. Given this critical work, we ask that NCEZID be funded at \$699.27 million.

Antibiotic Resistance Solutions Initiative (ARSI)

We urge \$200 million in funding for the Initiative in fiscal year 2019. IDSA members see the impact daily that antimicrobial resistance (AMR) has on patients. The Federal response to antimicrobial resistance must be sustained to staunch the tide that now results in more than two million infections and 23,000 deaths each year. In April 2018, a CDC Vital Signs report, Containment of Novel Multidrug-Resistant Organisms and Resistance Mechanisms, showed that early aggressive action does slow the spread of resistant bacteria in healthcare settings, thereby reducing such infections. The analysis details evidence that confirms the value of the investment, including increased funding at CDC, to combat AMR.

The report also highlights the need for continued and robust funding for AMR given that nationwide testing last year documented 221 cases of so-called "nightmare bacteria," that can spread resistance to last-resort antibiotics. The report spells out the need to accelerate efforts to curb resistance or face an increasing burden from these health threats including novel resistance mutations. Despite the grim warnings in the report, the administration's budget proposal would cut funding for ARSI, threatening recent progress toward prevention and detection of multi-drug resistant infections. The requested fiscal year 2019 funding would allow CDC to expand Healthcare-Associated Infections (HAI)/AMR prevention efforts in all 50 States, six large cities, and Puerto Rico. The CDC projects that over 5 years the initiative will yield substantial declines in the leading resistant infections affecting our communities. This funding will lead to a 60 percent decline in healthcare-associated carbapenem-resistant Enterobacteriaceae (CRE), a 50 percent reduction in *Clostridium difficile*, a 50 percent decline in bloodstream methicillin-resistant *Staphylococcus aureus* (MRSA), a 35 percent decline in healthcare-associated multidrug-resistant *Pseudomonas* spp., and a 25 percent reduction in multidrug-resistant *Salmonella* infections. This substantial payoff means a clear net positive for the Federal budget to recoup the direct costs of the program.

CDC Global Health Programs

The Administration's proposed cuts to CDC global health programs jeopardize efforts to end HIV as a worldwide public health threat, diminish the fight to limit drug-resistant tuberculosis, and endanger domestic health security by reducing the ability to detect, prevent and respond to infectious disease threats. IDSA urges the Subcommittee to increase this investment in global health activities in fiscal year 2019 by providing \$642 million in funding to support Global Health Programs that protect Americans by improving health capacity and outcomes overseas. This funding supports the global HIV program that is a key implementer of PEPFAR and facilitates access to life-saving antiretroviral treatment for 14 million people, including to pregnant women living with HIV to prevent transmission to their children. The CDC provides high-quality technical support for surveillance, infection control, diagnosis and treatment of tuberculosis in 25 high burden countries that this funding would enhance. The CDC global health program is critical to ensure America's health security, including strengthening laboratory capacities, disease surveillance and field epidemiology activities in the developing world. Such steps stop health threats overseas before they reach American soil. The CDC is a key implementer

of the Global Health Security Agenda that will expire in September 2019 from lack of funding if additional resources are not committed.

Vector-borne Diseases

A 2018 CDC Vital Signs report found significant increases in vector-borne diseases over the past decade, including a doubling of tick-borne diseases and outbreaks of mosquito-borne diseases like Zika and Chikungunya in the US for the first time. Robust funding of at \$26.410 million for CDC's vector-borne disease efforts is necessary to support State and local health department capacity for testing, surveillance, and prevention.

National Healthcare Safety Network (NHSN)

Funding of \$21 million in fiscal year 2019 would enhance NHSN reporting at more than 20,000 healthcare facilities, including acute-care hospitals, dialysis facilities, nursing homes and ambulatory surgical centers, and enable CDC to continue to provide data for national HAI elimination. Funding will also increase the number of facilities reporting antibiotic use and resistance data, which is essential to evaluate the impact of efforts to reduce inappropriate antibiotic use and prevent the development of resistance.

Advanced Molecular Detection Initiative (AMD)

Funding of \$30 million would allow CDC to more rapidly determine where emerging diseases come from, whether microbes are resistant to antibiotics, and how microbes are moving through a population. The AMD strengthens CDC's epidemiologic and laboratory expertise to guide public health action effectively.

Immunization Grant Program

\$650 million in funding for the CDC's Immunization Program would allow providers to obtain and store vaccines; establish and maintain vaccine registries, and educate the public about the importance of vaccines. The program helps to decrease the number of adults who die each year from vaccine-preventable illnesses and helps prevent outbreaks of diseases due to inadequate vaccination rates.

NATIONAL INSTITUTES OF HEALTH

National Institute of Allergy and Infectious Diseases (NIAID)

Within NIH, NIAID should be funded at \$5.414 billion. The NIAID plays a leading role in research for new rapid ID diagnostics, vaccines, and therapeutics. When clinicians can quickly distinguish between bacterial and viral infections with better diagnostics, targeted patient therapies help preserve our increasingly tenuous existing anti-infective drugs. These efforts, as well as research on new antimicrobials and vaccines, are set to ramp up with the \$50 million increased investment made last year. We ask that the Subcommittee continue this work in fiscal year 2019. The Antibacterial Resistance Leadership Group (ARLG), led by researchers at Duke University and the University of California San Francisco, is an example of extramural AMR research made possible by NIAID.

John C. Fogarty International Center

IDSAs urges \$78.500 million for the Center in fiscal year 2019. The Fogarty Center is instrumental to our Nation's global standing, global health security and our ability to detect and respond to pandemics. U.S. patients and researchers benefit from Fogarty funded breakthroughs on diseases including HIV, tuberculosis, malaria, cancer, diabetes, and heart disease. More than 80 percent of Fogarty's extramural grant budget goes to U.S. academic institutions, and 100 percent of funding engages U.S. scientists and researchers.

ASSISTANT SECRETARY FOR PREPAREDNESS AND RESPONSE

Biomedical Advanced Research and Development Authority

BARDA is a critical initiator of public-private collaborations for antibiotic, diagnostic and vaccine R&D. IDSA recommends that the Subcommittee provide \$700 million for BARDA in fiscal year 2019. Such funding is necessary to allow BARDA to pursue additional work on antibiotic development while maintaining its strong focus on medical countermeasures to address other biotreatments. While BARDA's current efforts have made important progress, the antibiotic pipeline remains insufficient to meet the needs of our physicians and patients, and severely complicates our responses to public health emergencies. The BARDA-NIH Combating Antibiotic Resistant Bacteria Biopharmaceutical Accelerator, or CARB-X, is one of the world's largest public-private partnerships focused on preclinical discovery and development

of new antimicrobial products. CARB-X is working to set up a diverse portfolio with more than 20 high-quality antibacterial products.

CENTER FOR MEDICARE AND MEDICAID SERVICES

Despite the significant and vital contributions ID physicians make to patient care, research and public health, their work continues to be under-compensated. Such stresses have fueled a 20 percent decline in physicians entering this field over the last 5 years. While over 90 percent of the care provided by ID physicians is considered evaluation and management (E/M), current E/M codes fail to reflect the increasing complexity of work undertaken by ID physicians to address the spectrum of serious and emerging public health threats. The complex ID care for patients includes the opioid user epidemic, hospital and post-visit care coordination and patient counseling. New CMS research is needed to identify and quantify elements required for complex medical decisionmaking in these patients with serious infections and their sequelae. The Subcommittee included language in the fiscal year 2017 omnibus appropriations bill directing CMS to conduct studies on E/M codes, but the agency has not yet undertaken this research despite acknowledging these deficiencies in the codes as recently as the 2018 Physician Payment Final Rule. However, we were pleased the Administration's budget plan included \$5 million in new funding for CMS Program Management to study service codes. We urge the Subcommittee to fully fund this effort and use this initial funding to study E/M codes.

INFECTIOUS DISEASES AND OPIOID USE

The opioid epidemic is driving increasing rates of multiple infectious diseases including HIV, hepatitis B and C, and infections of the heart, skin and soft tissue, bones, and joints. The IDSA urges the Subcommittee to provide funding that addresses the infectious disease consequences of this epidemic. Since the 2015 HIV and hepatitis C outbreak in Scott County, Indiana, the CDC has identified 220 additional counties in 26 States that are at risk for similar HIV outbreaks among people who inject drugs. Many jurisdictions have already reported increases in HIV cases linked to injection drug use. The CDC estimates a 133 percent increase in acute HCV infections directly arising from opioid use. While there are less data on many other infections due to insufficient reporting and surveillance, regional and State data analyses indicate a significant increase in hospital infections due to endocarditis (an infection of the heart valve requiring lengthy treatment) linked to injection drug use.

Federal fiscal year 2019 resources should support CDC—through the National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention; NCEZID; and the National Center for Injury Prevention and Control—to integrate interventions aimed at preventing, tracking, and treating infectious diseases with broader efforts to address the opioid epidemic. Funding should also support collaboration with the Centers for Medicare and Medicaid Services (CMS), SAMHSA, CDC, and HRSA, to support education and training for medical providers on the frontlines of the epidemic to help expand access to comprehensive, coordinated care. Finally, NIH and CDC funding are needed to expand research on opioid-related infectious diseases to include endocarditis, osteomyelitis, bacteremia, skin and soft tissue infections, and cerebral infections, in addition to HIV and hepatitis B and C and to address the unique barriers to care and treatment for justice-involved individuals and rural populations.

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 Paul Auwaerter, MD, President, Infectious Diseases Society of America.]

PREPARED STATEMENT OF THE INSTITUTE OF MAKERS OF EXPLOSIVES

INTEREST OF THE IME

The Institute of Makers of Explosives (IME) was founded in 1913 to provide accurate information and comprehensive recommendations concerning the safety and security of the commercial explosives industry. Our mission is to promote safety, and the protection of users, the public and environment, and to encourage the adoption of uniform rules and regulations in the manufacture, transportation, storage, han-

dling, use and disposal of explosive materials used in blasting and other essential operations.

IME represents the U.S. manufacturers and distributors of commercial explosive materials and oxidizers as well as other companies that provide related services. Millions of metric tons of high explosives, blasting agents, and oxidizers are consumed annually in the U.S. Of this, IME member companies and their affiliates produce nearly all of the high explosives and a great majority of the blasting agents and oxidizers. These products are used in every State and are distributed worldwide.

IME also publishes industry best practice standards in its Safety Library Publications (SLPs). These standards have been incorporated in Federal and State regulations and are used internationally. In addition, IME publishes a number of guidance documents on various subjects, such as our Safety and Security Guidelines for Ammonium Nitrate¹ and has produced several DVDs, including a DVD and Leader's Guide for first responders detailing the proper response to transportation incidents involving explosive materials.² The SLPs are regularly reviewed and updated by the Institute and represent the most current, reliable and expert recommendations on explosives management available to the industry. Last year, IME finalized: IME SLP 30, The Safe Handling of Solid Ammonium Nitrate. Based on the AN Guidelines mentioned above, SLP 30 is written to provide a best practice for the safe handling of ammonium nitrate to protect the public, workplace employees and commercial explosives businesses.

In addition, IME has developed a comprehensive quantitative risk assessment (QRA) software program, IMESA FR. The program is a windows-based computer model for assessing the risk from a variety of commercial explosives activities as an alternative to determining safe setback distances based on decades old quantity-distance tables. IMESA FR is a state-of-the-art tool that will prove invaluable to the commercial explosives industry in our continuing mission to ensure the health, safety and security of present and future generations of explosive managers, the public and the environment.

COMMENTS

The following comments reflect our commitment to worker and public safety.

Occupational Safety & Health Administration (OSHA)

IME reiterates our appreciation for the comments the Committee has made in the past encouraging OSHA to conduct a cost-benefit analysis before regulating AN within the scope of its review of "Process Safety Management and Prevention of Major Chemical Accidents (RIN: 1218-AC82)." With the particular rulemaking being moved to long term actions, IME believes the Committee can help advance worker safety by encouraging the OSHA to update the explosives and blasting agent standard.

IME requests that Congress direct OSHA to update the § 1910.109(i) standard for the following reasons:

1. IME supports the continued reliance on the § 1910.109(i) standard, and updating this standard to match current industry best practices.
 - a. The updates include; (1) a prohibition on the use of wooden storage bins, (2) an instruction that fires involving AN should not be fought (our recommendation against fighting AN fires is aimed at offsite first responders, not to trained, in-house fire brigades that respond to emergencies in accordance with facility emergency action plans), and (3) a requirement that facilities prepare emergency response plans in accordance with 29 CFR 1910.38, and share the plans with the local emergency responder community.
2. Current § 1910.109(i) rules have proven very effective. Since the standard was promulgated in 1974, there has not been an accidental detonation of AN at any facility compliant with this regulation.
3. The recommendations above in (1) are included in the previously mentioned IME Safety & Security Guidelines for Ammonium Nitrate (2013), SLP 30, and are largely consistent with the 2016 National Fire Protection Association (NFPA) 400 standard.

¹Safety and Security Guidelines for Ammonium Nitrate; IME, International Association of Fire Chiefs (IAFC), International Association of Explosive Engineers (ISEE), and the National Stone, Sand & Gravel Association (NSSGA), (2013).

²Responding to Highway Incidents Involving Commercial Explosives, IME and Department of Transportation (2013).

4. IME has already completed the outreach to bring in the fire chiefs and other industry partners. IAFC, ISEE, and NSSGA, have endorsed IME's recommendations.
5. AN is also subject to a number of other ATF, EPA, DHS, and DOT safety and security regulations. Updating the current regulations will provide clear and actionable steps that can be taken to ensure safety of workers and the public, without the substantial and recurring financial burden that compliance with PSM, for example, would impose on hundreds of sites nationwide.

The "technical" grade of AN used in the explosives industry has the same chemical composition as the "fertilizer" grade of AN used in the agricultural sector; only the density of the prill is different.

AN, in either form, is not a volatile or self-reactive chemical requiring constant diligence in its handling. Rather, it is a stable, relatively benign substance when it is managed properly—and proper management of AN is simple, well understood, and easily accomplished.

AN does not pose a threat of an accidental release of energy or fumes unless subjected to substantial and sustained heat (e.g., fire), contamination, or shock from a detonator or high impact projectiles.

For these reasons IME encourages Congress to direct OSHA to update 29 CFR 1910.109(i) to further enhance what is a proven, efficient standard for the safe management and handling of AN.

Mine Safety & Health Administration

The fiscal year 2019 budget request for MSHA contains initiatives that we support.

Regulatory Harmonization

Continue to work with stakeholders on regulatory reform of existing standards. MSHA will request data and information from the mining community to identify standards and regulations that could be improved or made effective or less burdensome by accommodating advances in technology, innovative techniques or less costly methods, including the requirements that could be streamlined or replaced in frequency, in accordance with E.O. 13777, Enforcing the Regulatory Reform Agenda.

Safety Alliances

IME formally entered into a voluntary alliance with MSHA to promote safety across the commercial explosives sector. MSHA's Alliance Program enables organizations, like IME, that are committed to mine safety and health to collaborate with MSHA to prevent injuries and illnesses in the workplace. Through the program, MSHA and its allies work together to reach out to, educate, and lead the Nation's mine operators and miners in improving and advancing mine safety and health. While the safety statistics classified under Explosives and Breaking Agents by MSHA are exemplary, IME believes that safety should never take a rest. We look forward to continuing our work with MSHA to promote safety across the entire commercial explosives industry.

Thank you for your attention to these requests.

[This statement was submitted by John Boling, Vice President of Government Affairs.]

PREPARED STATEMENT OF THE INTERNATIONAL FOUNDATION FOR FUNCTIONAL GASTROINTESTINAL DISORDERS

FISCAL YEAR 2019 L—HHS APPROPRIATIONS RECOMMENDATIONS

-
- At least \$39.3 billion in program level funding for the National Institutes of Health (NIH)
 - Proportional funding increase for NIH's National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)
 - Continued focus on digestive disease research and education at the NIH
-

Chairman Blunt, Ranking Member Murray, and distinguished members of the Subcommittee, we thank you for the opportunity to present the views of the International Foundation for Functional Gastrointestinal Disorders (IFFGD) regarding the importance of supporting functional gastrointestinal and motility disorders (FGIMDs) research. Established in 1991, IFFGD is a patient-driven nonprofit organization dedicated to improving the lives of individuals affected by chronic gastro-

intestinal (GI) disorders, including FGIMDs, by providing education and support to patients, healthcare providers, and the public. IFFGD also works to bolster critical research aimed at advancing the development of better treatment options and, eventually, cures for these conditions and has worked closely with the National Institutes of Health (NIH) on research priorities in this area.

As a patient myself, I am keenly aware of the need for increased research, more effective and efficient treatments, and the hope for cures for these debilitating and sometimes even life-threatening conditions. Nearly two decades ago, as a young adult, I was diagnosed with irritable bowel syndrome (IBS). I underwent extensive testing and workups over many years in a costly and fruitless effort to discover what was causing my symptoms and how to treat them. Eventually, I ended up self-treating as best as I could and spent years trying to teach myself to live with my illness. Unfortunately, I am not alone in these experiences. Since becoming President of IFFGD I have heard my story echoed back to me by thousands of others. Patients affected by these disorders face significant delays in diagnosis, frequent misdiagnosis, and inappropriate treatments including unnecessary surgery.

The path to diagnosis and care is slowed by the dearth of research in this area. We ask for your consideration of supporting critical research into the basic mechanisms and clinical care of FGIMDs through your support of increased funding for the NIH. Thank you for your time and your consideration of the priorities of the FGIMD community as you work to craft the fiscal year 2019 L–HHS Appropriations Bill.

ABOUT FUNCTIONAL GASTROINTESTINAL AND MOTILITY DISORDERS

FGIMDs are the most common digestive disorders in the general population, occurring in about 1 in 4 people in the U.S. and accounting for 40 percent of GI problems seen by medical providers. 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 FGIMDs are: dyspepsia, gastroparesis, IBS, gastroesophageal reflux disease (GERD), bowel incontinence, and cyclic vomiting syndrome. Most FGIMDs have no cure and limited treatment options, leaving patients to face a lifetime of chronic disease management. The costs associated with these diseases range from \$25-\$30 billion annually; economic costs are also reflected in work absenteeism and lost productivity.

SUPPORT FOR RESEARCH AT THE NIH

IFFGD urges Congress to fund the NIH at the level of \$39.3 billion or more for fiscal year 2019. Strengthening and preserving the Nation's biomedical research enterprise through the NIH fosters economic growth and sustains innovations that enhance the health and well-being of the American people. Concurrent with overall NIH funding, IFFGD supports the growth of research activities on FGIMDs to bolster the medical knowledge base and improve treatment, particularly through the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). The 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.

PATIENT PERSPECTIVE

I would like to share with you the patient perspective of one of our members:

“My name is Melissa, in early February 2014, I spent a week in the hospital and was eventually diagnosed with gastroparesis. My life changed in ways I could not have imagined—overnight. One day, I was able to eat at buffets and the next day, I was unable to tolerate all foods and liquids. I was hospitalized with severe pain and vomiting, put through a battery of tests, diagnosed, given only a brief explanation of my illness and its treatment, and sent home.

For the next few weeks, I was on a liquids-only diet, and I was told that I had to gradually work my way up to soft foods and (eventually) solids. Unfortunately, nothing like that has occurred. I am able to eat some soft foods, in tiny amounts, but it is becoming clear to me that I will never again be able to eat “normal” foods in “normal” amounts.

At first, I told myself that I would not let this stupid disease define or control me—it simply WOULD NOT be the center of my life. But as time passed, I began to see how foolish that was. Every single day, every second of every day, I think about food. I see it; I smell it; I cook it and feed it to the other members of my household; but I cannot have it myself. I look in the mirror, and I see a skeleton. I try to eat even small amounts of food, and I am in agony. I am weak and fatigued

to levels I didn't think were possible. Some mornings, I don't think I have enough energy to get out of bed. I can barely concentrate and function enough to do everyday tasks. And almost every single night, my husband has to help me up the stairs to bed because he is afraid that if he doesn't, I might fall down those stairs. My 10-year-old daughter has seen me vomiting, screaming in pain, lying on the floor crying, and on the verge of passing out.

I grieve over the fact that I can no longer travel or get out of the house for much of anything. I grieve over missing family events and not being able to attend my daughter's activities. I grieve over not being able to go out to eat, or on a picnic, or to another concert, or any of the other things I know are not possible anymore. I worry that I will not get to see my daughter graduate, or get married, or have children.

I am not on the verge of death today, but when I look in the mirror and think about how tired I am, I realize that people like this do not have long life spans—and it bothers me. I get frustrated because people do not understand how my life is affected by all of this. They ask me all of the time if I am okay now. I can't seem to convince them that I am never going to be okay again—not in the way they mean it. I am told that I “just need to eat.” My own doctor accused me of being an anorexic and told my husband to “watch me.” And though I know people mean well and are trying their best to help, it still makes me so frustrated.

There are hundreds (maybe thousands) of posts in my Facebook feed every day from people who have had to go to the ER or back in the hospital for dehydration, pain, or other such conditions. I know so many people now who have feeding tubes or ports for nutrition. I know many who have developed other serious conditions because of the gastroparesis. I sometimes look at them and think that this will surely be my future, too, and it scares me.

What I do understand is that it is important to me to let people know what I go through—what all gastroparesis sufferers likely go through. I am sharing these personal details in such a public forum because I think it is important for people to see this disease. But I think it is equally important to share how much I have been blessed BECAUSE OF this disease and to let others know how much they matter and how much of a difference they can make.”

Melissa's and my stories are far from unique. There are millions of people across the U.S. suffering and sometimes dying because of these disorders. We thank you for the opportunity to testify before your committee on behalf of all of them and for your time and consideration of our requests.

[This statement was submitted by Ceciel T. Rooker, President, International Foundation for Functional Gastrointestinal Disorders.]

PREPARED STATEMENT OF THE INTERSTITIAL CYSTITIS ASSOCIATION

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2019

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- Provide \$1 million for the IC Education and Awareness Program and the IC Epidemiology Study at the Centers for Disease Control and Prevention (CDC)
 - Provide \$39.3 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 endometriosis, vulvodynia, and overactive bladder. IC patients have significantly more sleep dysfunction, and higher rates of depression, anxiety, and sexual dysfunction.

Some studies suggest that certain conditions occur more commonly in people with IC than in the general population. These conditions include allergies, irritable bowel syndrome, endometriosis, vulvodynia, fibromyalgia, and migraine headaches. Chronic fatigue syndrome, pelvic floor dysfunction, and Sjogren's syndrome have also been reported.

IC PUBLIC AWARENESS AND EDUCATION THROUGH CDC

ICA recommends a specific appropriation of \$1 million in fiscal year 2018 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 is coming to the end of the focus of the IC program on an epidemiology study and before this the program focused primarily on education and awareness. The IC community is concerned that focusing solely on an epidemiology study instead of a renewed focus on education and awareness activities is detrimental to patients and their families. The CDC IC Education and Awareness Program is the only Federal program dedicated to improving public and provider awareness of this devastating disease, reducing the time to diagnosis for patients, and disseminating information on pain management and IC treatment options. ICA urges Congress to provide funding for IC education and awareness in fiscal year 2019.

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 through 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.

IC RESEARCH THROUGH THE NATIONAL INSTITUTES OF HEALTH

ICA recommends a funding level of \$39.3 billion for NIH in fiscal year 2018. 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. Research currently underway holds great promise to improving our understanding of IC and developing better treatments and a cure. The NIDDK Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network studies the underlying causes of chronic urological pain syndromes, including epidemiology. The MAPP Study 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

My name is Amy Macnow and I was diagnosed with Interstitial Cystitis about 3 years ago. A chronic bladder disease with no cure. The first time in my life I've been sick with anything serious.

IC is a tough disease to diagnose, so it took some time. That is one of the most challenging things to deal with, finding a Dr. that specializes in IC that can help diagnose and treat. I can't stress enough how important finding the right Dr. is. IC patients need a Dr. who understands and is willing to go along with them on this long, frustrating, painful and confusing road. I have found strength through having this that I never knew I had, strength to keep going when all treatments so far have failed me.

There are a small number of treatments available for managing IC symptoms, but they only work on a small percentage of patients. I have tried those treatments and some drugs that "might" help. I manage my diet, take lots of supplements and have to see all kinds of Doctors now. I have six! That includes holistic medicine doctors, physical therapists, and acupuncturist. That's along with my regular MD, Urologist and two different gynecologists. This is what my life has become. The life of an IC patient.

I deal with one or more symptoms of IC EVERY SINGLE DAY. Some days definitely better than others, but every single day. It affects my life in so many ways. Work, social, travel and my intimate relationships. I never know how I'm going to feel from one day to the next. Anxiety and fear included.

I must say I am a bit hopeful though. Hopeful that with more awareness raised we will start seeing more treatments, more trials. More research and funding so one day there will be a cure. That is what I hope for. I can learn how to live with IC. I have learned to be strong, but I want to feel better. I want to be healthy again. I am one of millions who feel this way.

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 JAMESTOWN S'KLALLAM TRIBE

Chairman Blunt, Ranking Member Murray and distinguished members of this Subcommittee, on behalf of the Jamestown S'Klallam Tribe, I would like to thank you for this opportunity to submit written testimony on our funding priorities and recommendations for the fiscal year 2019 appropriations process. The Federal budget for Tribal programs and services should be reflective of the Federal Governments solemn promise to honor and uphold its Trust and Treaty obligations to American Indians and Alaska Natives (AI/ANs) given in exchange for vast tracks of Tribal lands and resources. However, budgetary reductions to non-defense discretionary programs, delayed passage of spending bills, the absence of data to support Tribal funding requests, the failure to ensure Tribal governmental parity with State and local governments in various laws and regulations, and the severe and persistent underfunding of programs and services for AI/AN and has severely impacted our ability to maximize funding to effectively and efficiently meet the basic needs of our Tribal communities and citizens. As a result, our communities are more vulnerable to health risks and disease, have a higher incidence of poverty, greater educational discrepancies, and lower labor force participation rates.

We have shown time and again that the Federal investment in our communities is a good investment. For example, the Jamestown Health and Dental Clinics serve Tribal citizens, local veterans, as well as, our non-Native surrounding communities. In providing these services, our Tribe has realized a significant return on our investment and this revenue is used to address healthcare needs, reduce healthcare costs, and increase prevention and treatment services. This is just one example of the immense potential that results when Congress empowers Tribes to manage their own programs and services in a way that best aligns with their communities and local needs through Self-Governance.

TRIBAL SPECIFIC HEALTH & EDUCATION APPROPRIATION PRIORITIES

- Fund Medicare/Medicaid Expansion
- ESSA Title VII Impact Aid—\$2 Billion
- Child Welfare Programs (Title IV—B, Subpart 1 & Subpart 2)—\$280 million/
\$50 million
- Older Americans Act Title VI—\$32 million

FUND MEDICARE/MEDICAID EXPANSION

Historic and persistent underfunding of the Indian Healthcare System is reflected in higher rates of disease and illness and shorter life expectancy in Tribal communities. Per capita expenditures for AI/ANs healthcare were just \$3,136 per person compared to \$8,760 per person nationally based on the Indian Health Service fiscal year 2015 data. Given the inadequate funding for Tribal healthcare, Congress authorized the Indian Health Service (IHS) and Tribal health facilities to use Medicaid funding to supplement IHS funding for Medicaid eligible individuals while, at the same time, ensuring that States would not have to bear any associated costs. It is vital that the Federal Government continue to fully fund Medicaid for eligible AI/AN because the 3rd party revenue is used to supplement Tribal health programs. Medicare/Medicaid has allowed our Tribe to partner with our local communities to provide much needed healthcare services to local non-Native community members, while at the same time, serving as supplemental revenue which we use to leverage the Federal dollar to address the unmet healthcare needs of our Tribal community and citizens. Any changes to the way we receive Medicare and Medicaid funding would negatively impact not only our Tribe but our surrounding communities and the local economy. Our innovative approach to healthcare is an effective and efficient use of the Federal investment resulting in better health services and reduced healthcare costs.

ESSA Title VII Impact Aid—\$2 Billion

Our mission to enhance self-reliance, self-sufficiency and developing strong intellectually astute Tribal citizens includes providing opportunities for personal growth through education. Education is extremely important to our Tribe and continued and increased funding for ESSA Title VII is needed to not only ensure the success of our students and future Tribal leaders but to secure the welfare and vitality of our Tribal community and culture. Currently, 93 percent of Native students are enrolled in local public schools. Impact Aid provides essential funding to public schools serving Native students. Schools use the money for a variety of purposes, including, paying teacher salaries, purchasing text books and computers or for other educational tools and objectives. Underfunding of Impact Aid has negative consequences for AI/AN students as school districts struggle to meet their basic educational needs. Fully and forward funding Impact Act would ensure local school districts are not burdened with budgetary constraints as they work together with Tribes and parents of AI/AN students to improve educational opportunities.

Child Welfare Programs Title IV B (Subpart 1)—\$280 Million & Promoting Safe and Stable Families Title IV B (Subpart 2)—\$50 Million

Tribal child welfare case workers are deeply committed to keeping children with their families and communities in order to maintain cultural connections and cultural survival. Title IV B provides funding to Tribes to support community based child welfare services. Tribal tradition and culture is an integral component of Tribal child welfare programs because it has been proven that culturally tailored programs and services lead to better outcomes for AI/AN children and families. Cultural integration leads to increased community participation and support for these programs which in turn results in a more effective response rate. Maximum flexibility in the use of these funds is essential to allow Tribes to provide ancillary services, including, parenting classes, conducting home visits, and addressing issues, such as, alcohol and substance abuse that have a direct correlation to American Indian/Alaska Native children becoming integrated into the child welfare system.

Older Americans Act—\$32 Million

Reducing isolation through community and cultural activities and ensuring our Elders receive proper nutrition and healthcare is a priority for our Tribe. Title VI of the Older Americans Act is the primary funding source for the provision of these programs and services. Our meal delivery program has been in service for over 20 years and serves over 1200 meals per month on average to our elders. We use Title VI funds to prepare and deliver well-balanced meals to our elders that incorporate traditional foods, such as, elk and fish and vegetables grown in our community garden. Providing support services to our elders is deeply rooted in our beliefs and ensures the survival of our culture, traditions, and language. Our elders are the pathway to the past, present and future for the next seven generations.

NATIONAL HEALTH & EDUCATION APPROPRIATION PRIORITIES

—Special Diabetes Program for Indians—\$200 Million

—Alcohol and Substance Abuse Treatment—\$114 Million Above the Fiscal Year 2016 Level

Special Diabetes Program for Indians—\$200 Million

The Special Diabetes Program for Indians is a critical program that is saving lives in our Tribal communities. This program has grown to become one of this Nation's most strategic and effective Federal investments that is addressing the diabetes epidemic in Indian country. In some Indian communities, nearly 60 percent of the population has been diagnosed with this disease leading to higher medical expenditures and lower life expectancies. Diabetes related health complications include heart disease, neuropathy, vision issues, and a death rate that is 1.6 times higher for AI/AN than the general population. However, the Federal investment has already demonstrated significant improvements for our citizens and communities. SDPI supports over 300 diabetes prevention programs in the Indian Health Service, Tribal, and Urban facilities in 35 States, and the results to date have been extraordinary. In our community, blood sugar levels have decreased, the risk of cardiovascular disease has been reduced, diabetes-related kidney disease progression has slowed, and primary prevention and weight management programs for adults and youth have increased. The program has also encouraged adoption of health lifestyle behaviors and an enhanced focus on AI/AN traditional and cultural practices of cultivating native food sources and healthy traditional food options. Tribes request permanent reauthorization, remaining a mandatory rather than discretionary appropriation and a minimum increase of \$50 million for a total of \$200 million for SDPI.

Alcohol and Substance Abuse Treatment—\$114.5 Million Above Fiscal Year 2016 Level

Alcohol and Substance abuse has plagued Tribal communities for years. A number of factors contribute to the high rates of abuse among AI/ANs, including, intergenerational trauma, broken families, poverty, erosion of traditional values, and limited socioeconomic opportunities. Tribal communities will continue to struggle with addiction and the inter-related social issues unless targeted funding is provided to Tribes to address these issues in a culturally appropriate way.

The Jamestown S'Klallam Tribe continues to support the requests and recommendations of our Regional and National Indian Organizations. Thank you.

[This statement was submitted by Hon. W. Ron Allen, Tribal Chairman/CEO, Jamestown S'Klallam Tribe.]

PREPARED STATEMENT OF JOHNSON & JOHNSON

On behalf of Johnson & Johnson's 135,000 global employees, I am pleased to provide written testimony to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies in support of increased funding for the National Institutes of Health (NIH) fiscal year 2019 budget.

Robust funding for NIH is necessary to ensure the agency's ability to fuel innovation in medical research that advances healthcare here in the United States and around the world, as well as to fortify America's position at the forefront of research. This funding request also represents what is required to remain competitive in addressing emerging health threats confronting the United States and to continue to encourage the pursuit of innovative solutions to address these challenges.

As a physician and scientist, I have dedicated much of my life to translating basic scientific research into medical advances. In my current role as Global Head of Johnson & Johnson Global External Innovation and as a board member of Research!

America, the Nation's largest not-for-profit public education and advocacy alliance, I am acutely aware of the value of our country's investment in research.

In the United States, the vast majority of research into the root causes of disease is publicly funded by the NIH through research grants to more than 2,500 institutions across the country. This research underpins the life sciences economy and enables healthcare companies to transform scientific discoveries of today into the breakthrough healthcare products of tomorrow. Furthermore, the research funded by the NIH often enables the business case for the enormous, at-risk investment of money and effort it takes to discover and develop an important new medical treatment.

At Johnson & Johnson, our vision is to positively impact human health through innovation. In 2017, \$10.6 billion was invested in research and development across our pharmaceutical, consumer and medical devices companies. Our teams of scientists work tirelessly to accelerate the translation of scientific discoveries into meaningful treatments for patients in need. Much of our work, and that of scientists across the industry, would not be possible without the constant progression of the understanding of underlying disease biology—precisely the type of research funded by the NIH.

In addition, Johnson & Johnson recognizes the crucial importance of early-stage companies and the critical role NIH plays in supporting these small businesses through Small Business Innovation Research (SBIR) and Small Business Technology Transfer (STTR) funding. At the Johnson & Johnson Innovation incubator sites, JLABS, we help entrepreneurs and scientists realize their dreams of creating healthcare solutions that improve lives by identifying and nurturing highly innovative ideas in areas of potentially disruptive, cutting-edge research, which may lead to novel platforms, products or technologies. These are advances that the scientific community could only imagine several years ago, yet they are becoming a reality today through the support of public-private partnerships like these.

The work of the NIH is tied not only to innovation and the vitality of the life sciences, but also to the health of our national economy. NIH is the lifeblood of basic research for America, and is also an incredible economic engine. In fiscal year 2017, NIH research funding directly and indirectly supported over 400,000 jobs and spurred nearly \$69 billion in new economic activity. Moreover, the pace of medical research must keep up with the aging of our population. There is an urgent need, both on the individual and socioeconomic level, for strategies to prevent illnesses associated with aging or lifestyle. Diseases such as Alzheimer's, ALS, diabetes, cancer and heart disease threaten to overwhelm our healthcare system in a matter of years with enormous costs of care if we don't find ways to prevent, treat or cure them.

Investments in biomedical research at the end of the 20th century by the Federal Government, and pharmaceutical, medical device and biotechnology companies, combined with the work of industry and NIH-funded investigators across the country, have produced fundamental scientific advances, vast new datasets, and increasingly sophisticated areas of scientific research. As the NIH is working on projects in areas like precision medicine, gene therapy and vaccines to prevent infectious diseases like the influenza and HIV, there has never been a more critical and promising time to work in medical research.

Johnson & Johnson believes that a commitment to fully funding the NIH represents a commitment to fueling innovation in medical research. It is also a commitment to our families by advancing science to match medical need, to our current and future generations of scientists by stimulating the life sciences community and to the prosperity of our Nation as a worldwide leader in medical research. Sustainable, robust investment is needed to strengthen this research and to realize its benefits for improving people's lives and reducing the burden and associated costs of today's major diseases all around the world.

[This statement was submitted by William N. Hait, MD, PhD, Global Head, Johnson & Johnson Global External Innovation.]

PREPARED STATEMENT OF KANSAS NEUROLOGICAL INSTITUTE
PARENT-GUARDIAN GROUP

Chairman Blunt, Ranking Member Murray, Members of the Subcommittee:

Thank you for the opportunity to provide Outside Witness Testimony before the Senate LHHS Appropriations Subcommittee. My interest is related to care and life-long involvement with our grandson, Aidan, whose profound afflictions have been present since he was a young toddler. Our respectful and urgent request is for the Subcommittee to take distinct measures through the Appropriations process, to honor the weakest members of society—those who are affected with the most severe

and profound Intellectual and Developmental Disabilities (I/DD). The December 6, 2017 letter from Congressman Goodlatte, Chair of the House Judiciary Committee, to Attorney General Jeff Sessions, regarding the displacement of fragile Americans from licensed ICFs/IID in good standing, largely clarifies our concerns. <https://www.vor.net/news-and-events/item/representative-bob-goodlatte-s-letter-to-a-g-jeff-sessions>

The Developmental Disabilities Assistance & Bill of Rights Act of 2000 (DD Act) programs' administrative office, the Health & Human Services Administration on Community Living (ACL), remains unresponsive to concerns of families and legal guardians of profoundly affected DD individuals who require close 24/7 care. ACL employees and State DD Act program administrators hired under previous administrations continue a troubling disregard for our most vulnerable, at-risk citizens. Congressional oversight is desperately needed.

The growing number of abuse and deaths of individuals with developmental disabilities occurring in community settings are often marginalized, most notably by the DD Act program Protection and Advocacy (P&A) systems, which operate in every State. Under the ACL umbrella, P&A organizations, through litigation, lobbying, etc. continue to denigrate and close specialized facilities for citizens with developmental disabilities, which are under Federal law.

Currently in Ohio, families are enduring a class action lawsuit brought by the federally funded Protection and Advocacy system against the licensed facilities for their loved ones with disabilities. Such actions by P&A representatives, carried out through skilled deception, reveals a flagrant mis-use of public funds. Tragic outcomes in scattered community settings are happening to such a degree that your colleague, Senator Chris Murphy, called for a nation-wide investigation in March of 2013.

We respectfully request the Committee to support the following fiscal year 2019 House Appropriations report language:

“ The Committee also notes that in *Olmstead v. L.C.* (1999), a majority of the Supreme Court held that the Americans with Disabilities Act does not condone or require removing individuals from institutional settings when they are unable to handle or benefit from a community-based setting, and that Federal law does not require the imposition of community-based treatment on patients who do not desire it.”

This leads to questions as to why Protection and Advocacy organizations are:

- Over-imposing an extreme ideology which harms vulnerable citizens
- Allowed to disregard Federal law—and, perhaps most importantly,
- Why no one is holding federally funded P&A's accountable?

On behalf of the most vulnerable individuals unable to advocate or defend themselves, we respectfully ask the Senate Appropriations Committee/Subcommittee on LHHS to halt funds used for Class Action lawsuits by Protection and Advocacy systems.

We strongly urge the Committee to include bill language that ensures funding for P&A's is not used to remove Congressionally authorized supports.

Respectfully.

[This statement was submitted by Joan Kelley, Vice-president, Kansas Neurological Institute Parent Guardian Group.]

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Respectfully.

[This statement was submitted by Joan Kelley, Vice-president, Kansas Neurological Institute Parent Guardian Group Member.]

PREPARED STATEMENT OF THE LOWER ELWHA KLALLAM TRIBE

The Lower Elwha Klallam Tribe submits this written testimony for the record on the fiscal year 2019 President's Budget Request for Labor, Health and Human Services and Education and Related Agencies programs. The Lower Elwha Klallam Tribe supports a “Department-wide Tribal Health and Well-Being Coordinated Budget for the Department of Health and Human Services”. Linked with the issue of mental health is alcohol and substance abuse. Such a plan is critical to American Indians and Alaska Natives (AI/AN) because of the epidemic rates of alcohol and substance abuse in our communities. An integration plan of these services would be inclusive of the Substance Abuse and Mental Health Services Administration (SAMHSA), Administration for Children and Families (ACF), Health Resources and Services Administration (HRSA), Centers for Disease Control and Prevention (CDC) and the Indian Health Service, even though the IHS appropriations is not included in this Appropriations Subcommittee.

The Lower Elwha Klallam Tribal Health Department operates a multi-disciplinary, ambulatory health department with 9 programs and 81 personnel. We provide services to Lower Elwha Klallam Tribal members, other federally recognized AI/ANs, and other underserved people residing in the greater Clallam County area. As a Tribally operated facility, we provide direct patient care services that include medical, dental, mental health, substance abuse, community health, prevention health, integrative services, and purchased/referred care.

In an effort to present meaningful testimony absent the President's fiscal year 2019 budget proposal, the Lower Elwha Klallam Tribe submits the following requests for fiscal year 2019:

- + \$50 million—Tribal Behavioral Health Grants—Substance Abuse and Mental Health Services Administration (SAMHSA);
- + \$50 Million—Increasing Tribal Access to Promoting Safe and Stable Families (PSSF); and
- + \$3 million—Tribal Court Improvement—Tribal Court Improvement Grants assist Tribal courts.

\$50 million—Tribal Behavioral Health Grants

Substance Abuse and Mental Health Services Administration (SAMHSA)

The Lower Elwha Klallam Tribe has a critical need to address the mental health and chemical dependency epidemic in our community. For our youth, substance abuse and suicide prevention efforts, the Tribe finds that there is no budget equity and performance measures value when Tribes have to compete with each other for critically needed funding to address the widespread status of substance abuse and mental health needs of our citizens. Tribal communities have a historical and escalating need that is uncommon to the rest of the population and requires additional resources to effectively treat the overwhelming need. The Lower Elwha Klallam Tribe continues to see the effects of heroin and opioid abuse in all ages at alarming, epidemic rates within Clallam County.

The Lower Elwha Klallam Tribe uses third party revenue to subsidize its substance abuse prevention and mental health programs in an attempt to adequately address the treatment and long term needs of our patient population with addiction and behavioral disorders. The Tribe realizes the need for trauma-informed, long-term, AI/AN treatment facilities to assist those caught in the cycle of addictions. Instead of ignoring the rising heroine and opioid epidemic, the Tribe is in support of a budget that will allow Tribes to facilitate culturally relevant, trauma-informed treatment services to our patients so that they can continue their journey of wellness in a manner that far surpasses the current 30–45 day in-patient treatment process that public insurance does not adequately authorize or reimburse.

In the United States, we do not approach the treatment of other chronic diseases, like cancer or heart disease, in this fashion. The Tribe is requesting that the payment and reimbursement model for chemical dependency in-patient and mental health services be critically scrutinized. The Tribe urges Congress to fund the integration plan to financially support its efforts in developing a Native best practice treatment and payment system utilizing trauma-informed care targeted at its families and communities.

- + \$50 Million—Increasing Tribal Access to “Promoting Safe and Stable Families (PSSF)”

Administration for Children and Families (ACF)

We support a budget request for \$50 million increase in the discretionary PSSF appropriations from the fiscal year 2016 enacted level to increase the capacity of Tribes to administer child welfare services. AI/AN children are disproportionately represented at two times their population in State child welfare systems nationally. Among individual State foster care systems they are overrepresented at as much as 10 times their population rate. This proposal aims to address this disproportionality by investing in Tribal child welfare systems and, in turn, providing culturally appropriate services to Tribal families.

Many Tribes lack infrastructure and stable funding. The Fostering Connections to Success and Increasing Adoptions Act of 2008 allowed Tribes to directly administer Title IV–E programs, but many Tribes need to build their child welfare programs before they are able to consider developing a program meeting the requirements of Title IV–E. With this increase, total funding reserved for formula grants for Tribes would be \$56 million, including \$36 million discretionary and \$20 million mandatory. We also support a proposal to improve access to PSSF funding for Tribal grantees by eliminating the current statutory threshold of \$10,000 to receive a grant. It will be replaced with a minimum grant award of \$10,000 for all Tribes with approved plans, combined with a hold harmless provision that guarantees that currently funded Tribes receive not less than their current award, so as not to unintentionally undermine the capacity of currently funded grantees. This proposal allows access to critically important funding for preventive services for all Tribes that wish to participate in the program and assures greater stability and predictability in funding year-to-year.

- + \$3.0 Million—Tribal Court Improvement—Tribal Court Improvement Grants assist Tribal courts to:

- Conduct assessments of how Tribal courts handle child welfare proceedings

- Make improvements to court processes to provide for the safety, permanency, and well-being of children as set forth in the Adoption and Safe Families Act (ASFA) and increase and improve engagement of the entire family in court processes relating to child welfare, family preservation, family reunification, and adoption
 - Ensure children’s safety, permanency, and well-being needs are met in a timely and complete manner (through better collection and analysis of data)
 - Provide training for judges, attorneys, and legal personnel in child welfare cases
- This increase will allow the Administration for Children and Families (ACF) to fund a total of 25 Tribal court improvement grants. The expansion of the Tribal Court Improvement Program would continue to strengthen the Tribal court’s capacity to exercise jurisdiction in Indian Child Welfare Act cases and to adjudicate child welfare cases in Tribal court.

CLOSING

There are additional funding areas and payment models that need to be addressed and worked on for the overall health of American Indian and Alaska Native citizens residing throughout the United States; however, the support of the Congress and the Administration with the efforts outlined in this request will help to begin addressing these needs and is greatly appreciated.

Thank you.

[This statement was submitted by Hon. Frances G. Charles, Chairwoman, Lower Elwha Klallam Tribe.]

 PREPARED STATEMENT OF THE LYMPHATIC EDUCATION & RESEARCH NETWORK

Chairman Blunt, Ranking Member Murray, and distinguished members of the Subcommittee, thank you for considering the views of the Lymphatic Education & Research Network (LE&RN) as you begin work on fiscal year 2019 appropriations for the National Institutes of Health (NIH) and all research and public health activities across the Department of Health and Human Services (HHS).

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, damage to the lymphatic system from surgery or an accident, or from parasites as in lymphatic filariasis. Up to 10 million Americans and an estimated 170 million worldwide suffer from LE and related lymphatic diseases. This includes up to 30 percent of breast cancer survivors, children born with lymphatic diseases, veterans who have suffered physical trauma, and tens of millions living with filariasis. Currently, there are no cures and few treatments for these diseases.

Beyond lymphatic diseases such as lymphedema, lipedema and filariasis, lymphatic research is impacting research on cancer metastasis, heart disease, Alzheimer’s, AIDS, Rheumatoid Arthritis, Multiple Sclerosis, Diabetes, obesity and a host of other diseases.

FISCAL YEAR 2019 APPROPRIATIONS RECOMMENDATIONS

LE&RN joins the broader medical research community in thanking Congress for providing a \$3 billion funding increase for NIH for fiscal year 2018 and in requesting at least a subsequent \$2 billion funding increase for fiscal year 2019 to bring NIH’s budget up to \$39.3 billion, which is consistent with the necessary level of funding identified through the 21st Century Cures Act.

In this regard, please provide proportional funding increases for all NIH Institutes and Centers, including, but not limited to the National Heart, Lung, and Blood Institute (NHLBI), the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the National Institute of Allergy and Infectious Diseases (NIAID), the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), the National Eye Institute (NEI), the National Cancer Institute (NCI), and the National Center for Advancing Translational Sciences (NCATS). Lymphatics research impacts many conditions and is studied across various Institutes and Centers at NIH. Additionally, in late 2015, the National Institutes of Health (NIH) hosted a Lymphatic Symposium that brought together leading researchers and community stakeholders. This meeting resulted in identification of 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 lymphatic and lymphedema research activities, we ask the Subcommittee to encourage further collaboration amongst relevant Institutes and Centers conducting important research in this area.

LE&RN also joins the broader public health community in asking Congress to provide the Centers for Disease Control and Prevention (CDC) with \$8.445 billion through fiscal year 2019 and to provide stability in funding regarding resources made available through the Prevention and Public Health Fund, especially those public health and cancer related activities with the potential to increase awareness, education, and surveillance of lymphatic diseases. Please also encourage CDC to partner with stakeholder organizations to advance relevant projects in this regard.

PATIENT PERSPECTIVE

I would like to share with you the patient perspective of one of our members, Catherine, from Elkins, Arkansas:

“After I had gastric bypass in 2003 and lost 200 pounds, I started noticing my legs swelling and asked my doctor about it. She gave me water pills, which did not help. Every time I would see her I would never get any answers as to why my legs were swelling.

I had made an appointment with a surgeon about getting my extra skin removed on my stomach and she couldn’t do the surgery because my blood platelets were too low, but she did say I had lymphedema and ordered me the strongest compression hose you can get, 40/50, which years down the road I found out they were hurting me more than helping. Then, I started wearing ones that weren’t so strong. I now wear compression wraps that my mother sends to me when she orders a new pair for herself. (She too has lymphedema.)

There are days like today that my legs hurt so much. I don’t know what to do or who to talk to. It’s very depressing because my family just thinks that I can press through it and that it’s not so bad. They just don’t understand. I just wish I could find a doctor who knows what’s going on with me and tell me if I’m even wearing the wraps right or how long to wear them. I have so many questions that never seem to get answered. It’s so depressing. I wish there was someone to talk to.”

Catherine’s story helps to demonstrate the need for increased awareness of these devastating diseases. In this regard, I would also like to share excerpts from an NPR article written earlier this year entitled, “She Survived Breast Cancer, But Says A Treatment Side Effect ‘Almost Killed’ Her,” which shed light on the struggle with lymphedema that many breast cancer survivors endure:

“After Virginia Harrod was diagnosed with stage 3 breast cancer in 2014, she had a double mastectomy. Surgeons also removed 16 lymph nodes from under her armpit and the area around her breast, to see how far the cancer had spread and to determine what further treatment might be needed. Then she underwent radiation therapy.

As it turned out, the removal of those lymph nodes, along with the radiation, put Harrod at risk for another disorder—lymphedema, a painful and debilitating swelling of the soft tissue of the arms or legs, and/or an increased vulnerability to infection. The lymph system problem she developed months after her surgery was a direct result of her lifesaving cancer treatment. “Cancer was a piece of cake,” Harrod says. “It was the lymphedema that almost killed me.”

Harrod is a county prosecutor in Kentucky, and was able to return to work just 10 days after her mastectomy. Her recovery from cancer seemed to be proceeding well, she says, until the day—nine months after the surgery—when her cat scratched her hand. She didn’t think much of it, she says, until the next day. “My right arm started itching terribly,” Harrod says, “and these bizarre little red blisters were forming.”

Harrod figured it was hives, but her doctor recognized the symptoms as a serious and advancing infection—cellulitis—and sent her to the hospital for IV antibiotics.

Harrod was in the hospital for eight days, and that’s when she first learned she had lymphedema. Over the next 10 months, she was readmitted twice more with dangerous infections.

It’s usually a lifelong condition. Still, many people have never heard of it. Dr. Joseph H. Dayan, a reconstructive surgeon with Memorial Sloan Kettering Cancer Center, says he sees patients every week who have survived breast cancer but break down in tears in his office.

“They’re crying, not only because they struggle with lymphedema,” he says, “but because many people, including some doctors, do not recognize this as a debilitating condition” that can require laborious, daily care.

“People just don’t see it,” Dayan says. “They don’t see the disability.” Even for many doctors, he says, “lymphedema is overshadowed by the fact that cancer is the priority.”

Thank you for the opportunity to testify before your committee and for your time and consideration of our requests.

[This statement was submitted by William Repicci, President and Ceo, Lymphatic Education & Research Network.]

PREPARED STATEMENT OF THE MARFAN FOUNDATION

THE FOUNDATION’S FISCAL YEAR 2019 L–HHS APPROPRIATIONS RECOMMENDATIONS

—\$8.445 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.

—\$750,000 for a new rare cardiovascular conditions program at the National Center for Chronic Disease Prevention and Health Promotion (NCCDHP) to advance awareness activities that would improve health for communities affected by these conditions and lower healthcare costs with timely diagnosis and proper management.

—At least \$39.3 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); National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS); National Eye Institute (NEI); and National Center for Advancing Translational Sciences (NCATS).

Chairman Blunt, Ranking Member Murray and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the heritable connective tissue disorders community as you work to craft the fiscal year 2019 L–HHS Appropriations Bill.

ABOUT MARFAN SYNDROME AND HERITABLE CONNECTIVE TISSUE DISORDERS

Connective tissue is found throughout the body and heritable connective tissue disorders, like Marfan syndrome, can affect many different parts of the body. Features of the disorders are most often found in the heart, blood vessels, bones, joints, and eyes. Many of these disorders are genetic conditions that cause the aorta (the main blood vessel that carries blood from the heart to the rest of the body) to enlarge, a life-threatening problem that requires appropriate and timely medical intervention. Additionally, life-long chronic and progressive issues remain a continuous burden.

ABOUT THE FOUNDATION

The Marfan Foundation creates a brighter future for everyone affected by Marfan syndrome and related disorders.

—We pursue the most innovative research and make sure that it receives proper funding.

—We create an informed public and educated patient community to increase early diagnosis and ensure life-saving treatment.

—We provide relentless support to families, caregivers, and healthcare providers.

We will not rest until we’ve achieved victory—a world in which everyone with Marfan syndrome or a related disorder receives a proper diagnosis, gets the necessary treatment, and lives a long and full life.

CENTERS FOR DISEASE CONTROL AND PREVENTION

At the direction of Congress, the Centers for Disease Control and Prevention (CDC) currently makes a notable annual investment in public health programs focused on the most common cardiovascular conditions. These activities are tremendously valuable in terms of advancing science, raising awareness, improving health, and lowering healthcare costs. These successful efforts should be recognized and a parallel program should be established in fiscal year 2019 for rare heart conditions.

While any individual condition can be considered “rare”, when rare heart conditions are considered together, they impact millions of Americans—any CDC activities would significantly benefit public health. Moreover, many of these conditions are chronic, serious, and have numerous comorbidities. An ongoing CDC campaign should focus on multiple rare heart conditions in a systematic fashion through meaningful collaboration with stakeholder organizations.

Please provide CDC with a specific funding level of \$750,000 in fiscal year 2019 (and moving forward) for a new rare cardiovascular conditions program at the National Center for Chronic Disease Prevention and Health Promotion.

NATIONAL INSTITUTES OF HEALTH

NIH, specifically NIAMS and NHLBI, have worked closely with the Foundation to investigate the mechanisms of these conditions. In recent decades, this research has yielded significant scientific breakthroughs that have the potential to improve the lives of affected individuals. In order to ensure that the heritable connective tissue disorders research portfolios can continue to expand and advance, NIH requires meaningful funding increases to invest in emerging and promising activities.

PATIENT PERSPECTIVE

Other than his height, Nick Vogel, a 6’9” volleyball player from San Diego, did not display easily-detectable characteristics of Marfan syndrome. Intensive screening for the disorder isn’t indicated nor affordable for the average 16–18 year old who plays the sport, where being tall is standard. It wasn’t until a routine echocardiogram was performed by the USA Volleyball Team’s physician that an abnormality was detected in Nick’s aorta. Nick received the news while playing for Club Team Friedrichshafen in Germany, and was told to stop all strenuous activity immediately.

Genetic sequencing throughout the following weeks would reveal an FBN1 mutation, and Nick subsequently retired from volleyball at the age of 25. Since then, it has become Nick’s mission (along with his mother Rita) to raise awareness, to educate, and to support athletes who may be affected by Marfan or related disorders. Without the echocardiogram and subsequent genetic testing, Nick may not have received his diagnosis until he had suffered a potentially life-ending aortic aneurysm, and by then, it would be too late.

[This statement was submitted by Michael Weamer, President and CEO, The Marfan Foundation.]

PREPARED STATEMENT OF MAYOR ROBERT CROWELL

Chairman Blunt, Ranking Member Murray and Committee Members:

Thank you for the opportunity to inform you of essential services for our community. As the committee works on fiscal year 2019 appropriations, please consider the following letter that explains the critical importance of Title X to local communities in our Nation. This program’s principal role supporting providers to serve as essential health access points for contraceptive care and related preventive services is important to our community.

Carson City’s Title X service area spans 856 square miles to include Carson City and the adjoining Douglas County. The total population of these two counties is approximately 102,000. Young adults with young families are attracted to our area by employment opportunities within the tourist and construction industries. These families generally have income falling at the lower end of prevailing wage scales.

Carson City Health and Human Services (CCHHS) is a local health department that provides just over 5,000 high-quality family planning and other preventive health visits to thousands of low income and/or uninsured individuals. Eight-seven percent of those we serve are women and 13 percent are men. Sixty-six percent have incomes below 100 percent of the Federal Poverty Level, 50 percent are uninsured, and 30 percent have public insurance. Access to a healthcare provider is not readily available to all residents in our community; CCHHS is designated by CMS as an

Essential Community Provider. Services at our Title X sites are provided at a lower cost than physician-based clinics, as our Title X clinics are staffed with nurse practitioners and registered nurses.

In some arenas, Title X Family Planning has been reduced to ideological arguments surrounding birth control and abortion. In our practice, the need for contraception brings women in for services, but during the visit so much more is provided. In following the U.S. Preventive Task Force guidelines, men and women are screened for weight, height, body mass index, high blood pressure and diabetes; domestic violence and human trafficking; tobacco, alcohol and other drug use; sexually transmitted infections and HIV; cervical and breast cancer; and their desire for starting a family in the future. In addition, we offer pregnancy testing, health education, along with medical screenings that help men and women to be at their healthiest when wanting to start a family. We, also, offer abstinence programs to pre-teens and teens. Providing good healthcare is about offering to clients whatever they need to improve their health and well-being.

Carson City's Title X Family Planning also plays an essential role in testing and treating sexually transmitted infections. Out of 25 medical providers in Carson City our Title X service site reported 45 percent of all positive Chlamydia cases during 2014. Out of 22 medical providers in the Douglas County our Title X service site reported 33 percent of all positive Chlamydia cases during 2014. Contrary to public belief, men and women do not always want to share their reproductive health needs with their primary care physician. Instead, residents come to their local Title X clinic to be tested, treated and to discuss their sexual health needs.

Carson City Health and Human Services has been in the forefront of using an electronic health record and billing for public health services in Nevada. Our local health department has invested in building the infrastructure that supports quality care for our residents. We are a responsible steward of Federal dollars—seeking out multiple revenues streams in order to sustain our safety net reproductive health program. The Title X program is an essential piece of overall funding as we continue to provide health services within our community. Without Title X funding many of our most-at-need residents will be without the healthcare that we offer.

In 2014, Nevada's Title X Family Planning Services helped to prevent 3,100 unintended pregnancies, which likely would have resulted in 1,500 unintended births and 1,100 abortions. Without publicly funded family planning, unintended pregnancies and unplanned birth in Nevada would be 16 percent higher. For every dollar invested in Title X supported services a savings of \$7.09 is recognized. In 2010 alone, Nevada recognized 20.5 million dollars in savings. Data from the National Ambulatory Medical Care Survey shows only 65 percent of generalist physicians accept new Medicaid patients. When individuals do seek care with primary care physicians, only 23 percent of the visits address reproductive health needs. Title X family planning clinics are part of the medical safety net. But even more important in our Nevada communities and across the country, Title X Family Planning is a cohesive part of the overall fabric of comprehensive healthcare. Title X Family planning clinics serve the preventive health needs within a community so private medical providers and federally qualified health centers can focus much needed and under—available services on the care of acute and chronic diseases.

Yours Respectfully,
Mayor Robert Crowell.

PREPARED STATEMENT OF MEALS ON WHEELS AMERICA

Dear Chairman Blunt, Ranking Member Murray and Members of the Subcommittee:

Thank you for the opportunity to present testimony concerning fiscal year 2019 appropriations for the Older Americans Act (OAA) Nutrition Program administered by the Administration for Community Living (ACL)/Administration on Aging (AoA) within the U.S. Department of Health and Human Services. I am providing this testimony on behalf of the 2.4 million seniors who depend on congregate and home-delivered meals to remain healthier and independent in their homes, as well as the millions of volunteers and more than 5,000 local senior nutrition programs that care for them in your own States and across the country. We are grateful for your ongoing support of these proven and effective nutrition programs, including the \$59 million increase provided in H.R. 1625, the Consolidated Appropriations Act of 2018. We also appreciate your concern for the issues surrounding senior hunger and isolation, including the growing number of those who need Meals on Wheels but remain on waiting lists for services due to limited funding. In fiscal year 2019, we urge you to continue to build on the long-standing bipartisan, bicameral support and increase

Federal funding for the OAA Nutrition Program by \$100 million over fiscal year 2018 levels, for a total of \$996.7 million. Our specific line-item requests are:

- Congregate Nutrition Services (Title III, C-1)—\$490,342,000
- Home-Delivered Nutrition Services (Title III, C-2)—\$346,342,000
- Nutrition Services Incentive Program (Title III, NSIP)—\$160,069,000

At this critical juncture in our nation's history, when both the need and demand for OAA Nutrition Program services are rapidly climbing, we ask that you give this request your utmost consideration. This program is one of the best examples of a successful public-private partnership in which vulnerable seniors not only receive nutritious meals, but also receive opportunities for socialization, safety checks and connections to community resources that reduce healthcare costs and benefit our communities and taxpayers, as a whole.

For more than 50 years, the OAA has been the primary piece of legislation supporting vital services for older adults and their caregivers, with congregate and home-delivered services being the only Federal programs designed to meet both the social and nutritional needs of our nation's most at-risk seniors. Proudly, the OAA Nutrition Program has delivered over 8 billion meals since its inception, and the network of service providers has the infrastructure and capability to serve even more, if properly funded.

The person-centered, community-driven approach that Meals on Wheels programs and millions of dedicated volunteers carry out each day enables seniors to live more nourished and independent lives longer in their own homes—where they want to be—reducing unnecessary and costly visits to the emergency room, admissions and readmissions to hospitals, and premature nursing home placements. In short, the OAA Nutrition Program delivers more than just a meal to those who are fortunate enough to receive its services and is an essential part of the solution to reducing healthcare expenditures resulting from an aging population that is increasingly threatened by hunger and isolation.

INADEQUATE FUNDING PLACES MORE AND MORE AMERICANS AT RISK

Today, one in four seniors lives alone and 8.6 million seniors may not know from where their next meal will come. Yet, in 2016, funding provided through the OAA was only able to support the provision of meals to 2.4 million seniors nationwide. In addition, a 2015 Government Accountability Office report found that about 83% of food insecure seniors and 83% of physically-impaired seniors did not receive OAA meals, but likely needed them. Further highlighting the problem, the OAA network overall is serving 16 million fewer meals to seniors in need than it was in 2005—representing a 6.6% decrease—due in large part to Federal funding not keeping pace with inflation or need. Over that same time, the population of individuals 60 and older grew by 38%. Simply put, too few seniors who need meals are receiving them.

While the \$59 million increase as part of the fiscal year 2018 Omnibus Appropriations Bill was an encouraging, desperately needed step in the right direction, an increase of this level is not nearly enough to close the gap between seniors in need and those served. Taking into account that 12,000 more Americans turn 60 each day, this gap will undoubtedly continue to grow and contribute to poorer health and increased healthcare utilization among seniors if left unabated. We can and must do better.

SERVING THE MOST VULNERABLE

Data from ACL's State Program Reports and National Survey of OAA Participants demonstrates that the seniors receiving meals at home and in congregate settings, such as senior centers, need and rely on these services to help them remain more healthy, safe and independent. Often, the single meal provided through the OAA Nutrition Program represents half or more of a senior's total daily food intake. Further, the meal delivery volunteers, staff and/or peers at a congregate dining facility may also be the only individuals a senior meal recipient sees in a given day.

Below is the profile description of at-risk seniors receiving Meals on Wheels through the OAA:

- 59% are 75+ years old
- 59% are women
- 35% live at or below the poverty level
- 46% self-report fair or poor health
- 15% are veterans
- 25% live in rural areas
- 28% are a racial and/or ethnic minority
- 82% take 3+ medications daily

The extreme vulnerability of this population was further underscored in a groundbreaking 2015 study entitled *More Than a Meal*, commissioned by Meals on Wheels America. The study found that seniors on Meals on Wheels waiting lists were significantly more likely than a nationally representative sample of comparably aged Americans to:

- report poorer self-rated health (71% vs. 26%);
- screen positive for depression (28% vs. 14%), and anxiety (31% vs. 16%);
- report recent falls (27% vs. 10%), and fear of falling that limited their ability to stay active (79% vs. 42%).

Even a slight reduction in nutritional intake for a vulnerable senior can accelerate physical and mental impairment and impede recovery from illness, injury, treatment or surgery. A senior struggling with hunger has physical limitations comparable to food-secure seniors 14 years older, thereby causing a significant discrepancy between chronological and physical age. Compounding the struggles of hunger with the negative effects of loneliness on health—which is comparably detrimental to smoking up to 15 cigarettes a day—results in profound social and economic consequences. Without adequate Federal funding, more and more seniors are forced to make daily trade-offs between food, rent, utilities and medicine, which often prematurely lands them in the emergency room, hospital and/or costly long-term care facilities.

THE SOLUTION EXISTS

Older adults are often at risk of poor nutrition given the myriad of social, economic and functional challenges that may accompany aging and limit ability to access, prepare and consume nutritious foods. Food insecurity and malnutrition are associated with poor health and \$77 billion in healthcare costs annually. Especially frail seniors, like those served through Meals on Wheels, mostly comprise the 5% of individuals who account for over 50% of healthcare spending. Food-insecure seniors are at higher risk of falls, which contributes another \$50 billion in total medical costs in 2015. However, the *More Than a Meal* study referenced above found that those seniors who received daily home-delivered meals (the traditional Meals on Wheels model of a daily, home-delivered meal, friendly visit and safety check) experienced the greatest improvements in health and quality of life. Specifically, between baseline and follow-up, seniors receiving daily home-delivered meals were more likely to exhibit improvements in physical and mental health, including reductions in falls and the fear of falling, as well as report fewer hospitalizations, reduced levels of anxiety, feelings of isolation, loneliness and worry about being able to remain at home.

Investing in Meals on Wheels has also been shown to reduce hospital readmissions and post-discharge costs. Further, in-home interactions with a senior enables early detection of a change in condition or worse yet, a medical emergency that can be immediately addressed. In previous testimony, I have provided the Subcommittee with information relating to the significant reductions in post-discharge costs—some as high as 31%—associated with interventions by Meals on Wheels. In pilot studies in six States, 30-day readmission rates post-medical intervention ranged from 6–7% for Meals on Wheels recipients in comparison to national readmission rates of 15–33% over the same period. Every \$25 per year per older adult spent on home-delivered meals results in a reduction of up to 1% of the low-care nursing home population, saving hundreds of millions of dollars in annual Medicaid costs alone, for individuals and taxpayers. The infrastructure and cost-effective solutions to support this unique population already exist through the OAA network of more than 5,000 local, community-based programs. With Federal funding as the foundation for 8 out of 10 Meals on Wheels programs that rely on the OAA to provide such critical social and nutrition services to America's most at-risk seniors, now is the time to invest further in these programs.

DELIVERING A STRONG RETURN ON INVESTMENT FOR OUR NATION

We know you are tasked with making tough decisions during this appropriations cycle; nonetheless, we make the ask for a \$100 million increase for home-delivered nutrition services because of the growing unmet need and the powerful return to seniors and taxpayers alike. Taking into account the undeniable success of this public-private partnership—where \$1 appropriated through the OAA leverages about \$2 or more in other sources—a funding increase of \$100 million could enable the Meals on Wheels network to raise an additional \$200 million, creating the potential to serve an additional 88,000 seniors in need annually. While still not enough to provide meals to every senior in need, such a funding increase would build on the down

payment that was made through the fiscal year 2018 appropriations and further boost Meals on Wheels programs' capacity to serve.

The OAA Nutrition Program currently takes up less than one-sixth of 1% of the total non-defense discretionary budget; meanwhile, Medicare and Medicaid costs continue to rise year over year. Investing in providing meals designed specifically for seniors' nutritional needs, as well as creating opportunities for socialization and injury and/or illness prevention, can change this. OAA Nutrition Programs are an under-leveraged solution, with the potential to produce billions of dollars in savings to the Mandatory side of the budget. By increasing funding for meals, more seniors can remain in their own homes, driving healthcare costs down significantly. After all, we can deliver Meals on Wheels to a senior for an entire year for the same cost or less on average as just one day in the hospital or ten days in a nursing home.

As your Subcommittee crafts and considers the fiscal year 2019 Labor-HHS-Education Appropriations Bill, we ask that you provide, at a minimum, \$996,753,000 for all three nutrition programs authorized under the OAA (Congregate Nutrition Program, Home-Delivered Nutrition Program and the Nutrition Services Incentive Program). To demonstrate additional support for this increase, more than 30 of your colleagues signed onto a letter on April 13, 2018, calling for a 12% increase to all OAA programs. Again, we thank you for your leadership and continued support through the appropriations process. We hope our testimony has been instructive and are pleased to offer our assistance and expertise at any time throughout this process.

[This statement was submitted by Ellie Hollander, President and CEO, Meals on Wheels America.]

PREPARED STATEMENT OF THE MEDICAL LIBRARY ASSOCIATION AND ASSOCIATION OF
ACADEMIC HEALTH SCIENCES LIBRARIES

I, Mary M. Langman, Director, Information Issues and Policy, Medical Library Association (MLA), submit this statement on behalf of MLA and the Association of Academic Health Sciences Libraries (AAHSL). MLA is a global, nonprofit, educational organization with a membership of more than 400 institutions and 3,000 professionals in the health information field. AAHSL supports academic health sciences libraries and directors in advancing the patient care, research, education and community service missions of academic health centers through visionary executive leadership and expertise in health information, scholarly communication, and knowledge management. We thank the Subcommittee for the opportunity to submit testimony supporting appropriations for the National Library of Medicine (NLM), an agency of the National Institutes of Health (NIH), and recommend at least \$449,000,000 for NLM in fiscal year 2019.

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 results of research readily available to all who need it. NLM is taking on additional responsibilities for NIH-wide efforts in big data and data science. As health sciences librarians who use NLM's programs and services every day, we can attest that NLM resources literally save lives making NLM an investment in good health.

NLM LEVERAGES NIH INVESTMENTS IN BIOMEDICAL RESEARCH

NLM's budget supports intramural services, research, and programs that sustain the Nation's biomedical research enterprise and more—it builds, sustains, and augments a suite of almost 300 databases which provide information access to health professionals, researchers, educators, and the public. It also supports the acquisition, organization, preservation, and dissemination of the world's biomedical literature. In fiscal year 2019 and beyond, NLM's budget must be augmented to support 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, and the public, enabling such data and information to be used more efficiently and effectively to drive innovation and improve health. NLM also plays a critical role in NIH's data science initiatives and in enhancing interoperability of health information technology, including electronic health records (EHRs). NLM leads the development, maintenance and dissemination of key standards for health data interchange that are now required of certified EHRs. NLM also addresses Con-

gressional priorities through ClinicalTrials.gov, response to the opioid crisis, and disaster preparedness and response efforts.

GROWING DEMAND FOR NLM'S INFORMATION SERVICES

NLM delivers more than 50 trillion bytes of data to millions of users daily that helps researchers advance scientific discovery and accelerate its translation into new therapies; provides health practitioners with information that improves medical care and lowers its costs; and gives the public access to resources and tools that promote wellness and disease prevention. Every day, medical librarians across the Nation use NLM's services to assist clinicians, students, researchers, and the public in accessing information to save lives and improve health. Without NLM, our Nation's medical libraries would be unable to provide quality information services that our Nation's health professionals, educators, researchers and patients increasingly need.

NLM's data repositories and online integrated services such as GenBank, dbGaP, Genetics Home Reference (GHR), PubMed, and PubMed Central (PMC) are revolutionizing medicine and ushering in an era of personalized medicine. GenBank is the definitive source of gene sequence information. Some 2 million users accessed consumer-level information about genetics from GHR which contains more than 2,500 summaries of genetic conditions, genes, gene families, and chromosomes. PubMed, with more than 27 million references to the biomedical literature, is the world's most heavily used source of bibliographic information with almost 1.2 million new citations added in fiscal year 2016 and more than 2.4 million users each day. PubMed Central is NLM's digital archive which provides public access to the full-text versions of more than 4.2 million biomedical journal articles, including those produced by NIH-funded researchers. On a typical weekday approximately 1.4 million users download more than 2.8 million articles.

NLM's traditional print and electronic collections increase steadily each year, standing at more than 21 million items—books, journals, technical reports, manuscripts, microfilms, photographs and images. NLM ensures the availability of this information for future generations, making it 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.

ENCOURAGE NLM PARTNERSHIPS

NLM's outreach programs are essential to the MLA and AAHSL membership and to the profession. Through the National Network of Libraries of Medicine (NNLM), with over 6,500 members nationwide, NLM educates medical librarians, health professionals, and the general public about its services and provides training in their effective use. The NNLM serves the public by promoting educational outreach for public libraries, secondary schools, senior centers and other consumer settings, and its outreach to underserved populations helps reduce health disparities. NLM's "Partners in Information Access" provides local public health officials with online information that protects public health. The NNLM is partnering 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.

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.

EMERGENCY PREPAREDNESS AND RESPONSE

NLM's Disaster Information Management Research Center collects and organizes disaster-related health information, ensures effective use of libraries and librarians in disaster planning and response, and develops information services to assist responders. NLM responds to specific disasters worldwide with specialized information resources appropriate to the need, including bioterrorism, chemical emergencies, fires and wildfires, earthquakes, tornadoes, and pandemic disease outbreaks (e.g., Zika). MLA and NLM's Disaster Information Specialization builds the capacity of librarians to provide disaster-related health information outreach. Working with libraries and publishers, NLM provides free full-text articles from hundreds of biomedical journals and reference books to medical teams responding to disasters.

BIOINFORMATICS RESEARCH AND HEALTH INFORMATION TECHNOLOGY

NLM 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 adoption of interoperable 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.

DISSEMINATION OF CLINICAL TRIAL INFORMATION

ClinicalTrials.gov, the world's largest clinical trials registry, now includes more than 238,000 registered studies and summary results for more than 24,500 trials. As health sciences librarians who fulfill requests for information from clinicians, scientists, and patients, we applaud NIH and NLM for implementing requirements for clinical trials registration and results submission consistent with the FDA Amendments Act of 2007, and for applying them to all NIH-supported clinical trials. These efforts increase transparency of clinical trial results and provide patients and clinicians with information to guide healthcare decisions. They also ensure biomedical researchers have access to results that can inform future protocols and discoveries.

IMPROVING PUBLIC ACCESS TO FUNDED RESEARCH RESULTS

The Department of Health and Human Services (DHHS) announced a common policy approach to expand public access to the results of HHS-funded scientific research. Its operating divisions, and other Federal agencies, will use NLM's PubMed Central (PMC) as a common repository to provide access to peer-reviewed publications resulting from their research.

We look forward to continuing this dialogue and thank you for your efforts to support funding of at least \$449,000,000 for NLM in fiscal year 2019, with additional increases in future years.

PREPARED STATEMENT OF THE MESOTHELIOMA APPLIED RESEARCH FOUNDATION

My name is Rich DeAugustinis. I am a patient advocate submitting testimony on behalf of the Mesothelioma Applied Research Foundation, and the thousands of patients afflicted with the disease in the United States. I am requesting that the Senate Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies include \$500,000 in the Senate's fiscal year 2019 Labor/HHS appropriations bill to fund the development of a national mesothelioma patient registry, thus paving the way for critical advances in mesothelioma research, and ultimately better patient outcomes for those dealing with this horrible disease.

Mesothelioma is a cancer that occurs most frequently in the lining of the lung or abdomen, and sometimes even in the lining of the heart or testis. The 5-year survival rate for mesothelioma patients is grim and ranges between 5–9 percent, with most patients dying within 2 years. Over the last 30 years, mesothelioma has claimed the lives of nearly 100,000 Americans.

My wife is one of those that lost her life to this horrible, preventable disease. I lost her to mesothelioma in May 2017 after a 15-month battle with the disease. She was only 47 and in the prime of her life. She was a beloved wife, a devoted mother, a business owner and a hell of an engineer (we graduated from Georgia Tech together in 1992).

Tara ran her own consultancy in recent years before her death, doing strategy and business integration with a number of clients. She created considerable economic benefit and shareowner value to the enterprises she was a part of during her career, contributing to the growth of the tax base for the State of Georgia and the United States of America.

But mesothelioma took that all away. Now my daughter Aubrey and I are facing life without her due to this horrible disease. We need the Federal Government to take steps to help prevent future tragedies, by creating a national patient registry for mesothelioma. Currently, there is no formal Federal registry to keep track of

mesothelioma patients' demographics or other important information that could help identify gaps in current mesothelioma treatment.

The SEER registry managed by the CDC isn't useful for mesothelioma patients, as they generally die before data is fully captured by the Centers for Disease Control and Prevention (CDC). In fact, CDC's own most recent research findings report an alarming number of younger patients being diagnosed with this dreaded disease, often with no clear exposure to asbestos. The same report also identifies a worrisome overall rise in mesothelioma cases in the United States over the last 15 years.

The creation of a national mesothelioma patient registry is critically important because it would allow the medical and scientific community to:

- Establish successful treatment outcomes;
- Develop and revise standards of care and treatment and best practices for patients with mesothelioma;
- Allow physicians across the country to share evidence-based information;
- Implement benchmarks to improve care in mesothelioma clinics; and
- Identify centers that provide the most beneficial care to mesothelioma patients.

The profound impact of patient registries has been demonstrated in other diseases (such as gastrointestinal stromal tumors, Gaucher's disease, newborn screening for inborn errors of metabolism, interstitial pulmonary fibrosis, and muscular dystrophy) which, following their implementation, have seen an acceleration in treatment development and acceleration toward cures.

On behalf of mesothelioma patients and their families across the country, I urge you to help us eradicate mesothelioma by including \$500,000 in the Senate's fiscal year 2019 Labor/HHS appropriations bill to fund the development of a national mesothelioma patient registry.

PREPARED STATEMENT OF METAIVIVOR

FISCAL YEAR 2019 APPROPRIATIONS RECOMMENDATIONS

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- Please provide the National Institutes of Health (NIH) with an increase of at least a \$2 billion in discretionary funding for fiscal year 2019 to bring annual funding up to a minimum of \$39.1 billion.
 - Please continue to support additional investment for the 21st Century Cures Act and otherwise ensure the National Cancer Institute (NCI) has adequate resources.
 - The research portfolio focused on controlling and eliminating cancer that has already disseminated (metastasized) is extremely limited; yet metastatic cancer is responsible for 90 percent of all cancer deaths. I am here today to ask you to please provide meaningful, annual funding increases for NCI to allow research in this important area to move forward. Further, please consider advancing committee recommendations that further encourage NIH and NCI to prioritize research into controlling and eliminating cancer that has already disseminated.
 - The 21st Century Cures Act and associated Cancer Moonshot, of which my organization, METAivivor, is a part, holds tremendous potential to improve the lives of individuals and families affected by metastatic stage IV cancer. However, the current plan outlines very few opportunities in the area of metastasis except for a tangential connection to the proposed tumor atlas through studying cancer progression. We are asking that you support full annual funding for the activities outlined in the 21st Century Cures Act and work with your colleagues to ensure this program includes new research that will benefit patients, whose cancer has already metastasized.
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Chairman Blunt, Ranking Member Murray, and distinguished members of the Subcommittee, thank you once again for considering the views of METAivivor and the stage IV metastatic cancer community as you work on fiscal year 2019 appropriations for medical research. The community is deeply grateful for the \$3 billion funding increase provided to NIH in fiscal year 2018. This investment along with past funding increases is providing additional opportunity to our scientific investigators and allowing NIH to enhance numerous research portfolios and initiate critical projects.

THE FACTS ABOUT METASTATIC STAGE IV CANCER

A metastasis is defined by the dissemination or spread of cancer from its original location to other vital organs in the body. Very few cancers cause death without metastasis. Examples of the latter would be brain and pancreatic cancers.

An estimated 609,640 Americans will die this year from cancer. Close to 548,676 of these deaths (90 percent) will be caused by a metastasis. If we wish to lower the death rate, we must tackle metastasis. For roughly 30 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 many cancers, it is believed there are multiple causes, few of which are known, making prevention a formidable and more likely unachievable 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, no drug is universal. For any given patient, some drugs fail altogether and others last only a few months. While true that some drugs continue to work year after year for a select group of patients, this is the exception rather than the rule. We need not only more treatments and therapies, we need better drugs for all metastatic/stage IV cancer patients if we hope to change the death rate. And for these, we need more research.

ABOUT METAVIVOR

METAvisor Research and Support, Inc. is a volunteer-led, national non-profit known throughout the US and Internationally. METAvisor's mission is to fund stage IV metastatic breast cancer research to transition the disease from terminal to one that is chronic yet manageable and to improve the quality of life of those living with metastatic breast cancer through support, awareness, advocacy and education. It is further known for its peer-to-peer support program created in 2007 as a METAvisor precursor to meet the unique support needs of the metastatic patient community. 100 percent of every donation goes to fund stage IV metastatic breast cancer research grants. To date, METAvisor has awarded \$4.2 million for 46 disseminated (metastatic) breast cancer research grants.

THE GOVERNMENT, NIH RESEARCH AND 21ST CENTURY CURES

While METAvisor takes pride in what our terminally ill group of volunteers has accomplished, \$4.2 million is a drop in the bucket in terms of cancer research. Our government and the NIH/NCI need to step up to the plate. It is our sincerest hope that one day efforts such as METAvisor's will make a difference for the growing number of metastatic patients dying every year.

The U.S. Government holds the responsibility for all its citizens. The National Cancer Institute (NCI) carries the responsibility for all cancer patients, not just those with early stage disease. Thus, we strongly encourage the NCI to expand its portfolio to include a program of respectable size that addresses the metastatic condition and funds the research that will ultimately, significantly extend life with quality and hopefully end death for at least a segment of our community.

We are grateful that NIH has initiated important new projects in metastatic cancer research. The administration's fiscal year 2019 budget request outlines numerous ongoing and emerging activities in the overall field of metastasis to include the prevention of metastasis. We urge Congress and the NIH to ensure a respectable percentage of these projects focus on controlling existing metastases. Much more must be done. We currently have more meritorious scientific questions than answers. The rate of cancer mortality is unacceptable. And it will only be changed by learning how to effectively treat metastatic cancer. Please increase the focus and investment in this important area of research and provide NIH and NCI with enough resources to facilitate growth in the portfolio. Ongoing infusions of funds will ensure that we can capitalize on emerging science and that breakthroughs are quickly translated to innovative therapies and improved diagnostic tools that can reverse the disease process and save lives.

The Department of Defense recently launched a metastatic breast cancer research taskforce to bolster research efforts moving forward. NIH would benefit from a similar sustained focus on efforts that help control and eliminate cancer that has already disseminated.

MY STORY

DIAN (“CJ”) CORNELIUSSEN-JAMES, LTCOL USAF RET
METASTATIC PATIENT

Being Healthy Is No Guarantee: I am a retired Air Force Intelligence Officer. Like many military professionals, I was thought to be an example of good health. I was lean, ran daily, attended aerobic classes, ate mostly vegetarian . . . per my doctor, I was doing all the right things. Nine months after my Air Force retirement I had my annual mammogram. Like all the previous scans, it was clean. Yet 3 months later I found a lump in my axillary. Shortly thereafter I was diagnosed with Stage IIB breast cancer. Following surgery, chemotherapy and radiation I was put on a drug maintenance program. Despite these efforts, less than a year later my cancer had spread to my lung where it grew rapidly, doubling in size within 90 days. My breast cancer had metastasized. I did some research and learned that only 1–3 percent survived the disease and that the average survival was only one to 3 years.

A Pervasive Positive Attitude and a Denial of Realities are Thwarting Research: A diagnosis with metastatic cancer is devastating, but I consoled myself in the belief that considerable research was focused on finding solutions. After all, one frequently heard that we were winning the war on cancer, especially when it came to breast cancer. I thought that surely millions of dollars were being spent trying to help those who metastasized. That bubble burst when in 2006, I was watching a CNN Dr. Sanjay Gupta Special and learned that an independent count in 2004 had established that the NIH was putting only a pitiful 0.5 percent of its \$5 billion cancer budget into metastasis research. I found that there was a pervasive, yet inaccurate belief that healthy, vigilant people did not metastasize. Thus, efforts to prevent and early detect cancer were being promoted and applauded while demands by metastasis researchers and metastatic patients to fund research focused on lengthening and improving the lives of those who do indeed metastasize, were being largely ignored. Indeed, one senior metastasis research told me that the NIH had answered his request for increased funding for metastasis research by saying: “Why close the barn door after the horse has escaped?” Ours is a disease that everyone prefers to ignore until it strikes their own families. Only then do they seek change. Only then do they realize the reality of the seemingly impenetrable brick wall that we face. And so the cycle continues.

It Took the Terminally Ill to Effect Change: Outraged over this situation, in 2007 I started a peer-to-peer support program for metastatic breast cancer. We further began raising funds for research that we intended to donate, but when no organizations would allow us to earmark those funds for metastasis research, I asked three fellow metastatic patients to join me in founding METAvivor. Our goal was to fund our own research grants aimed solely at benefitting the already metastasized patient. It was January 2009. We got off to a very difficult start. Co-Founder Karen Presswood, my Director of Research and a leading CVS pharmacist died in August 2009, Co-Founder Rhonda Rhodes, my Vice President and Founder of a healthcare consulting firm for underprivileged children died in January 2010. Co-Founder, Avis Halberstadt, my treasurer, a retired math teacher and SAT coach died July 2014. Nine additional Board Members have died since 2009. They are among the roughly 1,500 Americans dying every single day of a metastasized cancer. That is a staggering number.

The Metavivor Research Program: Despite METAvivor’s critical losses, we have created the first competitive, scientific peer reviewed research grant program to ever focus solely on finding solutions for the already metastasized patient. By working as volunteers and putting 100 percent of every donation into our research grants . . . and by foregoing bucket lists and precious time with our families despite our terminal conditions, our team has built a highly reputable program that has thus far funded 46 research projects for a total of \$4.2 million to benefit the metastatic breast cancer community. But we can only do so much on our own.

It is Time . . . time for our government to do its part. On behalf of the entire metastatic community, I implore you to take steps now to build a solid, government funded metastasis research program focused on finding solutions for every metastatic patient. Thank you.

[This statement was submitted by Dian “CJ” Corneliussen-James, Director Emeritus and Founder, METAvivor Research and Support.]

PREPARED STATEMENT OF THE MICHAEL J. FOX FOUNDATION FOR
PARKINSON'S RESEARCH

The Michael J. Fox Foundation for Parkinson's Research (MJFF) appreciates the opportunity to comment on fiscal year 2019 appropriations for the U.S. Department of Health and Human Services. Our comments focus on the importance of Federal investment in biomedical research at the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC). MJFF supports at least \$39.3 billion for NIH, as well as the full authorized amount of \$5 million to implement the National Neurological Conditions Surveillance System at CDC.

In providing more than \$800 million in PD research to date, our Foundation has fundamentally altered the trajectory of progress toward a cure. However, MJFF investments are a complement to, rather than a substitute for, federally funded research. Robust and reliable Federal funding is imperative to drive progress. There are many potential Parkinson's breakthroughs on the horizon, which are critically needed by the millions living with this disease and the many more who will age into Parkinson's risk.

NATIONAL INSTITUTES OF HEALTH

NIH Research Furthers Progress toward New Treatments and a Cure

Parkinson's is a chronic, progressive neurological disorder affecting nearly 1 million people in the United States. The disease costs Americans at least \$26 billion each year. Without intervention, the prevalence of Parkinson's is expected to more than double by 2040. The financial impact and rising prevalence can be mitigated through research to treat and cure PD.

Investing in NIH research on the front end to develop innovative therapies and cures can lower back-end costs. Eighty percent of the Parkinson's population relies on Medicare for healthcare coverage, and up to one-third of people with PD are dual eligible for Medicaid due to their income or disability status. Approximately 10 percent of Americans with Parkinson's disease are military veterans. New treatments would relieve the burden on Medicare, Medicaid and the Department of Veterans Affairs. Additionally, NIH funds research in all 50 States, and every dollar of funding generates two dollars in local economic growth.

Despite gains in the past 3 years, NIH funding has not kept pace with medical inflation, and NIH purchasing power has declined since 2003. In 2017, NIH only funded about 12 percent of investigator-initiated grants, leaving an untold number of breakthroughs undiscovered. Patients and the medical community deserve stable and reliable funding that allows for research progress and supports innovative projects that bring us closer to cures.

While industry and philanthropy have prioritized Parkinson's research—as evidenced, for example, in the public-private partnership described in this testimony—these investments are not enough. Researchers rely on federally funded basic research to make the discoveries from which come deeper understanding and therapeutic development. The biggest non-profit organizations and most generous philanthropists cannot come close to the resources or scope of a Federal agency committed to human health such as NIH.

The following projects leveraged Federal dollars to push Parkinson's disease forward last year.

AMP PD: A Private/Public Partnership for a New Era

In January 2018, MJFF, NIH and five life sciences companies announced a public-private partnership to advance understanding, measurement and treatment of Parkinson's disease. Following NIH's Accelerating Medicines Partnership (AMP) model, the new AMP PD project will apply cutting-edge technologies to tease apart microscopic differences in the cells of people with PD. MJFF and the five industry partners are contributing a combined total of \$12 million over 5 years to AMP PD. National Institute of Neurological Disorders and Stroke (NINDS), part of NIH, is matching those funds with an additional \$12 million contribution. In line with MJFF and NIH open-access policies, the partners will make data and analyses generated through this program publicly available to the broad biomedical community.

This partnership demonstrates the amazing potential created when Federal dollars are combined with resources from philanthropy and private business to accelerate research and resource development. The open access nature of data arising from the partnership will push research forward and ensure future dollars spent build on existing discoveries.

Identifying Genetic Links to Parkinson's Disease

About 20 years ago, researchers thought Parkinson's had no genetic connection. Today scientists have a growing list of genetic variants and mutations linked to the disease. While we've learned a lot in two decades, we know there is more to discover. By comparing and contrasting the DNA of tens of thousands of people with Parkinson's and people without the disease, scientists are able to identify genes that may be involved with the disease.

Previous studies using this strategy have identified a number of potential genetic risk factors. In a recent study of data from 425,000 people, the largest of its kind for PD, NIH scientists along with private partners confirmed a number of previously reported genetic risk factors and identified 17 new variants associated with PD.

The Federal Government is in a unique position to access and analyze these vast amounts of data, applying cutting-edge technologies and statistical expertise to illuminate differences in our genes that may predispose us to disease. Scientists can follow those genes to investigate cellular dysfunction associated with Parkinson's—increasing our disease understanding and nominating therapeutic targets.

Training Computers to Analyze Living Cells

Seeing what happens in living cells is a vital part of understanding disease. Because the human eye cannot distinguish individual cells, even with a microscope, researchers have had to use dyes and staining methods to make cell characteristics visible. However, the chemicals used in this process can be lethal to the cells, and the process is painstaking and time-consuming.

Ten years ago, a researcher at the Gladstone Institutes in California invented a robotic microscope that could track individual cells. Now he is using a computer and machine-learning methods to profile the cells imaged by the robotic microscope: reporting if the cell is alive, identifying its nucleus and naming its cell type. This automated analysis significantly speeds up research into the living cells, which has wide-reaching implications for the study of disease and for drug development toward new therapies. Not limited to Parkinson's research, this approach can help shed new light on the mechanisms behind many complex diseases such as Alzheimer's and amyotrophic lateral sclerosis (ALS).

CENTERS FOR DISEASE CONTROL AND PREVENTION

More Data Can Speed Breakthroughs

While there are rough estimates of the number of people diagnosed with PD, we do not currently have accurate and comprehensive information on how many people are living with the disease, who they are and where they are located. This lack of core knowledge makes it difficult to assess potential environmental triggers and other patterns of disease. This absence of data also slows Parkinson's research and drug development and makes it difficult to ensure healthcare services are allocated properly.

The National Neurological Conditions Surveillance System, which was authorized at \$5 million each year by the 21st Century Cures Act, will collect data on the number and location of people with neurological diseases. The database will provide a foundation for understanding many factors, such as clusters of diagnoses in certain geographic regions, variances in the number of men and women diagnosed with neurological diseases, and differences in healthcare practices among patients. CDC will work efficiently to create the system by pulling information from existing sources, such as Medicare, Medicaid and Veterans Affairs databases, as well as State and local registries.

CONTINUED SUPPORT FOR RESEARCH IS CRITICAL TO DRIVE PROGRESS

Momentum in Parkinson's disease research is strong. While we are uncovering more about the causes and progression of Parkinson's and testing many new treatments, many questions remain and more people are facing a PD diagnosis. We need the financial and data resources to find answers and slow the rise in disease prevalence. Robust investments in NIH and CDC will continue to propel research forward, leading to life-changing treatments and, ultimately, a cure.

Please allocate \$39.3 billion for NIH, as well as the full-authorized amount of \$5 million to implement the National Neurological Conditions Surveillance System at CDC. Thank you for the opportunity to testify.

PREPARED STATEMENT OF THE MINE SAFETY AND HEALTH ADMINISTRATION

We are writing in support of the fiscal year 2019 Budget Request for the Mine Safety and Health Administration (MSHA), which is part of the U.S. Department of Labor. In particular, we urge the Subcommittee to support a full appropriation for State assistance grants for safety and health training of our Nation's miners pursuant to section 503(a) of the Mine Safety and Health Act of 1977. Under the State Grants Program in fiscal year 2018, MSHA awarded \$10,537,000 grant funding to 47 States, Guam, Native Village of Barrow, and the Navajo Nation. This amount reflects a needed increase from \$8,441,000 awarded in prior fiscal years before fiscal year 2017. The States appreciate this increase, which is essential to addressing inflationary and programmatic cost increases experienced by the States, and providing important safety training to the Nation's miners. We urge the Subcommittee to maintain this statutorily authorized level of \$10 million for State assistance grants so that States are able to meet the training needs of miners and to fully and effectively carry out State responsibilities under section 503(a) of the Act. We believe the States can 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.

It should be kept in mind that, whereas MSHA over the years has narrowly interpreted State assistance grants as meaning "training grants" only, Section 503 was structured to be much broader 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 Mine Health and Safety Act of 1969 (Coal Act), 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 Federal Mine Safety and Health Act (Mine Act) of 1977 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 in Congress.

With respect to the training component of our mine safety 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. States are struggling to maintain efficient and effective miner training and certification programs in spite of increased numbers of trainees and the incremental costs associated therewith. The situation has been further complicated by statutory, regulatory and policy requirements that have grown out of the various reports and recommendations attending the Upper Big Branch investigation. We greatly appreciate Congress' recognition of this fact and this Subcommittee's strong support for State assistance grants, especially over the past few years when the Administration sought to eliminate or substantially reduce those moneys.

Our experience over the past 35 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. The most recent accounting of the number of miners trained by a sampling of the States based on fiscal year 2017 reporting for coal and metal/nonmetal is as follows:

- Kentucky: 10,916 miners trained
- Alaska: 929 miners trained (A noticeable upswing in numbers of miners trained is expected in Alaska for fiscal year 2018. The number of miners trained during the first quarter of fiscal year 2018 increased by 10 percent over the number trained during the same period in fiscal year 2017.)
- New Mexico: 2,431 miners trained
- Illinois: 17,094 miners and contractors trained (including Aggregate Part 46, Accident Prevention, Certification and Mine Rescue; and EMT training)
- Indiana: 5,773 miners and contractors trained
- Oklahoma: 3,921 miners trained
- Pennsylvania: 5,304 miners trained
- Ohio: 5,989 miners trained
- Colorado: 5,352 miners trained
- Arkansas: 2,388 miners trained
- Nevada: 2,474 miners trained

- North Carolina: 7,146 miners trained
- Maryland: 611 miners trained
- Arizona: 2,489 miners trained
- Virginia: 5,200 miners trained (Includes coal and minerals mining; 28,400 training sessions total were conducted with the miners throughout the year in various settings)
- Mississippi: 236 miners and contractors trained

Note that numbers of miners trained has been decreased in some years due to reductions and/or delays in State grant funding. This continues to be a serious challenge for State training programs in fiscal year 2018 with States still awaiting the allocation of grant awards as of April 20, 2018—more than 6 months into the fiscal year. We understand the fiscal year 2018 Funding Opportunity Announcement is currently under review at MSHA and expected to be published at the end of April. Delays in authorizing grant allocations disrupt the States' ability to run effective training programs that rely on certain, consistent, and timely funding. In fiscal year 2017, MSHA allowed for incremental State grant funding during the fiscal year (as other Federal agencies do) to overcome these challenges. Several States received incremental funding in fiscal year 2017, including: Alabama, Arizona, Connecticut, Iowa, Ohio, Pennsylvania, South Dakota, and Tennessee. We appreciate MSHA having instituted the incremental State grant funding approach in fiscal year 2017 and encourage its continued use in future years. Having access to the funds in a timely manner is critical to the States in order to operate their training programs effectively.

As you consider our support of MSHA's budget for State training grants, please keep in mind that the States play a particularly critical role in providing special assistance to small mine operators (those coal mine operators who employ 50 or fewer miners or 20 or fewer miners in the metal/nonmetal area) and the Spanish-speaking community in meeting their required training needs.

We appreciate the opportunity to submit our views on the MSHA fiscal year 2019 budget request as part of the overall Department of Labor budget. Please feel free to contact us for additional information or to answer any questions you may have.

[This statement was submitted by Thomas L. Clarke, Executive Director, Interstate Mining Compact Commission.]

PREPARED STATEMENT OF MOREHOUSE SCHOOL OF MEDICINE

DEPARTMENT OF HEALTH AND HUMAN SERVICES AND DEPARTMENT OF EDUCATION

Chairman Blunt, Ranking Member Murray, and distinguished members of the Subcommittee, thank you for the opportunity to submit testimony on behalf of Morehouse School of Medicine (MSM). I am Valerie Montgomery Rice and I serve as President and Dean of MSM located in Atlanta, Georgia. My testimony will give a brief history of MSM, discuss how MSM creates advancements in health research and equity, and highlight the sources of funding which allow MSM to serve its Georgia communities. Through our social mission, we at MSM serve underrepresented communities, address health disparities, supply the health workforce with highly qualified health professionals, and research chronic diseases impacting vulnerable populations. With this in mind, I am making the following recommendations for the fiscal year 2019 appropriations process:

- \$8.56 billion for the Health Resources and Services Administration (HRSA)
- \$30 million for HRSA's Health Workforce: Centers of Excellence (COE)
- \$16 million for HRSA's Health Workforce: The National HCOP Academy
- \$2 million for HRSA's Health Workforce: Faculty Loan Repayment
- \$50 million for HRSA's Health Workforce: Scholarships for Disadvantaged Students
- \$40 million for HRSA's Health Workforce: Area Health Education Centers
- \$39.3 billion for the National Institutes of Health
- \$312 million for the National Institute on Minority Health and Health Disparities
- \$50.00 million for the Centers for Disease Control and Prevention's Racial and Ethnic Approaches to Community Health (REACH) program
- \$60 million for the Department of Health and Human Services' Office of Minority Health
- \$53.90 million for the Department of Health and Human Services' Minority HIV/AIDS initiative
- \$75 million for The Department of Education's Strengthening Historically Black Graduate Institutions Title III Program

Morehouse School of Medicine was founded in 1975 as the Medical Education Program at Morehouse College. In 1981, MSM became an independently chartered institution and today, MSM is among the Nation's leading educators of primary care physicians and is recognized as the top institution among U.S. medical schools for our social mission. Our faculty and alumni are noted in their fields for excellence in teaching, research, and public policy. Through our clinical and research enterprises and community-based outreach and engagement, MSM is forging inroads by creating and advancing health equity and health outcomes for all communities at the highest level of excellence. Morehouse School of Medicine recognizes the challenges facing the health workforce in the coming decade and with your continued support, we are positioned to facilitate a class size growth of 20 percent across all of our disciplines by 2020. In 2017, we successfully expanded our educational training for medical students through our remote campus location in Columbus, Georgia, thus providing more opportunities for MSM to reach more communities in rural areas of the State.

At Morehouse School of Medicine, we foster success in our diverse student body population in order to cultivate health equity. Matriculation and academic success among underrepresented minorities are key priorities of MSM. Through our pipeline initiatives like the EMPOWER Conference and MSM's Health Careers Opportunity Program, we support diverse student learners ranging from kindergartners to those in their post-baccalaureate studies. Through these pipeline programs, we are able to provide the necessary guidance to navigate Science, Technology, Engineering, Arts and Mathematics ("STEAM") studies, professional healthcareers, and entry into medical school programs when applicable.

Through investments in our research infrastructure with funding from the National Institute of Health (NIH) and the Health Resources and Services Administration (HRSA), Morehouse School of Medicine's research stature and reputation has grown exponentially over the last decade. In 2017, we were able to make advancements in our four core research areas of cancer, cardiovascular diseases, neurological diseases, and infectious diseases. In 2017, we secured over \$40 million in grant funding for new and renewed research projects. This funding was used, in part, to address the opioid crisis in rural communities across Georgia, discover a new method to test patients for concussions using RNA profiles, and enhance our knowledge of sleep and its functionality outside the biological clock within the human brain.

As Congress begins the fiscal year 2019 process, MSM asks that you further prioritize Title VII health professions training programs, medical research, research infrastructure, and graduate medical education, particularly with hospitals and agencies that partner with historically black medical schools like MSM. With support for these initiatives, desired outcomes such as improving the quality, geographic distribution, and diversity of the healthcare workforce for the purpose of creating an equitable healthcare system for our Nation is possible. Chairman Blunt, Ranking Member Murray, and members of the committee, thank you for your time and your consideration of these requests. Please consider Morehouse School of Medicine as a resource if you have any questions or if you would like additional information.

[This statement was submitted by Valerie Montgomery Rice, M.D., President and Dean, Morehouse School of Medicine.]

PREPARED STATEMENT OF NATION ASSOCIATION FOR GERIATRIC EDUCATION

As the Co-Project Directors of the Gateway Geriatric Workforce Enhancement Program at Saint Louis University School of Medicine, we are pleased to submit this joint statement for the record recommending appropriations of at least \$51 million in fiscal year 2019 to support geriatrics workforce training under the Geriatrics Workforce Enhancement Program (GWEP) and the Geriatric Academic Career Award (GACA) program administered by the Health Resources and Services Administration (HRSA). We thank you for your past support and particularly for the increase of \$2 million in the Consolidated Appropriations Act, 2018.

In fiscal year 2015, HRSA combined the geriatric education programs in Titles VII and VIII of the Public Health Service Act, including the Geriatric Academic Career Award, as well as portions of the Alzheimer's Disease Prevention, Education, and Outreach Program to establish the Geriatrics Workforce Enhancement Program (GWEP). The GWEP is now the only Federal program designed to develop a healthcare workforce specifically trained to care for the complex health needs of older Americans with the most effective and efficient methods, providing higher quality care and saving valuable resources by reducing unnecessary costs. As you

are aware, the number of Americans ages 65 and older will double from 46 million today to over 98 million by 2060, creating an imperative for policymakers to enhance the education of health professionals to improve care of older persons and, thus decrease costs of care.

Proven results from activities under the GWEP and its predecessor programs include an important increase in the number of teaching faculty with geriatrics expertise in a variety of disciplines, plus thousands of healthcare providers and family caregivers better prepared to support older Americans with complex chronic conditions. Therefore, NAGE requests a total of at least \$51 million for these programs, which are critical to cost-effective care for the rapidly expanding elderly population. In 2015, HRSA provided funding for 44 GWEPs in 29 States which have worked with 365 health delivery sites. Our funding request would allow for approximately eight additional GWEPs in rural and underserved communities. In this request, we propose to reestablish competitive grants for the Geriatrics Academic Career Award (GACA) by providing \$100,000 to each GWEP or other institutions to create a GACA. GWEPs were funded at \$40.7 million in fiscal year 2018. We recognize that the Subcommittee faces complex decisions in a constrained budget environment, but we believe a top priority should be a commitment to geriatric education programs that help the nation's health workforce better serve the rapidly increasing number of older persons.

The Nation faces a shortage of geriatrics health professionals and direct service workers. There are not enough geriatricians, advanced practice nurses, and other health professionals with the knowledge, skills, and training in geriatrics to meet the needs of our rapidly growing population of older adults and to support their family caregivers. Too often, the result is expensive walk-in care and inappropriate return to hospital within thirty days of discharge. We believe that funding for GWEP-based geriatric education supports your important work to establish a sustainable future for the nation's healthcare and Social Security systems by ensuring that (a) healthcare specialists trained in geriatric care do not become an expensive resource from which only a select few are able to benefit and (b) direct service workers and family caregivers are prepared to support a lower cost, independent lifestyle for community residing elders.

In recent years, GWEPs have continued the impressive work of the Geriatric Education Centers. Approximately half of the GWEPs provide education for areas that are more than 50 percent rural. In the 2015–2017 academic year, GWEPs provided gerontological education to well over 100,000 healthcare professionals and students. Saint Louis University and other GWEPs are partnering with federally Qualified Health Centers to provide geriatric primary care education and didactic training. GWEPs create opportunities for healthcare providers in underserved and remote areas of the country to consult with top experts in geriatric care through Interactive Televideo (ITV), interactive teleconsults, and synchronous webcasts, and make available thousands of hours of online geriatric education programs.

The Gateway Geriatric Education Center at Saint Louis University has provided education to 25,611 health professionals and 5,904 members of the public since 2016. These health professionals have provided screenings for geriatric problems such as frailty, sarcopenia (muscle weakness), falls, and dementia to 9,280 older adults in all six Congressional districts in Missouri. More than 80 percent of this trainings and evaluation of older persons were in primary care settings and medically underserved communities. Developed specifically for the GWEP, the Rapid Geriatric Assessment has been computerized in multiple health systems, including Perry County Memorial Hospital in Perryville, Missouri, a critical access hospital in rural Perry County, and CARESTLHealth, a federally Qualified Health Center in north St. Louis city, Missouri. In Perry County, over 25 percent of the older adults in the county have been screened using this assessment process. Our screenings thus far, have identified 25.4 percent with dementia and 31.9 percent with falls. Early intervention for these conditions can decrease medical costs. Upon identifying concerns in any of the assessment areas, older patients are referred for other GWEP-initiated services, to include: Cognitive Stimulation Therapy—a non-pharmacologic intervention for persons with dementia or Exercise and Strengthening programming. In addition, our GWEP has provided education through in-person and on-line continuing education, through daily tweets on Twitter (@meddocslu)—828, to date—and with 102 postings to LinkedIn and Facebook. Our GWEP also co-produced a regional prime time television program on aging which was viewed by 340,739 persons. The YouTube site has had 103,200 views.

Highlights from other GWEPs include:

—The Dartmouth GWEP is disseminating education across the Nation in the highly successful Geriatric Interdisciplinary Team Training program.

- The South Central Foundation GWEP is providing support for improving home-based care for the native community throughout the State Alaska.
- In rural eastern North Carolina, the East Carolina University GWEP is disseminating training on caring for older members of the farming, fishing, and lumber industries.

These are some of the highlights of the contributions made by only four GWEPs. Obviously, the GWEPs are playing a major role in improving healthcare for all in the aging tsunami in the United States. Multiply this by 44 (the number of existing GWEPs) and you can begin to visualize the scope and impact of this program across the nation. It is important to note that every GWEP is focused on meeting the needs of rural and/or underserved populations; many serve predominantly people of color and those who are economically challenged.

GWEP awardees have received expanded authorization to provide family caregivers and direct service workers with instruction on prominent issues in the care of older adults, such as Alzheimer's Disease and other dementias, palliative care, self-care, chronic disease self-management, falls, and maintaining independence, among others. In Missouri, we have developed Cognitive Stimulation Therapy (CST) aimed at enhancing functioning in persons with moderate Alzheimer's disease. We have trained over 1200 persons to deliver this intervention and this has led to over 500 persons with dementia participating in this effective intervention which our research has shown to improve cognition. Our GWEP has recently been designated by the founders of CST as the North American CST Training Center.

HRSA estimates that 52,352 paid and family caregivers will participate in GWEP training programs over the current grant period. For example, the GWEP at Saint Louis University is partnering with several Area Agencies on Aging, the local Alzheimer's Association, a rural hospital, a rural osteopathic school, the regional Area Health Education Centers, and dementia-focused community care agencies to train staff and family caregivers in assessing and supporting them through the caregiving process. The 2016 National Academies of Sciences, Engineering, and Medicine (NASEM) report *Families Caring for an Aging America* acknowledged that training must go beyond the healthcare professions and support family caregivers. This will improve the quality of health outcomes while saving valuable resources in the healthcare system.

In summary, GWEPs have improved the supply, distribution, diversity, capabilities, and quality of healthcare professionals who care for our nation's growing older adult population, including the underserved and minorities. They train physicians, nurses, social workers, dentists, mental health professionals, pharmacists, and caregivers. In some States, the GWEP is offering training to first responders to keep elders safe in their communities. Some of the professionals trained through GWEPs will become academicians in geriatric medicine, dentistry, psychiatry, nursing, and allied health professions, thereby giving additional cohorts of professionals the skills they need to properly serve older Americans. Furthermore, GWEPs create and deliver community-based programs that provide patients, families, and caregivers with the skills to care for older adults and improve health outcomes, including Alzheimer's disease education. The GWEPs are serving as change agents and helping to transform a fragmented and outmoded system.

We ask for your continued support for geriatric programs to adequately prepare the next generation of health professionals and care providers for the rapidly changing and emerging needs of the growing and aging population.

On behalf of NAGE and those who have benefitted in Missouri and from our colleagues around the country, thank you for your thoughtful consideration of our request for funding for GWEPs and GACAs in fiscal year 2019. NAGE is a non-profit membership organization representing GWEPs, Geriatric Education Centers, Centers on Aging, and other programs that provide education and training to healthcare professionals and others in geriatrics and gerontology.

[This statement was submitted by John E. Morley, MB, BCh, Dammert Professor of Gerontology, Chair, Division of Geriatric Medicine, Dept. Internal Medicine, Saint Louis University School of Medicine, Co-Project Director, Gateway Geriatric Workforce Enhancement Program and Marla Berg-Weger, PhD., LCSW, Professor, School of Social Work, Saint Louis University, Executive Director, Gateway Geriatric Education Center; Co-Project Director, Gateway Geriatric Workforce Enhancement Program.]

PREPARED STATEMENT OF THE NATIONAL ALLIANCE FOR EYE AND VISION RESEARCH

EXECUTIVE SUMMARY

NAEVR (National Alliance for Eye and Vision Research), on behalf of the vision community, thanks Congress for the \$2 billion NIH funding increases in fiscal year 2016 and fiscal year 2017 and the \$3 billion increase in fiscal year 2018. Congress is helping NIH (National Institutes of Health) to regain lost ground after years of effectively flat budgets that did not keep up with biomedical inflation, thereby reducing purchasing power. With the fiscal year 2018 increase, Congress continued to make progress in reversing those losses by providing a substantial increase to all NIH Institutes and Centers (I/Cs), in addition to dedicated funding through the 21st Century Cures Act and other funding devoted to specific programs.

In fiscal year 2019, NAEVR recommends at least \$39.3 billion for the NIH, including funds provided through the 21st Century Cures Act for targeted initiatives. This funding level would continue the momentum of recent years by enabling meaningful base budget growth above inflation to expand NIH's capacity to support promising science in all disciplines, and would also ensure that the Innovation Account supplements NIH's base budget, as intended by Congress.

NAEVR also recommends at least \$800 million in fiscal year 2019 NEI (National Eye Institute) funding. In 2018, NEI celebrates the 50th anniversary of its creation by Congress as the lead Institute for our Nation's sight-saving and vision-restoring research. Congress must ensure robust NEI funding to address the challenges of The Decade of Vision 2010–2020—as recognized by Congress in S. Res. 209 in 2009—including an aging population, disproportionate risk/incidence of eye disease in fast-growing minority populations, and the impact on vision of numerous chronic diseases.

Despite NIH increases, NEI's fiscal year 2018 enacted funding of \$772.3 million is just 10 percent greater than the pre-sequester fiscal year 2012 funding of \$702 million. Averaged over 6 fiscal years, the 1.6 percent annual growth rate is less than the average annual biomedical inflation rate of 2.8 percent, thereby eroding purchasing power. In terms of Research Project Grants (RPGs)—which at NEI are primarily R01 Investigator-Initiated awards—in fiscal year 2017 NEI had 130 fewer RPGs (1,157) than the 1,287 RPGs at the high-water mark in fiscal year 2004. Since fiscal year 2004, the difference between what NEI was able to fund and the cumulative number of projects it would have funded if it had maintained 1,287 grants each year is 1,970 project-years (this number treats each year of a project individually, even though average length of an NIH grant is 4 years). Any one of these projects could have held the promise to save sight or restore vision.

We must maintain the momentum of vision research since vision health is vital to overall health and quality of life. Additionally, since the United States is a world leader in vision research and in training the next generation of vision scientists, the very health of the global vision research community is at stake.

NEI LEADS IN GENETIC AND REGENERATIVE MEDICINE RESEARCH

As recently as March 21, 2018, during the NEI's 50th Anniversary Congressional Reception, NIH Director Francis Collins, MD, PHD stated the following about the NEI:

“Due to the architecture, accessibility, and the elegance of the eye, vision research has always been a few steps ahead in biomedical research. Understanding the genetic basis of eye diseases has led the way for understanding the genetic basis of many common diseases.”

The NEI has been a leader in genetics/genomics research and regenerative medicine.

—*Genetics/Genomics*: Vision researchers have found more than 50 gene variants that cause a risk of developing age-related macular degeneration (AMD). For glaucoma, more than 16 genes have been identified. NEI support 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). Just within the past year, NEI's initial efforts have 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 not only treat the disease, but may ultimately prevent it.

—*Regenerative Medicine*: NEI is at the forefront of regenerative medicine with its Audacious Goals Initiative (AGI), which was launched in 2013 with the goal of restoring vision. Initially asking a broad constituency of scientists within the vision community and beyond to consider what could be done if researchers employed this new era of biology, the AGI currently funds major research consortia

that are developing innovative ways to image the visual system. Researchers can now look at individual nerve cells in the eyes of patients in an examination room and learn quite directly whether new treatments are successful. Another consortium is identifying biological factors that allow neurons to regenerate in the retina. And the AGI is gathering considerable momentum with current proposals to develop disease models that may result in clinical trials for therapies within the next decade.

This year, NEI scientists on the NIH campus will launch the first-ever clinical trial in the U.S. to test tissues derived from induced pluripotent stem cells. Retina pigment epithelium—tissue in the back of the eye that supports the light-sensing cells in the retina—is being created in a lab starting with patient blood cells. These tissues, when mature, will be implanted in patients with AMD. The hope is that this will be enough to save dying cells and vision.

THE NATION'S INVESTMENT IN THE NEI RESULTS IN NEW THERAPIES TO TREAT MAJOR EYE DISEASES

Speaking after Dr. Collins at the March 21 Reception, NEI Director Paul Sieving, MD, PhD observed that:

“As we look back 50 years, we remember times when people had untreatable eye diseases. These included AMD, diabetic retinopathy, and glaucoma. These were blinding conditions, and doctors had little more than hope to offer patients.”

The Federal commitment—made in 1968 when President Lyndon Johnson signed legislation creating the NEI—has made possible treatments and therapies for the very diseases that Dr. Sieving cited as previously resulting in blindness or severe vision loss:

- AMD*: The treatment of the “wet” form of AMD has made great strides resulting from use of Anti-Vascular Endothelial Growth Factor (VEGF) therapies—which emerged from initial NIH-funded research—that stabilize vision loss and may improve lost vision. The NEI has established an AMD Pathobiology Working Group within its National Advisory Eye Council to evaluate knowledge learned from its extensive AMD portfolio and identify what is still uncertain, such as the relationship between genes and biological pathways, therapies for the more-prevalent “dry” form of the disease, and how to diagnose and treat the disease much earlier. The NEI has launched a prospective international study of patients that uses the latest advances in retinal imaging to identify biomarkers of the disease and targets for early therapeutic interventions.
- Diabetic Retinopathy*: Over the span of 50 years, NEI has funded a number of randomized controlled trials (RCTs), which have led to major vision health improvements. In the 1960s, about half of patients with diabetic retinopathy were blind within 5 years of diagnosis. NEI-sponsored clinical trials—starting in the 1970s with the Diabetic Retinopathy Study and most currently with the Diabetic Retinopathy Clinical Research Network—have reduced the incidence of severe vision loss from diabetic retinopathy by 90 percent.
- Glaucoma*: The FDA has approved two new drug therapies emerging from decades of NEI research into the role of high intraocular pressure (IOP) as a causal risk factor for primary open-angle glaucoma (POAG), the most common form of the disease and a leading cause of vision loss and blindness. Targeting the eye’s trabecular meshwork—which is one of the pathways responsible for regulating fluid flow within the eye—the new generation of therapies reflects an expanding menu of drugs that lower IOP and better meet the needs of patients.

Critical to the diagnosis and monitoring of treatments for these eye diseases is Optical Coherence Tomography (OCT), which is a non-invasive, high-resolution imaging technology that displays a three-dimensional cross-sectional view of the layers of the retina. Developed over 25 years with \$423 million in NIH and National Science Foundation (NSF) funding, OCT has enabled better personalization of eye care to facilitate more efficient use of effective but costly drug therapies. A December 2017 American Journal of Ophthalmology article reported that OCT saved Medicare \$9 billion and patients \$2.2 billion in co-pays by reducing unnecessary injections. As the technology continues to be applied to new medical conditions, such as Alzheimer’s disease and Parkinson’s disease, it supports a private commercial market of \$1 billion and more than 16,000 high-paying jobs. <https://doi.org/10.1016/j.ajo.2017.09.027>.

CONGRESS MUST PROVIDE ROBUST FUNDING FOR THE NEI AS IT ADDRESSES THE
INCREASING BURDEN OF VISION IMPAIRMENT AND EYE DISEASE

Despite recent NIH increases, NEI's fiscal year 2018 enacted funding of \$772.3 million is just 10 percent greater than the pre-sequester fiscal year 2012 funding of \$702 million. Averaged over the 6 fiscal years, the 1.6 percent annual growth rate is less than the average annual biomedical inflation rate of 2.8 percent, thereby eroding purchasing power. Robust NEI funding is necessary due to the growing burden of eye disease:

—NEI's current \$772.3 million budget is just 0.53 percent of the \$145 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. <http://forecasting.preventblindness.org/>.

—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 \$2.30 per-person, per-year for vision research, while the cost of treating low vision and blindness is at least \$6,680 per-person, per-year. <http://costofvision.preventblindness.org/>.

—In a May 2016 JAMA Ophthalmology article, NEI-funded researchers reported that the number of people with legal blindness will increase by 21 percent each decade to 2 million by 2050, while best-corrected visual impairment will grow by 25 percent each decade, doubling to 6.95 million people—with the greatest burden affecting those 80 years or older. <http://jamanetwork.com/journals/jamaophthalmology/article-abstract/2523780?resultClick=1>.

—In an August 2016 JAMA Ophthalmology article, the Alliance for Eye and Vision Research (AEVR, NAEVR's educational foundation) reported that a majority of Americans across all racial and ethnic lines describe losing vision as having the greatest impact on their day-to-day life. Other studies have reported that patients with diabetes who are experiencing vision loss or going blind would be willing to trade years of remaining life to regain perfect vision, since they are concerned about their quality of life. <http://jamanetwork.com/journals/jamaophthalmology/article-abstract/2540516?resultClick=1>.

Our Nation's investment in vision health is an investment in its overall health. NEI's breakthrough research is a cost-effective investment, since it is leading to treatments and therapies that can ultimately delay, save, and prevent health expenditures. It can also increase productivity, help individuals to maintain their independence, and generally improve the quality of life—especially since vision loss is associated with increased depression and accelerated mortality.

Without adequate funding, however, the NEI may not be able to fund breakthrough research. Congress demonstrated strong support for vision research with the creation of the NEI and recognition of its past accomplishments and current/future challenges. NEI must be robustly funded to continue U.S. leadership in vision research and training.

In summary, NAEVR requests fiscal year 2019 NIH funding of at least \$39.3 billion and NEI funding of at least \$800 million.

NAEVR, which serves as the "Friends of the NEI," is a 501(c)4 non-profit advocacy coalition comprised of 55 professional (ophthalmology and optometry), patient and consumer, private funding foundation, and industry organizations involved in eye and vision research. Visit NAEVR's Web site at www.eyersearch.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

Mr. Chairman and Members of the Subcommittee, I am pleased to present the views of the National Alliance for Public Charter Schools on the fiscal year 2019 budget for the U.S. Department of Education and specifically on the appropriation for the Charter Schools Program (CSP). The CSP plays a crucial role in expanding options for families and more are needed to meet growing demand across the country for high quality schools.

Let me take this opportunity to thank the Subcommittee for increasing the CSP appropriation from \$342 million in fiscal year 2017 to \$400 million in fiscal year 2018. This action will support the creation of hundreds of additional charter schools

servicing thousands of students and will provide sorely needed assistance to improve charter school facilities. The National Alliance and the entire public charter school community are grateful that the Congress responded to the successes of charter schools, the growing unmet demand of families for spaces in high-performing charter schools and our continuing facilities challenges by providing a 17 percent increase in CSP funding. For fiscal year 2019, the National Alliance requests \$500 million for the CSP, \$150 million for replication and expansion of high-performing charter schools. For the reasons that I will lay out in my testimony, we believe that the proposed \$100 million increase is necessary; given the high demand of families for high quality charter schools, as well as the needs of the charter school sector. We urge the Congress to make that investment.

THE GROWTH OF PUBLIC CHARTER SCHOOLS

Since beginning with only a handful of schools in the early 1990s, the charter school sector has grown to encompass more than 7,000 schools in 43 States and the District of Columbia serving more than 3 million pre-k to 12 students today. Between the fall of 2016 and the fall of 2017, more than 300 new charter schools opened across the country, and total enrollment grew by more than 150,000 students. Charter schools now educate 6 percent of K–12 students nationally; 56 percent of which are in urban areas, 26 percent in suburban areas, 7 percent in towns, and 11 percent in rural areas. Charter schools offer a wide range of programs and curricula, and, in particular, provide new options to students and families who otherwise might be trapped in lower-performing schools. In a growing number of school districts, charter schools account for a significant percentage of total enrollment; in the 2016–2017 school year, charter schools enrolled at least 10 percent in 208 districts and at least 30 percent in 19 districts. Charter schools are also more likely than other public schools to enroll students of color, as well as students from low-income families.

CSP funding has been invaluable to the growth of high quality charter schools in every area of the country. It has spurred the development and initial operations of new charter schools and the replication and expansion of successful ones. The Federal role in supporting the development and growth of high-quality charter schools has been indispensable. According to the latest data available, the CSP provided start-up, replication or expansion funds to 60 percent of all charter schools opened between SY 2006–06 and SY 2013–14.

CHARTER SCHOOL PERFORMANCE

Over its 26-year history, the charter school movement has been a leader in innovation, school choice, and education reform. Our schools have led efforts to eliminate achievement gaps, boost graduation rates, and revitalize communities. There is compelling evidence that charter schools are effective. Specifically, a 2015 study by the Center for Research in Education Outcomes (CREDO) at Stanford University, covering 41 urban communities in 22 States, found that:

- Students in urban charter schools gained 40 additional days of learning in math and 28 additional days in reading per year, compared to their peers in non-charter public schools.
- Four or more years of enrollment in an urban charter school resulted in 108 days of additional learning in math and 72 additional days in reading, again compared to traditional public schools.
- In urban charter schools, low-income Hispanic students gained 48 additional days of learning per year in math and 25 additional days in reading, while low-income Black students gained 59 additional days in math and 44 days in reading. Moreover, Hispanic students who were identified as English learners gained 79 additional days in math and 72 in reading.

Other studies, typically looking at a more limited number of schools and students, have also reported very positive findings.

THE CONTINUING UNMET DEMAND FOR SPACES IN CHARTER SCHOOLS

While individual families may be unaware of the academic research on charter school quality, many want their children to attend a charter school. In fact, new surveys indicate that an estimated 4.8 to 5.3 million additional students would attend a charter school if space were available in a convenient location. That means millions of American families are now settling for schools that are less than what they want for their children. And far too many of these students are stuck in schools so dreadful that members of this subcommittee would not accept them as adequate for their own children or grandchildren.

To be clear, even an increase of \$100 million in fiscal year 2019 would not satisfy this demand nor rescue every child trapped in a failing school. But it would represent “earnest money,” an earnest attempt by the Congress to better provide for the education of—and thereby safeguard the future of—America’s public school students.

CHARTER SCHOOL FACILITIES NEEDS

The limited availability and high cost of appropriate school facilities continues to constrain the growth of our schools. Charter schools often do not have access to the funding sources that support the facilities needs of district public schools, such as municipal bonds, local property tax revenues, and State school facilities programs. Charter schools very often must meet their facilities needs using funds that would otherwise support their academic programs. And because facilities financing costs are in so many communities even compromising academic programs it is not enough to afford appropriate space. This results in some charter schools having suboptimal facilities that do not include common and important amenities like kitchens, gymnasiums, libraries, and science labs; in addition to academic programming that is not as robust as it should or would be without the drag of high facilities costs. It’s the worst of both worlds. It’s a situation that requires urgent and immediate attention.

The National Alliance is advocating for a comprehensive national strategy for solving the facilities needs, including enactment of more State laws ensuring charter schools’ access to adequate facilities and, at the Federal level, creation of tax incentives and other mechanisms that make it easier for charter schools to access facilities funding. In the meantime, the limited facilities funding provided through the CSP—specifically, through the Credit Enhancement program and the State Facilities Incentive Grants program—is extremely important. Commendably, the Congress increased funding for the facilities programs to \$50 million in fiscal year 2018. We urge the Subcommittee to provide an additional increase in 2019.

CONCLUSION

The National Alliance for Public Charter Schools takes pride in the accomplishments of public charter schools over the past quarter century. More and more families now see charter schools as the best option for their children, and more and more States and local school districts recognize that charter schools are a vital element of the public educational landscape. While there is, of course, great variation in educational achievement and other outcomes across our schools (just as there is among district schools in general), we now have data demonstrating the success of charter schools in urban settings and elsewhere. Yet the charter school movement still faces major challenges, in meeting the demands for seats in our schools and ensuring that all charter schools have appropriate facilities. We therefore urge Congress to provide a \$500 million appropriation for the CSP for fiscal year 2019.

[This statement was submitted by Nina Rees, President and CEO, National Alliance for Public Charter Schools.]

PREPARED STATEMENT OF THE NATIONAL ALLIANCE ON MENTAL ILLNESS

Chairman Blunt, Ranking Member Murray, and distinguished members of the Subcommittee, on behalf of NAMI, the National Alliance on Mental Illness, I am pleased to offer our views on the Subcommittee’s fiscal year 2019 bill. NAMI is the Nation’s largest grassroots mental health organization dedicated to building better lives for the millions of Americans affected by mental illness. NAMI advocates for access to better treatments, supports, and medical research and innovation.

MENTAL HEALTH IN THE U.S.

Approximately 1 in 5 Americans live with a mental health condition—more than 43 million people.¹ Beyond the statistics, individuals who live with a mental health conditions are our neighbors, family members, and our friends. They contribute to all sectors of the U.S. economy—building small businesses, fighting our wars, growing our food, and composing works of art. However, without proper treatment, many Americans with mental health conditions are not able to reach their full potential.

¹ Insel, T. (2015, May 15). National Institute of Mental Health. Prevalence of Mental Illness. Retrieved April 26, 2018, from <https://www.nimh.nih.gov/health/statistics/mental-illness.shtml>.

This is why your renewed investment in innovative research and first-class treatment is vital to keep America strong.

HIGH COST OF MENTAL ILLNESS IN AMERICA

The social and economic costs associated with mental health conditions is devastating. According to a 2016 study, mental illness topped the list of the most costly conditions in the United States at \$201 billion in 2013, the year examined.² While this financial cost is an incredible burden on U.S. healthcare spending, I can attest to the fact that the personal human cost of untreated mental illness to individuals and families is much more devastating. At NAMI we hear from countless individuals who share their own stories of a family member or friend that wasn't able to reach their full potential because of a lack of necessary, innovative treatment and proactive medical research for mental illnesses. Some also carry the burden with them of someone lost far too soon to suicide. In fact, each year 44,965 Americans die by suicide, and it's currently the 10th leading cause of death in the United States.³ As you can see, the work of this Subcommittee and your commitment to adequate investment in mental health research, treatments and supports is vitally important to save American lives.

FISCAL YEAR 2018 OMNIBUS APPROPRIATIONS BILL

NAMI would like to thank the Chairman, Ranking Member, and the Subcommittee for the bipartisan effort on the fiscal year 2019 Omnibus bill, and the critical investments that were made for mental health research and treatment. We are especially grateful for the \$109.8 million increase for the National Institute of Mental Health (NIMH) and the \$140 million increase for the BRAIN Initiative, including the \$43 million allocation for the NIMH. NAMI is also very appreciative of the \$160 million increase for the Mental Health Block Grant program and the additional \$100 for the ongoing Certified Community Behavioral Health Center (CCBHC) program, a model that is improving quality of care and outcomes for people with serious mental illness.

NATIONAL INSTITUTE OF MENTAL HEALTH RESEARCH FUNDING

As a member of the Ad-Hoc Group for Medical Research, NAMI endorses the goal of at least \$39.3 billion for the National Institutes of Health (NIH), including funds provided to the agency through the 21st Century Cures Act for targeted initiatives. This represents a \$2 billion increase in base funding for the agency, in addition to the \$215 million increase scheduled through the 21st Century Cures Act Innovation Account, for a \$2.215 billion total increase.

SUPPORTING THE NATIONAL INSTITUTE OF MENTAL HEALTH STRATEGIC PLAN

NAMI supports the current 5-year NIMH (National Institute of Mental Health) Strategic Plan and its four overarching goals:

- Leveraging progress in genomics, imaging, and cognitive science to define the biology of complex behaviors;
- Building on the concept of mental disorders as neurodevelopmental disorders to chart trajectories and determine optimal times for interventions;
- Using discoveries to focus on new treatments, and eventual cures, based on precision medicine and moving trials into community settings; and
- Increasing the public health impact of NIMH research through improved services that improve access and quality of care.

ADVANCING SERVICES AND INTERVENTION RESEARCH

Approximately 100,000 young Americans experience a first episode of psychosis (FEP) each year. Intervening early is critical to altering the downward trajectory associated with psychosis. Accordingly, NAMI prioritized support for the NIMH Recovery After an Initial Schizophrenia Episode (RAISE) Project, which resulted in Coordinated Specialty Care (CSC) programs that are helping people with schizophrenia experience recovery. We urge further investment into maintaining CSC's positive treatment and quality-of-life outcomes over the long-term—as well as ex-

²Roehrig, C. (2016, May 18). Mental Disorders Top the List of the Most Costly Conditions in the United States: \$201 Billion. Health Affairs. Retrieved April 26, 2018, from <https://static1.squarespace.com/static/55f9afdf4b0f520d4e4ff43/t/574748a007eaa0c831d7d1da/1464289441778/Health+Aff-2016-Roehrig-hlthaff.2015.1659.pdf>.

³American Foundation for Suicide Prevention. (2016). Suicide Statistics. Retrieved April 26, 2018, from <https://afsp.org/about-suicide/suicide-statistics/>.

panding research into similarly effective interventions with young people struggling with other mental health conditions, such as bipolar disorder and major depressive disorder.

INVESTING IN EARLY PSYCHOSIS PREDICTION AND PREVENTION (EP3)

Our organization also supports NIMH's Early Psychosis Prediction and Prevention (EP3) initiative, which shows promise in detecting risk States for psychotic disorders and reducing the duration of untreated psychosis in adolescents that have experienced a first episode of psychosis. This important research into early identification and prevention of psychosis is potentially transformative and a high priority for NAMI.

ADVANCING PRECISION MEDICINE

We support NIMH efforts to translate basic research findings on brain function into more person-centered and multifaceted diagnoses and treatments for mental health conditions. The Research Domain Criteria (RDoC) is showing promise toward efforts to build a classification system based upon underlying biological and behavioral mechanisms, rather than on symptoms. Through continued development, we believe RDoC should begin to give us the precision currently lacking with traditional diagnostic approaches to mental health conditions.

FUNDING FOR SAMHSA PROGRAMS

NAMI supports programs at the Center for Mental Health Services (CMHS) at SAMHSA that are focused on replication and expansion of effective, evidence-based interventions to serve children and adults living with mental health conditions. We are extremely grateful for the Subcommittee's recent investment of \$160 million to the Mental Health Block Grant (MHBG)—a crucial program, boosting total funding to \$722.6 million.

Additionally, NAMI strongly supports to 10 percent set-aside in the MHBG for evidence-based programs that address the needs of individuals with early serious mental illness, including psychotic disorders, regardless of the age of the individual at onset—a requirement that was codified in the 21st Century Cures Act. As noted above, the NIMH RAISE study validated the most effective approaches for providing coordinated care for adolescents experiencing FEP. Among these is Coordinated Specialty Care (CSC), a collaborative, recovery-oriented approach that emulates the assertive community treatment approach, combining evidence-based services into an effective, coordinated package. CSC emphasizes shared decisionmaking, which NAMI strongly supports, with the recipient of services taking an active role in determining treatment preferences and recovery goals.

NAMI also supports the following funding priorities as outlined in the fiscal year 2019 PB Request for CMHS:

- Children's Mental Health Services at \$119 million, an increase over fiscal year 2018 Omnibus;
- Healthy Transitions, which helps young adults ages 16–25 with serious mental illness access treatment and gain employment and permanent housing, at \$20 million;
- Suicide Prevention Programs, including the Garrett Lee Smith Memorial Act at \$41.9 million and the Zero Suicide model program, a comprehensive, multi-setting approach to suicide prevention in health system at \$11 million;
- Criminal and Juvenile Justice Programs, which support treatment courts and community behavioral health services as an alternative to incarceration, at \$14.3 million;
- Continuation of the Assisted Outpatient Treatment (AOT) pilot program at \$15 million;
- Assertive Community Treatment for individuals with serious mental illness at \$15 million; and
- Mental Health System Transformation and Health Reform, which is focused on supported employment programs for adults and youth with serious mental illness, at \$3.8 million.

Another important program NAMI supports is the Project Aware program. NAMI is concerned with the proposed elimination of this program in the fiscal year 2019 PB Request. We strongly support the Subcommittee continuing to fund this vital program which supports several strategies for addressing mental health in schools. We are troubled by the proposed elimination of the Primary and Behavioral Health Care Integration (PBHCI) program which supports collaboration and infrastructure that increases primary healthcare and wellness services for children and adults with serious mental health conditions and co-occurring mental health and substance use

conditions. Continuation of this program is needed to support better care and health outcomes for people with mental illness, who are dying at least 10 years earlier than their peers, largely from treatable health conditions, like diabetes and heart disease. NAMI strongly encourages restoration of funding at \$51.5 million for this crucial program.

Additionally, NAMI encourages the Subcommittee to appropriate the \$12.5 million authorized in the 21st Century Cures Act for Crisis Services and Online Bed Registry Databases.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

We encourage the Subcommittee to fund Mental and Behavioral Health at \$36.9 million, Behavioral Health Workforce at \$75.0 million, and Increasing Access to Pediatric Mental Health Care at \$10.0 million—all level to fiscal year 2018 Omnibus funding. These programs are crucial to supporting development of the mental health workforce.

HOMELESS INDIVIDUALS LIVING WITH SERIOUS MENTAL ILLNESS

NAMI recommends \$64.6 million for Projects for Assistance in Transition from Homelessness (PATH) in fiscal year 2019, which is consistent with the PB Request. PATH provides funding for outreach to homeless individuals with serious mental illness and helps them navigate systems in order to obtain the housing and treatment services they need.

Finally, NAMI supports the request of \$33.4 million for SAMHSA's Treatment Systems for Homeless portfolio which supports services for those with alcohol/other drug addiction and who are experiencing homelessness, including veterans, and those experiencing chronic homelessness.

CONCLUSION

On behalf of NAMI, I would like to express our sincere gratitude to the Chairman, Ranking Member and entire Subcommittee for their investment in the necessary research, treatments, services and supports for Americans living with mental health conditions.

[This statement was submitted by Mary Giliberti, J.D., Chief Executive Officer, National Alliance on Mental Illness.]

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF CLINICAL NURSE SPECIALISTS

The National Association of Clinical Nurse Specialists (NACNS) is the voice of more than 72,000 clinical nurse specialists (CNSs). CNSs are licensed advanced practice registered nurses (APRN) who have graduate preparation (master's or doctorate) in nursing as a clinical nurse specialist. They have unique and advanced level competencies that meet the increased needs of improving quality and reducing costs in today's healthcare system. CNSs provide direct patient care, including assessment, diagnosis, and management of patient healthcare issues. They are leaders of change in health organizations, developers of scientific evidence-based programs to prevent avoidable complications, and coaches of those with chronic diseases to prevent hospital readmissions. CNSs are facilitators of multidisciplinary teams in acute and chronic care facilities to improve the quality and safety of care, including preventing hospital acquired infections, reducing length of stays, and preventing hospital readmissions.

The NACNS urges the subcommittee to fund the Title VIII Nursing Workforce Development Programs at \$266 million in fiscal year 2019.

According to the Bureau of Labor Statistics (BLS), the registered nurse (RN) workforce will grow 15 percent from 2016 to 2026, outpacing the 7 percent average for all occupations in the U.S. economy. BLS also projects that this growth will result in 438,100 job openings, representing one of the largest numeric increases for occupations. Overall, job opportunities for nurses are expected to increase because of employment growth and the need to replace those who retire over the coming decade.

In addition, employment of APRNs is projected to grow 31 percent from 2016 to 2026, much faster than the average for all occupations. Growth will occur because of an increase in the demand for healthcare services, particularly in medically underserved areas such as rural areas and inner cities. According to the BLS, "[s]everal factors will contribute to this demand, including the fact that APRNs can perform many of the same services as physicians . . . [and] APRNs are becoming

more widely recognized by the public as a source for primary healthcare.” The Bureau also notes that as States change their laws to correct the current governing barriers to practice, APRNs’ ability to practice to the full extent of their education, training, and certification, will be attained.

APRNs increasingly will be used in team-based models of care where they will provide preventive and primary care. APRNs also will be leading the care for the large, aging baby-boom population, which likely will experience ailments and complex conditions. Their advanced practice nursing care expertise will be tapped to keep these patients healthy and to treat those who have chronic and acute conditions.

BLS states that the healthcare sector is a critically important industrial complex for the Nation. It is key to economic recovery and development with the number of jobs climbing steadily, and projected to add more jobs than any of the other occupational groups. BLS estimates that healthcare occupations will grow 18 percent from 2016 to 2026, much faster than the average for all occupations, adding about 2.4 million new jobs. Over three million workers are in hospital settings, which often are the largest employer in a State. Even through the Great Recession, healthcare has been a stimulus program generating employment and income, and nursing is the predominant occupation in the healthcare industry with more than 4.6 million active, licensed RNs in the United States in April 2018.

The Nursing Workforce Development Programs provide training for entry-level and advanced degree nurses to improve the access to, and quality of, healthcare in underserved areas. The Title VIII nursing education programs are fundamental to the infrastructure delivering quality, cost-effective healthcare. NACNS applauds the subcommittee’s bipartisan efforts to recognize that a strong nursing workforce is essential to a health policy that provides high-value care for every dollar invested in capacity building for a 21st century nurse workforce. NACNS contends that it is critically important that Title VIII programs continue to have individual line items that include:

- Advanced Nursing Education (Sec. 811), which contains the Advanced Education Nursing Traineeships and Nurse Anesthetist Traineeships
- Nursing Workforce Diversity (Sec. 821)
- Nurse Education, Practice, Quality, and Retention (Sec. 831)
- NURSE Corps Loan Repayment and Scholarship Programs (Sec. 846)
- Nurse Faculty Loan Program (Sec. 846A)
- Comprehensive Geriatric Education (Sec. 855)

The current Federal funding falls short of the healthcare inequities facing our Nation today. Absent consistent support, boosts to Title VIII will not fulfill the expectation of generating quality health outcomes, nor will episodic increases in funding fill the gap generated by a nurse faculty shortage felt throughout the U.S. health system.

NACNS believes that health inequities, inflated costs, and poor quality of healthcare outcomes in regions of this country will not be reversed until concurrent shortages of RNs, APRNs, and qualified nurse educators are addressed. Your support will help ensure that future nurses exist who are prepared and qualified to take care of you, your family, and all those who will need our care. Without national efforts of some magnitude to match the healthcare reality facing the Nation today, it will be difficult to avoid the adverse effects on the health of our Nation from the inability of our under resourced nursing education programs to produce sufficient numbers of high quality RNs and APRNs.

In closing, NACNS urges the subcommittee to maintain the Title VIII Nursing Workforce Development Programs by funding them at a level of \$266 million in fiscal year 2019.

[This statement was submitted by Anne Hysong, MSN, APRN, CCNS, ACNS-BC, President, National Association of Clinical Nurse Specialists.]

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF
COUNTY AND CITY HEALTH OFFICIALS

The National Association of County and City Health Officials (NACCHO) is the voice of the nearly 3,000 local health departments across the country dedicated to keeping our communities healthy and safe by preventing addiction and disease, preparing for public health emergencies, and ensuring the food we eat, the water we drink and the air we breathe is free of harm. Local health departments depend on the support of the Department of Health and Human Services—most notably—the Centers for Disease Control and Prevention and the Office of the Assistant Secretary for Preparedness and Response to do this work. On behalf of local health de-

partments, NACCHO requests funding at the Centers for Disease Control and Prevention (CDC) and Office of the Assistant Secretary for Preparedness and Response (ASPR) for the following programs:

CENTERS FOR DISEASE CONTROL AND PREVENTION

As the Nation's—and the world's—expert resource and response center, the CDC provides critical funding and technical assistance for State, local, and national programs to strengthen public health capacity, share critical information, and improve health to save millions of lives annually. NACCHO requests \$8.445 billion in fiscal year 2019 for the CDC. As part of the CDC request, NACCHO seeks the continuation of the near \$1 billion Prevention and Public Health Fund (PPHF). This year, the PPHF accounted for nearly 12 percent of CDC's budget and continues to serve as a lifeline for core public health programs at the agency that have demonstrated positive health impacts across the country.

Public Health Emergency Preparedness Program

NACCHO appreciates the increased funding for emergency preparedness provided in fiscal year 2018 and urges the Subcommittee to provide \$824 million for the Public Health Emergency Preparedness (PHEP) Cooperative Agreements in fiscal year 2019. Without the support that PHEP provides, local health departments—55 percent of whom rely solely on Federal funding for emergency preparedness—would be without the critical resources necessary to effectively prepare for and respond to public health emergencies such as terrorist threats, infectious disease outbreaks, natural disasters, and biological, chemical, nuclear, and cyber emergencies. Unmitigated natural disasters and emergencies place an incredible amount of stress on Federal, State and local resources. In 2017, Congress spent a record breaking \$80 billion to provide relief from Hurricanes Harvey, Irma and Maria, and devastating wildfires in California. A comprehensive, cost saving and proactive public health approach to disaster preparedness helps communities to effectively mitigate the damage and costs of disasters and recover in the aftermath. Sustained funding to support local preparedness and response capacity helps local health departments build and convene diverse partners such as police, fire, transportation, planning departments, and community-based organizations and develop and implement evidence-based, community-centered strategies.

317 Immunization Program

NACCHO requests \$650 million for the 317 Immunization Program in fiscal year 2019. According to the CDC, childhood vaccines save over 10,000 lives and 5 million hospitalizations annually and account for an estimated \$10 in savings for every \$1 invested. The 317 Immunization program offers local health departments the ability to purchase cost effective and lifesaving vaccinations, conduct widespread outreach initiatives, provide immunization services to at-risk populations and work with physicians to ensure the proper storage and handling of vaccines. In light of recent vaccine-preventable infectious disease outbreaks in parts of California, Michigan and Minnesota, the ability of local health departments to prevent and control the spread of infectious diseases through effective, safe and timely vaccination is needed more now than ever. A strong and coordinated public health immunization infrastructure at the Federal, State and local levels is fundamental to preventing debilitating diseases such as measles, mumps, whooping cough and the flu in both children and adults.

Public Health Workforce

In fiscal year 2019, NACCHO requests \$57 million for Public Health Workforce Development. These funds support CDC's fellowship and training programs that fill critical gaps in the public health workforce, provide on-the-job training, and provide continuing education and training for the public health workforce. The Public Health Associates program also places CDC-trained staff in the field and strengthens local and state health department capacity and capabilities. The Federal Government has a significant commitment to support the training and development of the healthcare workforce. We urge the Committee to make such a commitment to the public health workforce.

Epidemiology and Laboratory Capacity

In fiscal year 2019, NACCHO requests at least \$195 million in ongoing funding through the Epidemiology and Laboratory Capacity (ELC) Grant Program to address emerging infectious disease threats. The ELC grant program is a single grant vehicle for multiple programmatic initiatives that go to 50 State health departments, six large cities, Puerto Rico, and the Republic of Palau. The ELC grants

strengthen local and State capacity to detect, track and respond to known infectious disease threats and maintaining core capacity to detect new threats as they emerge.

Core Infectious Diseases

In fiscal year 2019, NACCHO request \$429 million for the Core Infectious Disease (CID) Program. CID provides funding to 50 States and six cities (Chicago, Houston, Los Angeles County, New York City, Philadelphia, and Washington, D.C.) to identify and monitor the occurrence of known infectious diseases, identify newly emerging infectious diseases, and identify and respond to outbreaks. CID includes funding to address Antibiotic Resistance (AR), Emerging Infections, Healthcare-associated Infections, Infectious Disease Laboratories, High-consequence Pathogens, and Vector-borne Diseases. CDC's AR initiative is targeted at curbing the rate of infections attributed to bacteria that are resistant to antibiotics, which kill least 23,000 people each year.

NACCHO also urges additional funding to address vector-borne diseases, such as Zika, Chikungunya, Dengue, and West Nile in response to a NACCHO assessment that mosquito control capacity is sorely lacking across the United States.

Opioid Prescription Drug Overdose Prevention

More than 42,000 Americans lost their lives due to an opioid overdose in 2016, and so far the epidemic has cost the United States over \$80 billion. With rates of drug abuse and overdose continuing to rise, it is imperative that we act quickly to and save lives and precious resources and protect public health. NACCHO thanks the committee for increasing funding to CDC for opioid related initiatives by \$350 million in fiscal year 2018. We urge the committee to build upon that momentum and provide \$500 million in funding for CDC in fiscal year 2019 to bolster surveillance and allow communities to keep building on evidence-based and experience-tested methods of prevention. NACCHO has urged CDC to ensure that these funds reach local communities in order to respond effectively to this epidemic. When local health departments are given adequate resources, they rise to the occasion, implementing effective prescription drug overdose prevention interventions in the hardest hit communities, enhancing prescription drug monitoring programs, implementing insurer and health system interventions to improve prescribing practices, and collaborating with partners including law enforcement, community-based organizations and medical providers. For example, with adequate funding Seattle-King County Public Health has worked with local law enforcement, providers, and schools to increase awareness of the dangers of opioids and helped ensure widespread access to Naloxone and other overdose reversal drugs that have since saved hundreds of lives. Kansas City Health Department has been able to use data and analytical tools to better surveil the supply and use of opioids with the Subcommittee's support.

Preventive Health and Health Services Block Grant

NACCHO urges Congress to provide \$760 million for the Preventive Health and Health Services (PHHS) Block Grant in fiscal year 2018. The PHHS Block Grant gives States the autonomy and flexibility to solve State problems and support similar issues in local communities, while still being held accountable for demonstrating local, State, and national impact of their investments.

ASSISTANT SECRETARY FOR PREPAREDNESS AND RESPONSE

The ASPR (Assistant Secretary for Preparedness and Response) leads the Nation's medical and public health preparedness for, response to, and recovery from disasters and public health emergencies.

Hospital Preparedness Program

NACCHO thanks the Subcommittee for the \$10 million increase in fiscal year 2018 for the Hospital Preparedness Program (HPP) and recommends an additional increase to \$474 million in fiscal year 2019. HPP funding helps enhance coordination between local public health and the healthcare system to strengthen the ability of hospitals, medical first responders and medical provider networks to prepare for and respond in the case of an emergency. As the only source of Federal funding that supports regional healthcare system preparedness, HPP promotes a sustained national focus on improving patient outcomes, minimizing the need for supplemental State and Federal resources during emergencies, and enabling rapid recovery. HPP supports over 470 regional healthcare coalitions across the country, which are formal collaborations among healthcare and public health organizations focused on strengthening medical surge capacity and other healthcare preparedness capabilities.

Medical Reserve Corps

In fiscal year 2019, NACCHO requests \$11 million for the Medical Reserve Corps (MRC), a program created in 2002 after the 9/11 terrorist attacks to enable medical, public health, and other volunteers to address local health and preparedness needs. The program includes nearly 200,000 volunteers enrolled in almost 1,000 units across the Nation. More than two-thirds of MRC units are operated by local health departments. MRC volunteers are an important community asset, providing key public health services such as immunizations, health education and chronic disease screenings, in addition to quickly mobilizing individuals and health systems before, during and after emergency situations. Local health departments report that they most often engage MRC volunteers in emergency preparedness activities, an increase from 49 percent in 2010 to 65 percent in 2016. In a 1 year period between June 2015 and May 2016, MRC units logged more than 375,000 volunteer hours. MRC volunteers have also provided critical support and expertise in response to recent emergencies, including Hurricane Harvey and the California wildfires.

Our hope is that the Subcommittee will continue its efforts to provide funding for key public health programs that keep Americans healthy, safe, and productive. Thank you for your attention to these recommendations. NACCHO is happy to provide any additional information you may need.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF
STATE HEAD INJURY ADMINISTRATORS

Dear Chairman Blunt and Ranking Member Murray:

On behalf of the National Association of State Head Injury Administrators (NASHIA), thank you for the opportunity to submit testimony regarding the fiscal year 2019 appropriations for programs authorized by the Traumatic Brain Injury (TBI) Act 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, as well as funding for the TBI Model Systems administered by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) housed in the ACL.

NASHIA thanks the Committee for the additional \$2 million for fiscal year 2018 included in the omnibus spending bill passed in March for the ACL TBI Federal Grant Program. These funds should be split between grants for State Protection and Advocacy systems, known as disability rights in some States; and the Federal TBI State Implementation Grant program. The HHS' ACL Federal TBI State Implementation Grant Program is the only program that assists States in addressing the complex needs of individuals with TBI and their families.

For fiscal year 2019 NASHIA is requesting: \$11 million total for HHS' ACL TBI State Implementation Grant Program, representing a \$5 million increase for additional State grants to expand and improve service delivery; and \$5 million additional funding for CDC's National Center for Injury Prevention and Control to establish and oversee a national concussion surveillance system. Furthermore, NASHIA supports funding for CDC's falls prevention program (\$5 million) and the injury control research centers (\$9 million), both of which the President proposed to eliminate in fiscal year 2019.

In addition, NASHIA recommends \$15 million for the NIDILRR TBI Model Systems to expand the number of centers and research projects. NASHIA strongly opposes the President's budget recommendation to reduce funding and move NIDILRR from the ACL to the National Institutes of Health (NIH). NIDILRR was formerly located in the Department of Education and, as the result of the Workforce Innovation and Opportunity Act (WIOA) of 2014, was only recently transferred to the ACL.

NASHIA is a nonprofit organization representing States administering TBI services and is comprised of State Government agencies and associate members consisting of professionals, consumers, families, providers and others interested in TBI. Our mission is to assist States in promoting partnerships and building systems to meet the needs of individuals with TBI with the goal of all States having resources to assist individuals with TBI to return to home, community, work and school after sustaining a brain injury, as well as assistance to family members who often serve as primary caregivers. The TBI Act programs assist States to achieve this goal.

In 2013, 2.8 million Americans sought treatment for or died from a TBI as the result of a car crash, fall, sporting or recreational injury, an assault. The leading causes of non-fatal TBI are falls (35 percent), motor vehicle-related injuries (17 percent), and strikes or blows to the head from or against an object (17 percent), such as in sports injuries. The leading causes of TBI-related deaths are motor vehicle

crashes, suicides, and falls. The CDC estimates, based on data from two States, that 3.2 million—5.3 million persons in the United States are living with a TBI-related disability. Children aged 0—4 years, adolescents aged 15—19 years, and adults aged 75 years and older are among the most likely to have a TBI-related emergency department visit or to be hospitalized for a TBI. Adults aged 75 years and older have the highest rates of TBI-related hospitalizations and deaths among all age groups. Individuals who sustain a TBI often have resulting problems with cognition, emotions, language, physical mobility and sensory disabilities that can lead to lifelong problems.

TBI is a complex disability that challenges States' ability to provide the right services at the right time. Often, several private and public entities may be involved over the course of recovery including, medical and rehabilitative facilities and programs, including emergency departments, hospitals, trauma centers; post-acute rehabilitation programs; education; vocational rehabilitation; therapies to maintain physical and cognitive functioning; and community services and supports to enable the individuals to live as independently as possible. Payors for these type of services may include private health insurance, Workers' Compensation, Medicaid, private pay, and public assistance programs. Navigating this path to recovery is often overwhelming for the individual and their families. Many States have developed service coordination or case management systems supported by Medicaid, State funding or dedicated funding from fines or fees, referred to as trust fund programs to assist with the coordination of rehabilitative care, services and supports.

About half of the States have enacted legislation to establish a trust fund program specifically to fund TBI services; a few State legislatures appropriate general revenue to fund services; about half of the States have implemented brain injury Medicaid Home and Community-Based Services (HCBS) waiver programs; and some States use a combination of these funding sources to support the array of needs. These services include post-acute rehabilitation; personal care; service coordination or case management; assistance with activities of daily living; in-home accommodations and modifications; transportation; and therapies, including behavioral, cognitive, speech-language and physical therapies. With limited State resources to address these needs, many individuals, particularly those with behavioral issues, addiction problems, and poor judgment, will find themselves homeless or in correctional facilities.

Nineteen (19) States have just finished a 4-year Federal TBI State Implementation Grant and, along with other States, are currently awaiting the results of funding for new 3-year competitive grants to be determined by the ACL. Over the past 4 years, State grantees have identified and assisted high risk populations, which included youth and adults with TBI in juvenile justice and criminal justice systems; older adults with fall-related TBIs; and young children in pre-school programs through screening, training, and linking individuals to services. As States wind down these activities, the likelihood of continuing this work is slim without continued support.

Since 2009, all 50 States and the District of Columbia have enacted "return to play" laws following the State of Washington, which was the first State to do so, to address concussion management in youth athletes. States are now beginning to address "return to learn" issues to identify the academic needs of students after a concussion, regardless of cause. The requested \$5 million for the CDC's National Center for Injury Prevention and Control to establish and oversee a national concussion surveillance system will greatly assist States as they target their resources to better meet and understand the needs of individuals who sustain a concussion.

Currently, there are 16 TBI Model Systems Centers which provide comprehensive systems of specialty care from the point of injury through return to the community. They participate in independent and collaborative research projects developing and evaluating medical, rehabilitation, vocational and other services designed to address the physical, cognitive and psychological needs of individuals with TBI and share their findings to healthcare professionals; individuals with TBI; their families, caregivers and friends; and the general public. States benefit from their research and tools to assist with screening, training, and assessing program outcomes.

We are pleased that ACL is beginning to develop a Federal Interagency Coordinating Plan, as called for by the TBI Reauthorization of 2014, to align TBI resources with other Federal aging and disability programs to help States maximize and to coordinate Federal resources as States primarily incur the burden of TBI for individuals who need on-going, intermittent, or short-term services and supports that are not paid for through private healthcare insurance plans. The ACL resources include Lifespan Respite Care, Aging and Disability Resource Centers, Independent Living, NIDILRR, and Assistive Technology programs. Other Federal resources include the National Institutes of Health (NIH); CDC; Department of Veterans Affairs; Depart-

ment of Defense; disability benefits administered by the Social Security Administration; vocational rehabilitation and educational services funded by the Department of Education; children's programs (Title V) administered by HHS' Health Resources and Services Administration (HRSA); Medicaid and Medicare administered by the Centers for Medicare and Medicaid Services (CMS); job training programs through the Department of Labor (DOL); housing programs administered by the Department of Housing and Urban Development (HUD), and transportation programs.

In closing, the TBI State Implementation Grant Program has helped States to leverage other State and Federal funds and to bring partners together in order to address the complex needs of individuals with TBI and their families. To continue and expand resources we believe that all States should have access to the Federal program to address this growing and aging population. Therefore, we ask that you continue to fund and increase appropriations for this important program, as well as to establish the CDC national concussion surveillance system to improve and expand data needed to plan for service delivery; and to increase funding for NIDILRR TBI Model Systems to support research to address this critical issue.

Should you wish additional information, please do not hesitate to contact Rebecca Wolfkiel, Executive Director, at execdiretor@nashia.org. You may also contact Becky Corby, NASHIA Government Relations at rcorby@ridgepolicygroup.com or Susan L. Vaughn, Director of Public Policy, at publicpolicy@nashia.org. Thank you for your continued support.

[This statement was submitted by Susan L. Vaughn, Director of Public Policy.]

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF NUTRITION AND
AGING SERVICES PROGRAMS

Chairman Blunt, Ranking Member Murray: On behalf of the National Association of Nutrition and Aging Services Programs (NANASP), an 1,100-member non-partisan, nonprofit, membership organization for national advocates for senior health and well-being, we thank you for the opportunity to offer testimony in support of the Older Americans Act Title III(C) senior nutrition program within the Administration for Community Living (ACL) and for the Senior Community Service Employment Program within the Department of Labor. We support funding the Title III(C) nutrition program at \$996.7 million for fiscal year 2019 and the Senior Community Service Employment Program at \$463.8 million, the authorized level in the 2016 Older Americans Act Reauthorization, for fiscal year 2019.

OLDER AMERICANS ACT TITLE III(C) SENIOR NUTRITION PROGRAMS

Older Americans Act (OAA) congregate and home-delivered meals programs are provided in every State and congressional district in this Nation. Approximately 2.4 million seniors in 2014 received these services.

First, thank you for your bipartisan leadership in the passage of the fiscal year 2018 omnibus appropriation bill, and for the \$59 million funding increase for the III(C) nutrition programs. We also thank you for rejecting the President's call for the elimination of the Social Services Block Grant (SSBG), which also funds home-delivered meals, and funding it at \$1.7 billion.

Thank you as well for other funding increases in the OAA, including increases in the Supportive Services, Family Caregiver, and the Native American Programs, all of which complement our efforts to serve seniors. Further, we oppose all efforts of rescission of these critically-needed resources and we urge the OMB not to delay obligating funds intended for fiscal year 2018.

Unfortunately, these funding increases, though much needed, still do not keep pace with the rising cost of food, inflation, and the growing numbers of older adults. In fact, year over year, the number of older adults receiving meals is shrinking even as the need is growing: the OAA network overall is serving 19 million fewer meals to seniors in need than it was in 2005. We know that 58 percent of participants have indicated that one congregate meal provides one-half or more of their total food for the day, and that a 2015 Government Accountability Office report found that 83 percent of food-insecure seniors and 83 percent of physically-impaired seniors did not receive meals through the OAA, but likely needed them. Additional funding for congregate and home-delivered meals in fiscal year 2019 is critical to help to counteract inflation and provide millions of additional meals when combined with State and local funding.

Investing additional money in the OAA nutrition programs is fiscally responsible. Access to OAA meals is essential to keeping these older adults out of costly nursing facilities and hospitals. Data from ACL's National Survey of OAA Participants indi-

cates that 61 percent of congregate and 92 percent of home-delivered meal recipients say that the meals enable them to continue living in their homes. Further, on average, a senior can be fed for a year for about \$1,300, which is approximately the same as the cost of one day's stay in a hospital or less than the cost of 10 days in a nursing home. The cost savings to Medicare and Medicaid that this creates cannot be over-emphasized.

The OAA nutrition programs provide jobs to thousands across the country. The programs itself are also flexible, allowing local communities to tailor their local programs to meet the needs of the seniors they serve. These programs are the epitome of a public-private partnership; local programs work in tandem with State and local governments as well as private philanthropy to provide their services, and the OAA nutrition programs participants contribute to the cost of meals on a voluntary basis. In short, the OAA nutrition programs are the model of successful government, and they have worked for over 45 years.

SENIOR COMMUNITY SERVICE EMPLOYMENT PROGRAM

The Senior Community Service Employment Program (SCSEP), also known as Community Service Employment for Older Americans, is authorized by the Older Americans Act but administered and funded by the Department of Labor. It is the only Federal program that directly helps older workers.

SCSEP currently provides jobs for about 67,000 low-income older adults in every State and territory, and in nearly every county in every State. Many of these jobs are in the service of other older adults—SCSEP participants may work as senior center staff members, transportation providers, or home-delivered meals cooks and drivers.

SCSEP participants provided more than 34.8 million paid staff hours to over 20,000 local public and nonprofit agencies, such as American Job Centers, libraries, schools, and senior centers (including 7.6 million hours in aging services and programs) in PY2015. The value of the community service provided by SCSEP participants (using Independent Sector's estimated value of a volunteer hour) exceeded \$820 million, nearly twice the total SCSEP PY2015 appropriations of \$434.4 million.

SCSEP received \$400 million in fiscal year 2018, a repudiation of the elimination of the program as supported by the President and level-funding as compared to the previous year. However, this is not enough to meet the growing need for SCSEP—both in participants and in wages.

Our request is based on the fiscal year 2019 authorization levels of the 2016 OAA reauthorization—in fact, both of you voted in favor of these levels. These levels were carefully negotiated in a bipartisan manner between House and Senate Republicans and Democrats. They consider the rapid growth of the older adult population and the rising pace of inflation. They are sensible and fiscally responsible.

SCSEP is the only Federal program targeted to serve specifically low-income older adults seeking employment and training assistance; moreover, the Government Accountability Office has previously identified SCSEP as one of only three Federal workforce programs with no overlap or duplication.

The average age of a program participant is 62; according to the Department of Labor, 65 percent of all SCSEP participants in Program Year 2015 were women, 49 percent were minorities, and 88 percent were at or below the Federal poverty level.

By providing subsidized employment opportunities for this highly vulnerable and underemployed/unemployed segment of the population, SCSEP helps participants build their resumes and receive the training they need to transition into unsubsidized employment. These subsidized employment opportunities also provide staff members for other community programs that may lack funding for regular hires—not only senior centers, but also public libraries, schools, hospitals, and other community agencies.

Many States and localities are raising the minimum wage, and this dilutes SCSEP funding, which must increase to match these increases. This decreases the number of participants SCSEP can handle, yet the older population is growing. The last time there was an increase in funding for SCSEP, other than under the fiscal year 2009–fiscal year 2010 stimulus package, was when the Federal minimum wage was increased, also in 2009. Though wages have not increased at the Federal level since then, they have increased in enough States and localities to the point that SCSEP is becoming very strained.

As a job-creator and an unduplicated, successful program, SCSEP should receive top consideration for increased funding.

With more than 10,000 seniors turning 65 every day, now is the time to provide an even greater investment in these proven and cost-effective programs for older adults.

Thank you for your past and future support.

[This statement was submitted by Tony Sarmiento, Chair and Robert Blancato, Executive Director, National Association of Nutrition and Aging Services Programs.]

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF RSVP DIRECTORS

We appreciate the opportunity to submit testimony about the funding for the RSVP program in fiscal year 2019. RSVP is a senior volunteer program administered by the Corporation for National and Community Service (CNCS). The National Association of RSVP Directors (NARSVPD) seeks a fiscal year 2019 funding level of \$63 million. This additional \$14 million would grow the number of volunteers by 40,000 and allow RSVP to tutor and mentor more students, help more seniors live independent and productive lives, support more veterans and military families, and help combat opioid abuse.

RSVP deploys 208,000 volunteers in 627 programs that support the efforts of thousands of community organizations across the Nation. It provides opportunities for people 55 and over to make a difference in their communities through volunteer service. It offers maximum flexibility and choice to its volunteers by matching the personal interests and skills of volunteers with opportunities to help solve community problems. It offers supplemental insurance while volunteers are serving, pre-service orientation, and on-the-job training from the agency or organization in which volunteers are placed. RSVP volunteers get no stipend but are eligible for reimbursement for meals and mileage, as long as program budgets allow for it.

RSVP programs identify community needs and continually recruit, train, place, coach and mentor volunteers while they report to CNCS on how programs are meeting their performance goals and other matters.

RSVP is not means tested and recruits volunteers without regard to income. Most serve between 10 and 40 hours a week. Because RSVP is flexible, volunteers provide a wide variety of needed services, including transportation to medical services, offering respite to caregivers, delivering health and nutrition services, supporting veterans and military families, volunteering in parks, police stations and other locations, participating in disaster prevention and relief activities, helping prepare tax returns for elderly and low-income people and leveraging an additional 18,000 volunteers, among many other activities.

RSVP is cost-effective and an excellent investment:

- The average Federal RSVP grant is about \$75,000—less than the national annual median cost of a semi-private room in a nursing home in 2017 of almost \$86,000. In many States, it costs more to put one senior in a nursing home for a year than it does to support an RSVP program. Using Independent Sector's estimate of the value of an hour of volunteer service, RSVP volunteers provide more than \$1 billion worth of service to the Nation each year.
- RSVP grantees must provide a match. The required non-Federal share is a minimum 10 percent of the total grant in year one, 20 percent in year two, and 30 percent in year three and all subsequent years. CNCS projects that States and local communities will have contributed \$39 million in non-Federal support in fiscal year 2017. In fiscal year 2015, RSVP volunteers delivered an estimated 46 million hours of service. Working through a wide variety of nonprofits, city and county governments, local United Way organizations, and faith-based organizations, RSVP volunteers served 329,000 veterans in activities such as transportation and employment service referrals; mentored more than 78,000 children; provided independent living services to 797,000 adults, primarily frail seniors; provided respite services to nearly 20,300 family or informal caregivers; and engaged 20,100 veterans who served as RSVP volunteers.
- RSVP is an important source of disaster prevention and relief. In recent years, RSVP volunteers participated in recovery efforts in Alabama, Missouri, Kentucky, South Carolina, Texas, California, and New York.
- RSVP volunteers support students. The Oasis Jefferson County, Missouri RSVP Program received a grant to build on its proven model and expertise in engaging older adult volunteers by recruiting and placing 75 volunteers to address educational outcomes for economically disadvantaged and academically at-risk children. In Jefferson County, 50.7 percent of third graders are not proficient in reading. Over the course of 3 years, RSVP volunteers serve directly in 19 schools to provide literacy tutoring and support to 255 students over 5,040 hours of service.

In Davidson and Williamson Counties, Tennessee, RSVP's signature program Friends Learning in Pairs (FLIP), an intergenerational volunteer tutoring program.

Through weekly one-on-one tutoring sessions, RSVP volunteers provide the individual support that struggling young students need in order to succeed. During the 2014–15 school year, 124 RSVP volunteers provided one-on-one academic assistance to 446 elementary school students, contributing a total of 4,556 service hours. Over the program's 21-year history, 82 percent of participants met academic benchmarks. According to one teacher at Franklin Elementary, "I don't know where we would be without FLIP. They helped six children in my class improve at least a year's growth. These students were below level and made all benchmarks this year!"

RSVP helps seniors to live independently: volunteering helps keep seniors vibrant and RSVP volunteers help meet the needs of seniors to keep them in their homes.

In rural Pike County, Alabama, 25 Volunteers transport an average of 15 other seniors per week to medical appointments, drug stores, and to buy groceries or other necessities. They provide over 2500 trips annually enabling 86 seniors to get medical care and continue to live independently in their own homes and save over \$5.6 million in nursing home costs. Another 25 RSVP Volunteers call 85 mostly rural frail homebound seniors on a daily basis providing outreach and interaction, helping them remain mentally alert, feel safer, and enabling them to remain in their homes longer and avoid early institutionalization.

Fifteen RSVP volunteers assist with local meal deliveries to homebound seniors. Last year, RSVP volunteers delivered over 4800 meals, ensuring that seniors received a nutritious meal, interacted with volunteers and were able to remain in their homes and avoid premature institutionalization.

The 317 RSVP volunteers with the Flint Hills Volunteer Center in Manhattan, Kansas volunteered for a total of 25,250 hours, provided 1800 hours of volunteer tutoring, 2700 hours delivering meals to homebound individuals, 11,600 hours supporting soldiers at Fort Riley, and almost 900 hours serving veterans and their families. By helping seniors continue to live independently, they saved an estimated \$7.8 million in nursing home care costs.

Volunteers in the Athens, Alabama RSVP program staff the Volunteer Income Tax Assistance (VITA) program which helps put money back into the community. In the past year, they helped file 1891 returns that resulted in Earned Income Tax Credits worth \$324,411, Child Tax Credits worth \$119,395, Federal Returns of \$1,400,450, and State returns of \$117,24. VITA volunteers served 316 veterans.

RSVP volunteers support veterans and military families. Pike County RSVP has 20 RSVP volunteers who serve with its Veterans and Military Families initiative in which Troy University provides a classroom with 60 available computers and RSVP volunteers assist with job search, applying online and mock job interviews for veterans and military families, assisting veterans and military families in researching and locating housing, schools, and support services. All told, these RSVP volunteers helped more than 200 veterans and military last year. The first RSVP Veterans Coffeehouse in Connecticut was established by Thames Valley Council for Community Action's RSVP in Killingly in 2015. More than 433 guests, including 157 veterans, attended the coffeehouse during its first 6 months. The coffeehouse provides socialization for isolated veterans. Through connections made at the coffeehouse, several veterans have been able to gain access to additional services and benefits. Two veterans were awarded full disability for Agent Orange complications. A 92-year-old veteran received two new hearing aids at no charge. Eight veterans began receiving housing, energy, medical and food assistance through the Soldiers, Sailors & Marines Fund. Other veterans are gaining access to healthcare through the Veterans Administration as a result of coffeehouse connections.

RSVP is a "destination" for retiring "baby boomers." Some 10,000 "baby boomers" are retiring everyday and will do so every day for the next 20 years. RSVP is the only national program able to place large numbers senior volunteers in high quality volunteer positions. CNCS reported that RSVP has increased the number of baby boomers in the program and provides those volunteers with high quality activities that make use of their skills. Baby boomers enrolled in RSVP volunteer over 100 hours more than their counterparts who are not associated with RSVP. Virtually all of RSVP baby boomers who recruit/coordinate other volunteers are likely to continue in the program.

Take the case of Sylvia, a retired software engineer who volunteers with Reading Partners, which matches students with volunteers, as a volunteer with King County RSVP in Seattle. This is Sylvia's second year in the program. Last year she worked with a 3rd grader who was 6 months behind in reading proficiency. By the end of the year, she brought her student up to grade level. This year's student is a 1st grader. Sylvia says, the personal relationship formed between student and volunteer is a key motivator in a student's success. And, she adds, success breeds confidence and confidence breeds more success. Maya, the site coordinator at the elementary school where Sylvia volunteers says "This year, Sylvia is working with a 1st grader

who, thanks to her tutelage, is quickly approaching grade level in reading. With her background in math and the sciences, Sylvia is an expert at engaging students with books on dynamic STEM subjects—distant planets, fascinating animals, dramatic weather patterns—and shows her students that reading is essential for any subject area.”

Sylvia also finds time to volunteer at CourtWatch, a program under the auspices of King County Sexual Assault Resource Center, in which volunteers collect information is used both to track individual cases and to identify trends/patterns within the judicial system.

RSVP is helping in the fight against opioid abuse and can do more with additional resources. Last year, Fort Wayne RSVP received a grant that can be replicated at scale. It covers five mostly rural counties in Indiana: Adams, Wells, Huntington, and Whitley Counties. The main goal is to develop TRIADS — partnerships of three law enforcement, older adults, and community groups—in each county. TRIADS promote Older Adult safety and to reduce the fear of crime that older adults often experience. The TRIAD serves as a vehicle to promote citizen involvement to address opioid abuse in these mostly, rural counties. RSVP Volunteers are being recruited in each county to serve in TRIAD event planning and distribution of educational material with a focus on Opioid Abuse. Sheriffs are identifying topics for community education including lack of knowledge of opioids, the use of Narcan, and safe storage of medication in the homes, and proper disposal of medications. Because it is not means tested, RSVP is agile enough to meet local needs that may require different models. It can recruit doctors, nurses, other health professionals, as well as other experts.

We believe that restoring funding for RSVP to \$63 million will enable more volunteers to tutor and mentor more students, help seniors live independent and productive lives, support more veterans and military families, and help combat opioid abuse, resulting in significant benefits to both the volunteers and the communities they serve.

[This statement was submitted by Betty M. Ruth, President, National Association of RSVP Directors.]

PREPARED STATEMENT OF THE NATIONAL COALITION OF STD DIRECTORS

CDC’s DIVISION OF STD PREVENTION FUNDING HISTORY

| Fiscal Year | (\$ millions) |
|-------------|---------------|
| Funding: | |
| Request: | |
| 2019 | 227.3 |
| Level: | |
| 2018 | 157.3 |
| 2017 | 152.3 |
| 2016 | 157.3 |
| 2015 | 157.3 |

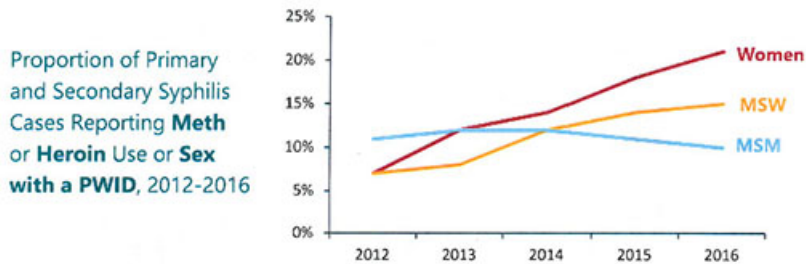
On behalf of the members of the National Coalition of STD Directors (NCSDD), I am requesting a total of \$227.310 million, a requested increase of \$70 million, for the Division of STD Prevention in fiscal year 2019 funding. The Division of STD Prevention is part of the National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention at the Centers for Disease Control and Prevention (CDC). NCSDD members represent sexually transmitted disease (STD) programs in health departments in all fifty States, seven cities counties and eight U.S. territories.

The United States leads all industrialized nations in the incidence of STDs. Twenty million new cases of STDs occur each year, which cost our healthcare system \$16 billion dollars annually. Stopping the spread of STDs requires early diagnosis and prompt treatment. STDs have serious life-long health consequences, including infertility, higher cancer risk, disability or death. These dire health consequences disproportionately impact women and newborn babies.

CDC reports that STDs are at a record high. In the last year, syphilis and gonorrhea rates both increased by 20 percent. Syphilis has increased among women at an even higher rate, which has resulted in a 30 percent increase in congenital syphilis—syphilis transmitted during pregnancy. Congenital syphilis is entirely preventable, and a single baby born with congenital syphilis is one too many. In 2016, rates of congenital syphilis increase for the fourth year in a row, with over 620 babies

born with congenital syphilis. Babies born with congenital syphilis are at risk for devastating life-long consequences and death.

In addition, CDC studies have shown that STD infection rates have increased along with heroin injections and prescription opioid misuse disorders. People who use drug, including opioids, have high rates of unsafe sex practices, such as sex without a condom, having sex partners who inject drugs, and engaging in sex work. Such high-risk sex behaviors put individuals at elevated risk for acquiring and STD and for transmitting an STD to their sexual networks. STDs have increased directly as a result of the increasing drug use; States across the country report drug use in 30–80 percent of their STD cases. Additionally, national data show that an increasing proportion of syphilis transmission among heterosexuals is occurring among people who use drugs, including people who inject drugs (PWID). As evidence by the graph below (taken from CDC materials) that this is increasing so for women; drug use is driving the increasing syphilis among women, which results in increasing congenital syphilis.



*MSW= Men who have sex with women

*MSM= Men who have sex with men

Within STD public health programs there is a unique and vital workforce: Disease Intervention Specialists, or DIS. DIS are key public health staff who, among other activities, contact those who may have been exposed to an STD to ensure they are tested and treated, leading to improved health in the individual and stopping the spread of disease in the community. Federal funding often supports the work of DIS making it possible for this workforce to utilize their skills beyond STD and HIV prevention by responding to other public health emergencies such as zika and ebola. This staff are key to any infectious disease response to the opioid crisis; DIS work in the community to track people diagnosed with reportable diseases and link them to appropriate diagnostic and treatment services.

In most States, Federal STD funding is the only funding for STD prevention. In fiscal year 2017, DSTDP was a cut \$5 million and while this funding was restored, the program is currently operating at fiscal year 2016 funding levels. The STD field remains historically under resourced, resulting more disease, additional costs to our healthcare system, and less educated clinicians.

While STDs are currently at their highest levels ever reported, Federal STD prevention funding has seen a \$16 million reduction in annual funding since 2003. This is a nearly reduction of 40 percent in buying power for CDC and its State, local, and territorial grantees. And since 2003:

- Cases of syphilis have increased 230 percent;
- Cases of chlamydia have increased 75 percent;
- Only one drug is now recommended for gonorrhea treatment due to emergence of drug resistance; in 2003, CDC recommended five different drugs for gonorrhea treatment

As a result of funding reductions at the State and Federal level, STD programs across the country have had to prioritize among the STDs their programs work on and the cases DIS follow-up on to stop the spread of that STD. Many programs prioritize work on HIV and syphilis, and do not have the resources to track down possible contacts for gonorrhea and chlamydia. This is particularly concerning because of the recent news of the first fully resistance case of gonorrhea reported in the United Kingdom. We may be in the cusp of an epidemic of drug-resistant gonorrhea and we are unprepared to deal with such an epidemic.

Funding DSTDP will move the country towards an STD-free America. The goals are to improve infant and maternal health, create healthy families, and decrease

costs to the healthcare system. If this request is fully funded, it will address the following issues:

- Prevent syphilis and eliminate congenital syphilis*: Syphilis is associated with significant complications if left untreated and facilitates transmission and acquisition of HIV. Congenital syphilis is now at the highest rate since 2000. Congenital syphilis is totally preventable, and each new case represents a major failure of our healthcare system. Passing on the infection during pregnancy can lead to infant death in 40 percent of the cases. Infants who survive may experience severe health and development issues.
- Prevent infertility through diagnosis and treatment for chlamydia*: In 2016, almost 1.6 million new cases of chlamydia were reported, but this statistic is believed to be less than one-quarter of all new cases. Up to 40 percent of women with untreated chlamydia develop pelvic inflammatory disease (PID); one in five women with untreated chlamydia will lose the ability to have children. Having the disease during pregnancy can result in passing the infection to the infant.
- Prevent gonorrhea to limit more costly treatments*: Untreated gonorrhea can cause serious and permanent health problems including infertility. Preventing and treating gonorrhea now, while it is easily curable, will reduce the high cost of treating gonorrhea once drug resistance develops. In 2015–2016, the rate of reported gonorrhea increased 18.5 percent, and increased 48.6 percent since the historic low in 2009.
- Special Initiative for Direct STD Services*: STD programs and their partners need additional funding to scale up effective testing and treatment for these infections. Effective testing and treatment is a key way to halt STDs. \$20 million of this request is for a special initiative for STD screening and treatment to better address these epidemics.

In fiscal year 2019 funding, please fund STD prevention at no less than \$227.3 million to allow an effective response to the highest levels of STD ever recorded. For more information, please contact NCSD's Director, Policy and Government Relations Stephanie Arnold Pang via email at sarnold@ncsddc.org.

[This statement was submitted by David C. Harvey, Executive Director, National Coalition of STD Directors.]

PREPARED STATEMENT OF THE NATIONAL COLLEGE ACCESS NETWORK

Dear Chairs Cole and Blunt and Ranking Members DeLauro and Murray:

Thank you for your strong leadership during the 2018 fiscal year appropriations discussions that secured significant investments in college affordability for low-income students in our country. As our mission states, the National College Access Network and its members are focused on helping historically underrepresented students achieve their educational dreams through any high-quality pathway of post-secondary education. The priorities shown through the fiscal year 2018 funding decisions will help students pursue these educational dreams. Today, we write to respectfully request a continued commitment to low-income students through additional investment in financial aid and related programs.

The National College Access Network, founded in 1995, represents more than 400 members across the country that all work toward NCAN's mission to build, strengthen, and empower communities 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. All are dedicated to helping underrepresented students access, afford, and succeed in higher education. The Federal investments that would most bolster this goal in fiscal year 2019 include the following:

Pell Grant Investments:

The Pell Grant award is the cornerstone of financial aid for low-income students. Without this need-based grant funding, an even smaller portion of low-income students would be able to access higher education. Congress recognized this importance in the fiscal year 2018 budget by increasing the maximum Pell Grant award by \$175, or 3 percent. This increase is crucial as automatic inflationary adjustments previously required by the Higher Education Act expire. Even with this increase, the purchasing power of the Pell Grant for a four-year college degree drops to an historic low of 28 percent.

Due to this loss of purchasing power, NCAN asks for consideration of a bold, multi-year proposal to address the long-term purchasing power of the Pell Grant. At its peak in 1975–76, the maximum Pell Grant award covered nearly four-fifths of a public four-year college education. NCAN realizes the fiscal challenges that face Congress and therefore recommends a multi-year interim step that would return Pell's purchasing power to 50 percent of the cost of a four-year public higher education. In order to reach that goal, as outlined below, NCAN respectfully requests a maximum Pell Grant of \$6,831.

| Academic Year | Public Four-Year Cost of Attendance | One-Year Percent Change | Pell Maximum Award | Percentage of CoA Covered by Pell Maximum | One Year Percent Change in Pell Maximum Award |
|---------------|-------------------------------------|-------------------------|--------------------|---|---|
| 08–09 | \$14,370 | — | \$4,731 | 33% | — |
| 09–10 | \$15,240 | 6.1% | \$5,350 | 35% | 13.1% |
| 10–11 | \$16,180 | 6.2% | \$5,550 | 34% | 3.7% |
| 11–12 | \$17,160 | 6.1% | \$5,550 | 32% | 0.0% |
| 12–13 | \$17,820 | 3.8% | \$5,550 | 31% | 0.0% |
| 13–14 | \$18,380 | 3.1% | \$5,645 | 31% | 1.7% |
| 14–15 | \$18,930 | 3.0% | \$5,730 | 30% | 1.5% |
| 15–16 | \$19,570 | 3.4% | \$5,775 | 30% | 0.8% |
| 16–17 | \$20,150 | 3.0% | \$5,815 | 29% | 0.7% |
| 17–18 | \$20,770 | 3.1% | \$5,920 | 29% | 1.8% |
| 18–19 | \$21,393 | 3.0% | \$6,095 | 28% | 3.0% |
| 19–20 | \$22,035 | 3.0% | \$6,831 | 31% | 12.1% |
| 20–21 | \$22,696 | 3.0% | \$7,717 | 34% | 13.0% |
| 21–22 | \$23,377 | 3.0% | \$8,649 | 37% | 12.1% |
| 22–23 | \$24,078 | 3.0% | \$9,390 | 39% | 8.6% |
| 23–24 | \$24,800 | 3.0% | \$10,168 | 41% | 8.3% |
| 24–25 | \$25,544 | 3.0% | \$10,984 | 43% | 8.0% |
| 25–26 | \$26,311 | 3.0% | \$11,840 | 45% | 7.8% |
| 26–27 | \$27,100 | 3.0% | \$12,737 | 47% | 7.6% |
| 27–28 | \$27,913 | 3.0% | \$13,957 | 50% | 9.6% |

If the initial installment of this multi-year approach is not fiscally possible, then we recommend that Congress continue to ensure an inflationary adjustment (estimated at 2 percent) to Pell and increase the maximum award to \$6,217 in the fiscal year 2019 appropriations bill.

Campus-Based Aid:

As low-income students are piecing together the resources to support their post-secondary pursuits, every dollar and every type of aid counts. For most low-income students, the Supplemental Educational Opportunity Grant (SEOG) and Federal Work-Study help to fill important holes in their financial aid packages.

The average SEOG award for dependent students was \$752 in 2017. For the 2018 fiscal year, Congress generously increased the SEOG budget by 14.6 percent, bringing it to \$840,000,000. This increase will allow institutions to offer SEOG awards to more students to or provide additional dollars, up to \$4000, to students who need it most. For fiscal year 2019, NCAN respectfully requests that Congress once again increase the SEOG program budget by 14.6 percent, for a total of \$963,000,000.

Fifty-eight percent of today's students work while enrolled in higher education. 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 travelling between work and campus. For the 2018 fiscal year, Congress provided a FWS investment of \$1.13 billion, an increase of 14.1 percent. For fiscal year 2019, NCAN respectfully requests that Congress once again increase the FWS program budget by 14.1 percent, for a total of \$1.29 billion.

Additionally, campus-based aid programs encourage institutions to increase their investment in need-based financial aid as both of these programs require a match. The larger Federal investment also means institutions will be increasing their investment, bringing more funds to students overall.

Federally Funded College Access Programs—TRIO and GEAR UP:

With approximately 1.8 million high school seniors defined as low-income annually, many programs are needed to meet all of their needs as they pursue their options after high school graduation. The NCAN community serves approximately 2 million students annually across ages—from middle school through college gradua-

tion. To reach all of 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: \$1,070,000 for TRIO and \$375 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. In particular, many of NCAN's largest members are able to maximize their impact on underrepresented students by participating in the AmeriCorps public-private partnership. Continuing support for CNCS, and in particular 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 echoes the request of the Voices for National Service to increase funding to provide for 100,000 volunteers during the fiscal year 2019.

Thank you for this opportunity to provide our funding priorities for the fiscal year 2019. High-income students are two times more likely to complete a postsecondary degree or credential than low-income students. Through continued supports—both financial and programmatic—our country can work together to close this attainment gap. Thank you again for your support of this important goal.

Sincerely,

[This statement was submitted by Kim Cook, Executive Director, National College Access Network.]

PREPARED STATEMENT OF THE NATIONAL COUNCIL FOR DIVERSITY IN THE
HEALTH PROFESSIONS

HEALTH RESOURCES AND SERVICES ADMINISTRATION

Chairman Blunt, Ranking Member Murray, 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. It is a council of the Nation's majority and minority 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. With this in mind, I am proud to put forth the following recommendations for the fiscal year 2019 appropriations process:

- \$8.56 billion for the Health Resources and Services Administration (HRSA)
- \$30 million for HRSA's Health Workforce: Centers of Excellence (COE)
- \$16 million for HRSA's Health Workforce: The National HCOP Academy
- \$2 million for HRSA's Health Workforce: Faculty Loan Repayment
- \$50 million for HRSA's Health Workforce: Scholarships for Disadvantaged Students

NCDHP is dedicated to promoting the education and training of a workforce that is prepared to provide quality and culturally responsive healthcare to the diverse US population. NCDHP members across the Nation are actively involved in health professions education and training, the development of educational pipeline programs for individuals from disadvantaged backgrounds, and the delivery of healthcare to the underserved. Through HRSA's Title VII workforce diversity programs, addressing the long-term healthcare and health professional needs of minority and underserved communities is obtainable. Pipeline program interventions exert a meaningful and positive effect on student outcomes in the health professions. When institutions are strengthened through programs like the COE program, the national capacity to produce a healthcare workforce whose racial and ethnic diversity is representative of the U.S. population is greatly enhanced. The COE program provides grants to health professions schools and other public and nonprofit health or educational entities to increase the supply and competence of underrepresented minority practitioners in the health professions workforce. Programs like the National HCOP Academies or HCOP increase the diversity of the non-nursing

health professions workforce by providing grants that improve the recruitment opportunities into the health professions and enhance the academic preparation of students from economically and educationally disadvantaged backgrounds. This program supports students from high school through the completion of their health professions degree. In many instances, it even offers opportunities such as summer enrichment programs to ensure the retention and interest of students recruited. Furthermore, The Title VII workforce diversity programs allow institutions to adhere to the best practices in increasing diversity in the health professions as well. These programs allow for institutions to further target and recruit disadvantaged students and offer holistic and comprehensive experiences to their students, institutions to recruit and retain invested faculty to work in underserved communities and underrepresented students, and students to have the financial means of funding their educational experiences.

We were pleased to see efforts to revitalize our Nation's commitment to diversifying the health workforce through the Title VII work force training programs like the COE and HCOP in fiscal year 2018. As you begin the fiscal year 2019 process, NCDHP asks that you further prioritize Title VII health professions training programs. Mr. Chairman and Ranking Member Murray, 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 fiscal year 2019 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 COUNCIL OF
STATE DIRECTORS OF ADULT EDUCATION

The National Council of State Directors of Adult Education (NCSDAE) appreciates the opportunity to submit testimony about the funding level for Adult Education programs in fiscal year 2019.

Adult Education helps 1.5 million Americans 16 years of age and older, to gain the skills necessary to obtain and sustain employment and enter postsecondary education and training. These individuals, who are no longer in school and are functioning below the high school completion level, would otherwise have few options to become self-sufficient. Services include coupling the foundational skills of reading, math, and English with job training, and incorporating college and career readiness skills. Public schools, community colleges, and community-based organizations provide programs at the local level.

Federal support for Adult Education leverages a significant investment by States. Indeed, the National Council of State Directors of Adult Education (NCSDAE) estimates that in 2015–2016, \$1.24 billion in non-Federal support matched \$543 million in Federal dollars. In fiscal year 2013, each Federal dollar invested in the Adult Education and Family Literacy Act (AEFLA) generated \$2.49 in non-Federal matching funds.

NCSDAE urges the Subcommittee to build on its record by increasing funding for Adult Education to at least \$664.5 million, the level authorized for fiscal year 2019 in the Workforce Innovation and Opportunity Act (WIOA), which was enacted with overwhelming bi-partisan support and recognized the crucial role Adult Education plays in preparing adults to enter the workforce, improve their employment status, or pursue postsecondary education. Such improvements as the law anticipates cannot be fully realized without sufficient resources. Adding \$35 million for Adult Education in the Consolidated Omnibus Appropriations Act of 2018 is an important step, which we greatly appreciate.

Adult Education programs serve only 1.5 million of the 24 million adults in the United States who lack a high school diploma—a decline of 44 percent from 2002 when almost 2.8 million students were served. Adjusted for inflation, funding has declined by 20 percent since fiscal year 2006. Additional resources would allow the system to build capacity to serve a larger portion of the 24 million.

The United States is confronting a skills gap. By 2020, 65 percent of all jobs in the United States will require some level of postsecondary education or training. Yet, nearly half of the U.S. workforce—about 88 million people—has only a high school education or less, and/or low English proficiency. In a recent survey, 92 percent of business leaders thought that U.S. workers were lacking the necessary skills.

Both urban and rural areas need trained employees. As of 2016, there were 476 counties in the U.S. in which 20 percent or more of the working age population

lacked a high school diploma or equivalent. Eighty percent of these counties are located in non-metro areas.

We cannot depend on a robust economy to solve this problem. A stronger economy will bring people back into the workforce but is also creating a need for education and training. Employers can teach job skills but aren't qualified to teach foundational and essential skills. Adult Education can train these students to fill the jobs industry needs today.

According to the Organization of Economic Cooperation and Development (OECD) Program of International Assessment of Adult Competencies (PIAAC), Americans lag behind the international average for basic skills in literacy and numeracy and "problem-solving in technology-rich environments (defined as 'using digital technology, communication tools and networks to acquire and evaluate information, communicate with others and perform practical tasks')." Other nations show consistent progress in enhancing the education levels of their adult populations. The U.S. is losing ground. Twenty percent of adults with a high school diploma have less-than-basic literacy skills and 35 percent of adults with a high school degree have less-than-basic numeracy skills. Without access to Adult Education, undereducated, under-prepared adults cannot qualify for jobs in high demand occupations nor can they qualify for entry into community colleges. We must invest in Adult Education because the jobs of the future will require postsecondary education.

It will be impossible to create a workforce with the skills to compete in the global 21st Century economy if we focus only on secondary schools and postsecondary institutions. We must also support Adult Education because much of America's future workforce consists of adults who are already working (according to the Bureau of Labor Statistics the median age of U.S. workers is expected to be 42.4 years old by 2014). They are beyond the reach of the high schools and postsecondary education. Adult education is the best way to re-engage them.

Some Examples:

The Alabama Adult Education shows what WIOA implementation can accomplish. It is working seamlessly with the other divisions of the Alabama Community College System to play a major role in workforce and economic development. It is partnering with all the Workforce Innovation and Opportunity Act (WIOA) partners, braiding funds and resources to train TANF and SNAP clients through Integrated Education and Training and Career Pathway models. It also collaborates with Pardon and Parole to assist felons to transition back to society by providing academic and workforce skills training as well as supportive services, which lead to employment. There are examples from across Alabama in which AE students have attained stackable certificates and credentials that are recognized by industry. Calhoun Community College is an example of how IET and Bridge programs have increased enrollment in adult education, community college training, and led to successful completers that have gained employment. The Reid State Community College Adult Education program is one in which Adult Education students are integrated into its Truck Driving program. Students are supported through contextualized academics and GED preparation embedded into the specific technical training that leads to CDL credentials and employment. Recently 11 students completed the short term Truck Driving program through Reid State Adult Education and College partnership and all are now working.

New York has an articulation agreement with its secondary Career and Technical Education program that allows students that complete the Health Services program enter its Practical Nursing program at a reduced tuition rate. It has also collaborated with CTE with the Diesel Mechanics program to have students get a Class B driving license through its CDL program. New York is in the process of developing a manufacturing class that will share equipment and blend students together. Finally, New York also offers adults the opportunity to participate in the secondary programs along with the high school students.

Every Adult Education student in Washington State is required to be on a dedicated college and career pathway to living wage employment. Basic Skills now provides students with the opportunity to develop skills to be college ready. In addition, employability skills are taught in every class at every level. In Washington State, WIOA Title II has dramatically changed the world of Basic Skills Education for adults. Washington has developed a comprehensive college and career pathway for all students. Students in levels 1-3 Adult Basic Education and English Language Acquisition take on-ramps to I-BEST and other college programming. The five program options include: High School 21+ (HS 21+) which allows students 21 years of age and older to receive a competency-based high school diploma. The program awards credit for prior learning, military experience, and work experience. Because it is competency based it allows a student to progress as outcomes are met, saving

both time and money. The I-BEST at work on-ramp-which works with incumbent workers in the workplace, team-taught by a basic skills instructor and a trainer from the company. Integrated Digital English Acceleration (I-DEA) is an ELA on-ramp which provides the lowest level ELL students with a year of rigorous curriculum and a laptop computer, with half of the instruction online with 24/7 Internet access to learning. I-DEA has shown a 16 percent higher-level completion rate over traditional programming for the last 3 years. On-ramps contextualized in employability & College readiness. Career specific on-ramps are contextualized to a specific career pathway like healthcare or welding. When students are ready, they can move into I-BEST or other college programming with their tuition funded. In their second quarter, they can access funding to continue all the way to their 2-year degree. Upon receiving a 2-year degree, they can also receive their high school diploma. They then can use those same funding sources to transfer into an applied baccalaureate degree program at a community college or a 4-year university. I-BEST has an 88 percent completion rate for credits attempted, and the College and Career Research Center found that I-BEST students attempt 50 percent more credits than traditional Workforce students and 7 credits more than academic transfer students. Basic skills students have an 83 percent completion rate based on performance points earned.

This foundational pathway work will frame basic skill's role in Washington over the next 5-8 years.

In Rhode Island, five of the six Perkins grants go to local school districts (the sixth goes to the community college). Two of those five sub-grant to adult education providers. The programs that they are holding include CNA, phlebotomy, customer service/clerical, and medical records/health information technician.

In Missouri, the Independence School District Adult Education program at the Don Bosco Center provides Contextualized Instruction in the following trades: Construction, Warehouse, Hospitality, and Nursing. It also partners with Job Corp in Excelsior Springs and Kansas City that provides certification in 12 different trades. Our program provides academic instruction and remediation using curriculum that is industry and skill specific. Another project in is a pilot Nursing Assistant class (CAN) for immigrants and refugees. This class is exceptional because it works with non-traditional students in a non-traditional nursing course. Most nursing classes require that students be proficient in English and score at 9th grade or above on Tests of Adult Basic Education (TABE). This program enrolled English as a Second Language (ESL) students scoring at upper Intermediate and Advanced levels in the class. Students attend 5.5 hours of Nursing Instruction on Mondays and participate in a contextualized ESL/Nursing remediation the remainder of the week with the ESL/IET teacher. The curriculum to teach English is based on the CNA nursing manual. When students complete the course and pass the State exam, they have been offered jobs at a local hospital that is eager for them to start because the students are multi-lingual. St. Luke's has even offered to pay for additional certification and training so that students may continue on their career pathway. To date, ISD's forklift driver training class has certified 56 students in 7 different types of forklift certification and OSHA safety certification. The majority of students have been refugees and immigrants. The course is 6 weeks. Students spend 1 day a week with the Forklift trainer in class and 1 day a week with him in the warehouse driving. The teacher uses the vocabulary words from the text and exam to teach English that is specific to this industry and assures that Reading, Writing, Listening, and Speaking are part of each lesson. Students also attend digital literacy class two days a week to learn workforce readiness skills that include resume writing and interview skills. ISD started a pilot this year with the Hospitality trades at Don Bosco. Her class which meets four days a week allows students to learn English reading, writing, listening, and speaking, and allows them to complete their certification in the hospitality field. ISD has partnered with hotels and restaurants in the area, and students are able to secure jobs based on the District's recommendation.

Maine has adopted College and Career Readiness Standards for all of its adult education literacy instruction. This is an evidence based approach to learning that in addition to literacy education, addresses career specific needs to be successful in employment as learners move along their career pathway.

Properly funding this robust adult education system would yield substantial fiscal and social benefits, adding to GDP growth, personal incomes, increased revenues, and savings on incarceration and healthcare. By neglecting the adults who need services, we affect their children, too. Almost 60 percent of children whose parents lack a college education live in low-income families, and are less likely themselves to get a good education and secure family sustaining jobs. Mothers and fathers who learn basic skills are better equipped to help their children succeed. A person with

a high school diploma or equivalent earns an average of \$9,620 more per year than a non-graduate.

Stimulated by WIOA, Adult Education is changing to meet the needs of our 21st century economy by combining academic instruction and occupational training, focusing on career pathways that include intensive wraparound services, creating Adult charter schools, and working more closely with employers. We urge you to fund Adult Education at the level authorized in WIOA so that the ambitious goals of that law may be realized. If Americans are to embark or continue on pathways that lead to good jobs and good wages, we must invest adequately in our Adult Education system to remain economically competitive.

Fiscal Year 2019 Funding Request: The National Council of State Directors of Adult Education strongly supports funding Adult Education at the level authorized in WIOA.

PREPARED STATEMENT OF THE NATIONAL COUNCIL OF HIGHER EDUCATION
RESOURCES

Dear Chairman Blunt and Ranking Member Murray:

The National Council of Higher Education Resources (NCHER) urges the subcommittee to include statutory language extending the authority for the U.S. Department of Education to pay Account Maintenance Fees (AMF) and language encouraging the Department to leverage the expertise of State and nonprofit organizations to assist student and parent borrowers repay their student loans in the fiscal year 2019 Labor, Health and Human Services, Education, and Related Agencies Appropriations Act. NCHER is a national, nonprofit trade association that represents State and nonprofit higher education agencies that work with students and families to develop, pay for, and attain their educational goals so they can pursue meaningful and rewarding work and become contributing members of society.

First, NCHER's State and nonprofit guarantors appreciate the subcommittee's recognition of the vital role that guaranty agencies play in the Federal student loan program, and commend you for including language extending AMF authority for an additional year in the Bipartisan Budget Act of 2018 (Public Law 115–123). Guaranty agencies are authorized under the Higher Education Act of 1965 to provide important services to students, borrowers, families, and the Federal Government by helping to manage the Federal Family Education Loan Program (FFELP) at the local level, and increasing access to and success in postsecondary education. Many guaranty agencies operate and provide student support services in more than one State. These agencies receive AMF payments from the Department to pay for their general operating expenses. The fees are crucial to ensuring that the agencies are able to perform critical functions that assist borrowers in avoiding default and protect Federal taxpayers as the FFELP continues to wind-down its operations. The fees are used to carry out the agencies' mandate to:

- Support college access and success activities, such as financial aid awareness, consumer education, FAFSA (Federal Application for Federal Student Aid) completion services and events, borrower assistance, and ombudsman support. These services are provided to students and families in States around the country, regardless of the type of loan they received to finance their postsecondary education. Today, the services are provided to Direct Loan applicants and borrowers.
- Assist struggling borrowers in avoiding default on their Federal student loans, and help defaulted borrowers rehabilitate their loans and repair their credit history.
- Provide schools with basic administrative support such as information on student loan defaults and loan transfers and training and technical assistance to lenders and schools.
- Maintain loan records for student and parent borrowers; monitor school enrollment and repayment status; conduct comprehensive compliance reviews of lenders and servicers; and conduct claim reviews and issue loan holder payments.

The fees are paid quarterly and based on the original principal balance of an agency's outstanding non-defaulted FFELP portfolio. According to the Congressional Budget Office, the annual extension of AMF authority is budget neutral. If AMF is eliminated, guaranty agencies will be unable to perform their basic FFELP administrative functions and could turn over their portfolios to the Department—driving up the agency's administrative costs. The agencies will also be forced to end their outreach programs to students and families that are not otherwise provided by the Department.

The President's budget request for fiscal year 2019 included the elimination of AMF. The budget office mistakenly believes that, because there are no new originations under FFELP, the fees are no longer necessary. However, there is still roughly \$203.4 billion in outstanding FFELP loans held by private lenders and guaranty agencies. The agencies provide—and must continue to provide—services and accountability for this sizeable Federal asset and the functions need to continue throughout the wind-down period. The fiscal year 2016, fiscal year 2017, and fiscal year 2018 appropriations bills included a 1 year extension of AMF because it is essential for guaranty agencies to provide important services on behalf of the Federal Government, and we urge the subcommittee to provide an additional 1 year extension in the fiscal year 2019 appropriations bill.

Second, according to recent statistics, Federal student loan debt totals nearly \$1.37 trillion, an amount that policymakers and some economists have cited is negatively impacting the ability of student borrowers to achieve postsecondary success, own a car, buy a house, or start a family. According to the Department, over 11 percent of borrowers who took out a Federal student loan defaulted on that loan within 3 years, a percentage that continues to be unnecessarily high. Clearly, student and parent borrowers need access to more specialized support services throughout their postsecondary education to help them understand their financial decisions.

State and nonprofit higher education agencies, including loan holders, loan authorities, servicers, and guaranty agencies, have been highly successful in providing important services to struggling borrowers for decades because they provide a holistic approach to student success. These agencies counsel students and families on early awareness of the variety of educational choices available beyond high school and creating a college-going culture, the appropriate courses to take in high school to facilitate entering the college major or career program of their choosing, how to apply for college and navigate the financial aid process, how to avoid overborrowing, and the importance of managing student loan debt, as well as budgeting and personal finance management skills. These agencies also act as borrower advocates to help struggling borrowers understand the student loan repayment process and options that may be available to them to help mitigate delinquencies and defaults. However, these important services are largely going away, and some have already been eliminated, because of a lack of resources resulting from declining Federal Family Education Loan Program portfolios.

NCHER believes the best solution to addressing the current challenge of borrowers struggling to repay their student loan debt is to encourage the Department of Education's nine national for-profit and not-for-profit student loan servicers to work with smaller State and nonprofit organizations—most of whom are small businesses and employ less than 500 employees—as subcontractors to provide personalized financial education and debt management services to struggling borrowers. The Consolidated Appropriations Act, 2017 included language directing the Department to put together a plan under which it will give credit to its Federal student loan servicers to subcontract with small businesses, including State and nonprofit organizations with expertise in assisting borrowers in the repayment of their student loan. In the budget justifications for fiscal year 2018, the Department stated that there must be a slight change to the small business designation as well to make clear that the definition of 'small business' in the student loan servicing context includes State and not-for-profit entities, and not just one that is organized for-profit. We urge the subcommittee to include the suggested language in the fiscal year 2019 appropriations bill. State and nonprofit organizations with more than 50 years of experience can help struggling borrowers address the current challenges in the Federal student loan program, but their work must qualify for small business credit.

NCHER appreciates the opportunity to provide feedback on its appropriations priorities. We look forward to working with the subcommittee as it begins drafting the fiscal year 2019 appropriations bill to maintain and improve those services provided to struggling borrowers.

Thank you.

[This statement was submitted by James P. Bergeron, President, National Council of Higher Education Resources.]

PREPARED STATEMENT OF THE NATIONAL COUNCIL OF SOCIAL SECURITY
MANAGEMENT ASSOCIATIONS

On behalf of the National Council of Social Security Management Associations (NCSSMA), thank you for the opportunity to submit this testimony regarding the Social Security Administration's (SSA's) fiscal year 2019 Appropriation. NCSSMA respectfully requests that Congress provide at least \$13.509 billion in fiscal year

2019 for SSA's Limitation on Administrative Expenses (LAE) account. This level of funding will help ensure the agency can continue to build on the improvements currently underway due to increased funding provided for fiscal year 2018 by Congress.

The table below outlines SSA resource levels in comparison to key workload service delivery performance numbers. SSA must have the resources necessary to improve and modernize customer service, make much-needed Information Technology (IT) infrastructure and systems upgrades, maintain program integrity workloads, deter and detect fraud and errors, and continue to address the high volumes of initial claims and post-entitlement work.

| SSA RESOURCES WITH KEY WORKLOAD SERVICE DELIVERY PERFORMANCE | | | | | |
|---|--|-------------------|-------------------|---------------------|-------------------------|
| | FY 2015 Actual | FY 2016 Actual | FY 2017 Actual | FY 2018 Actual | |
| SSA's Enacted LAE Funding (\$ in Millions) | \$11,806 | \$12,162 | \$12,482 | \$12,869 | |
| Full Time Permanent Staff (Field Office and Teleservice Center) | 33,710 | 32,859 | 31,669 | 30,995 ¹ | |
| Field Office | Visitors | 40,666,463 | 43,493,551 | 42,048,301 | 22,879,357 ¹ |
| | Left Without Service | 1,955,818 | 2,065,444 | 1,971,663 | 1,111,034 ¹ |
| | Wait Time W/O Appointment (Min) | 27.9 | 28.2 | 26.5 | 27.0 ¹ |
| | Wait Without Appointment Over 60 (Min) | 12.4% | 12.5% | 11.0% | 11.3% ¹ |
| | Calls Answered | 21,322,995 | 20,715,568 | 20,140,219 | 10,757,363 ¹ |
| | Calls Unanswered | 6,941,152 | 5,090,701 | 5,094,339 | 2,725,624 ¹ |
| | Phone Answer Rate | 75.3% | 80.3% | 79.8% | 79.8% ¹ |
| | SSI Redeterminations | 2,266,992 | 2,530,446 | -2,600,000 | -2,822,000 ² |
| | Medical CDRs | 525,875 | 799,013 | 853,754 | 874,000 ² |
| | Work CDRs | 247,215 | 247,772 | 285,133 | 313,546 ² |

¹ FY 2018 as of April 13, 2018.

² Figure from FY 2018 Congressional Justification.

We recognize the current fiscal constraints facing legislators, but we request that Congress provide fiscal year 2019 funding for SSA that is sufficient to improve service to the public while addressing stewardship responsibilities and making IT infrastructure and systems upgrades. We believe that the \$480 million increase provided for fiscal year 2018 is a significant step in the right direction, but that increased funding is needed for fiscal year 2019 as well in order to continue addressing disability backlogs in the hearing offices, initial claims and post-entitlement backlogs in the Program Service Centers and significantly reduced staffing levels in both field offices and teleservice centers. The following Report language accompanying the fiscal year 2018 Consolidated Appropriations Act, speaks to the urgency of this issue:

Field Offices.—The agreement is concerned that SSA may be reducing resources for field offices and expects SSA to continue to support frontline operations. In fiscal year 2017, SSA field offices served approximately 42 million visitors, a 5 percent increase over fiscal year 2015. The high volume of visitors, combined with factors such as complex workloads, shortened public operating hours, and staff shortages, have led to increased wait times in both field offices and the National 800 number. SSA is directed to submit a report to the Committees on Appropriations of the House of Representatives and the Senate within 90 days of enactment of this Act outlining its plan for ensuring that field offices, hearing offices, processing centers, and teleservice centers are receiving sufficient resources to maintain at least the current level of constituent services.

The table below outlines staffing, year-to-year losses and expected hiring in fiscal year 2018.

| FIELD OFFICE AND TELESERVICE CENTER EXPECTED HIRING AND LOSSES | | | | | | | | | | | | |
|--|-------|-------|---|--------|--------|--------|--|---------|-------|---|-------|-------|
| Estimated Hires in FY 2018 (Operations components only. Actual hires may be higher or lower depending on realized attrition.) | | | Full-time Permanent Staff End of Fiscal Year (Field and Teleservice Center) | | | | Staffing Losses Compared to FY 2018 (Field and Teleservice Center) | | | Replacement Ratio FY 2018 Hires to Overall Losses and Gains from Each Fiscal Year (Field and Teleservice Center) | | |
| TOTAL | Hires | % | FY 15 | FY 16 | FY 17 | FY 18 | FY 15 | FY 16 | FY 17 | FY 15 | FY 16 | FY 17 |
| | 2555 | 100% | 33,710 | 32,859 | 31,669 | 30,948 | (2,762) | (1,911) | (721) | 3.5 | 7.8 | 7.3 |
| FO ³ | 1240 | 48.5% | 29,007 | 28,361 | 27,400 | 26,896 | (2,111) | (1,465) | (504) | 4.7 | 5.6 | 5.2 |
| TSC ³ | 425 | 16.6% | 4,703 | 4,498 | 4,269 | 4,052 | (651) | (446) | (217) | 2.3 | 1.1 | 2.1 |
| PSC ³ | 350 | 13.7% | | | | | | | | | | |
| WSU ³ | 140 | 5.5% | | | | | | | | | | |
| OHO ³ | 400 | 15.7% | | | | | | | | | | |

³ FO – Field Office, TSC – Teleservice Center, PSC – Program Service Center, WSU – Workload Support Unit, OHO – Office of Hearings Operations

COMMUNITY-BASED SERVICE

The statements below demonstrate how sufficient resources for SSA have a positive impact on the agency's ability to deliver vital services to the American public and in fulfilling the agency's stewardship responsibilities.

A World War II veteran contacted the office about a Medicare B surcharge he and his wife had been paying for years. Even though the events described by the veteran dated back decades, the representative researched the issue, gathered statements and evidence, and helped the veteran to submit a request for premium surcharge rollback under equitable relief. After a few months, the request was granted, and the beneficiary and his wife not only reverted to the standard Medicare part B premium, they each received a premium refund for past surcharge amounts. Both were exceedingly grateful that an official of the government had taken the time to listen to them and take action to help them.—*Manager, Salisbury, NC*

On a daily basis, our office assists a high percentage of homeless individuals without access to phone or Internet services. This vulnerable segment of our population depends on face-to-face service to apply for benefits, obtain information about their benefits and receive benefit statement letters that they use to apply for State and local government services. The presence of our office helps ensure that our neediest population receives the service it so desperately needs.—*Supervisor, Manchester, NH*

A claimant contacted the office because he could not get his benefits reinstated for over a 6-month period. We were able to process a critical payment so that he could purchase school supplies for his children by the first day of school. He had not been able to purchase his prescriptions since his check stopped and, although he now had funds, he needed the Medicare reinstated. After a panicked phone call, the customer shared he was HIV positive and with medications, he was able to live an active life. After an escalated blood T cell count, his doctor said that he was on the verge of full-blown AIDS and medications were the only preventative measure. With the assistance of a Medicare congressional liaison, we expedited the reinstatement of his Medicare within 3 days. In the 20+ years working for the agency, I have never seen Medicare issues resolved so quickly.—*Supervisor, Georgetown, TX*

A terminally ill, Stage 4, cancer patient recently came into our office in dire need of medical care. The Claims Specialist in our office immediately went to work securing the necessary medical documentation needed to get the claimant's Disability Claim approved in a matter of days. Our office serves a rural area where most people lack access to high-speed Internet. Without a community-based field office, most would never have any direct contact with the government. Without our local field office, many customers would be forced to drive over an hour for service or do without service, due to lack of Internet availability.—*Manager, Union City, TN*

When SSA's administrative resource needs are unmet, it results in deterioration in key service areas and stewardship workloads. In fiscal year 2016, the agency saw an increase of about 2 million visitors from the previous year. The agency expects those numbers to remain relatively constant through fiscal year 2018. Approximately 4 million actions are currently pending in the agency's Program Service Centers. These actions are not just numbers, they are actual people, waiting to receive assistance from SSA. Beginning this fiscal year through February 2018, there has been a deterioration in SSA's 800 number service, with an over 32-minute wait. This is a 14-minute increase over the same period last year. At the close of fiscal year 2017, there were 1.05 million people waiting for a hearing decision, with the average processing time at a record-setting 605 days. It is only recently that pending hearings have fallen below the one million mark. Sadly, in fiscal year 2017 over 10,000

individuals died while waiting for a decision on their disability application, an increase of more than 1,300 deaths from the prior year. If SSA's administrative funding is not sufficient, these backlogs will increase and public service levels will degrade further.

FUNDING FOR FISCAL YEAR 2019

Sufficient resource allocations in fiscal year 2019 are required to address the massive hearings backlog, increases in other workloads, visitors, and telephone calls in field offices and to the National 800 Number, while at the same time maintaining deficit-reducing program integrity work. Resources are also necessary to advance SSA's efforts to undertake an IT Modernization project that will significantly enhance the agency's systems and improve productivity. SSA must continue to modernize its computer language, databases and systems infrastructure. Although the fiscal year 2018 Consolidated Appropriations Act designated \$280 million to support SSA's IT modernization efforts, without continued funding of SSA's IT needs in fiscal year 2019, there remains the risk for significant service disruptions and reduced system performance and production.

CONCLUSION

NCSSMA respectfully requests that Congress consider allocating at least \$13.509 billion for SSA's LAE account in fiscal year 2019 to meet the agency's multitude of public service responsibilities. SSA must have the resources necessary to provide quality service to the American public, maintain program integrity efforts that save taxpayer dollars, and continue to address the high volumes of initial claims being filed and post-entitlement work.

On behalf of NCSSMA members nationwide, thank you for the opportunity to submit this written testimony. We respectfully ask that you consider our comments, and would appreciate any assistance you can provide to ensure the American public receives the critical and necessary service they deserve from the Social Security Administration.

[This statement was submitted by Christopher Detzler, President, National Council of Social Security Management Associations.]

PREPARED STATEMENT OF THE NATIONAL FAMILY PLANNING & REPRODUCTIVE HEALTH ASSOCIATION

Chairman Blunt, Ranking Member Murray, and Subcommittee Members:

My name is Clare Coleman; I am the President & CEO of the National Family Planning & Reproductive Health Association (NFPRHA), a national membership association representing providers and administrators committed to helping people get the family planning education and care they need to make the best choices for themselves and their loved ones. Many of NFPRHA's members receive Federal funding from Medicaid and through Title X of the Public Health Service Act, the Nation's only program dedicated to family planning. As the committee works on the fiscal year 2019 appropriations bill, NFPRHA respectfully requests that you make a critical investment in Title X by including \$327 million for the program and that you include language reinforcing the program's principal role supporting providers to serve as essential health access points for contraceptive care and related preventive services in communities across the country. Doing so would help make progress to restore the capacity of the program to serve those in need.

Publicly funded family planning services are provided through State, county, and local health departments; hospitals; family planning councils; Planned Parenthood; federally qualified health centers; and other private nonprofit organizations. These diverse provider networks help millions of poor and low-income individuals as well as those who are underinsured or uninsured receive access to high-quality contraceptive care and other preventive health services in all 50 States, the District of Columbia, and U.S. territories.

An analysis published in the American Journal of Public Health in January 2016 found that Title X would need to be supported with approximately \$737 million in order for all low-income, uninsured women of reproductive age to access family planning services. It's also important to note that the Title X program also supports men, so the resource needs identified in the analysis are conservative. The fiscal year 2018 omnibus provided \$286.5 million for the program, which is just a fraction of what is needed.

The Title X network will continue to play an essential role in our Nation's service delivery framework regardless of how the healthcare economy evolves. "Churning"

and confidentiality issues, for example, play a role in keeping some individuals uninsured or unable to use the coverage they have for the full range of their family planning needs. Furthermore, the demand for Title X clinical services is likely to increase. As the Centers for Medicare & Medicaid Services approves new conditions that create potential obstacles for beneficiaries to receive coverage under State Medicaid programs, such as premiums and other cost-sharing requirements, these displaced individuals may turn to Title X health centers to receive their care.

More importantly, Title X-funded health centers, because of the high quality and specialty care they provide, remain in demand for individuals regardless of their payer source. The existing Title X-funded provider network follows the nationally recognized clinical standards for family planning care, known as Providing Quality Family Planning Services (QFP), which draws on other nationally recognized clinical guidelines and was jointly developed by the Office of Population Affairs and the Centers for Disease Control and Prevention (CDC) in 2014. While the administration removed all requirements for and references to the QFP in the recent funding opportunity announcement, high-quality contraceptive care and related preventive services will remain a hallmark for tenured providers despite the additional financial strain that will result if the administration is successful in its effort to shift Title X funding toward agencies focused on behavior change rather than clinical care.

Unfortunately, Title X, similar to other publicly funded health programs, has suffered budget cuts and flat funding for the last several years despite rising patient need. Between fiscal year 2010–2014, the Title X family planning program was cut a net \$31 million (– 10 percent), even though the number of women in need of publicly funded contraceptive services and supplies rose 5 percent in that period. Those funding cuts have not been restored. These findings are very disturbing given that six in ten women who access care at a Title X-funded health care center say that it is their primary source of care. In fiscal year 2019, the financial challenge looks no less dire for health centers.

As appropriators grapple with how best to distribute limited Federal resources, NFPRHA encourages the committee to continue to prioritize investments in programs, including Title X, that focus on outcomes and which provide a significant return on investment. Millions of low-income people depend on the Title X program for affordable access to the panoply of family planning services it supports, including contraceptive care, breast and cervical cancer screenings, STD testing and treatment, and HIV prevention services that help them stay healthy. However, politically motivated attacks are jeopardizing the Title X program's ability to help these vulnerable individuals and families. NFPRHA urges the committee to reverse this trend by reiterating congressional intent that Title X supports access to complete, medically accurate, high-quality clinical family planning and sexual health services and making a significant investment in the Nation's family planning safety net by appropriating \$327 million for Title X in fiscal year 2019.

* * *

NFPRHA appreciates the opportunity to provide this testimony. If you require additional information about the issues raised in this letter, please contact Lauren Weiss, Manager, Advocacy & Communications, at lweiss@nfprha.org.

Sincerely,

[This statement was submitted by Clare Coleman, President & CEO, National Family Planning & Reproductive Health Association.]

PREPARED STATEMENT OF THE NATIONAL HEAD START ASSOCIATION

Dear Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee: On behalf of the Head Start community, thank you for the opportunity to submit written testimony regarding funding for Head Start and Early Head Start (collectively "Head Start") in fiscal year 2019. The National Head Start Association (NHSA) respectfully requests that the Subcommittee allocate \$10,810,095,000 for programs within the Office of Head Start.

Tremendous thanks are also due to this Subcommittee and the entire Congress for continued significant and sustained support for early childhood education. I have received appreciation from Head Start programs from coast-to-coast and as far away as Alaska and Puerto Rico for your efforts to bolster our workforce, expand duration, and support Head Start programs recovering from the 2017 hurricane season. While work remains, these efforts have not and will not be forgotten.

In building on the meaningful fiscal year 2017 and fiscal year 2018 investments, the Head Start community has four distinct funding recommendations for the coming fiscal year and a request for congressional assistance in resolving an acknowledged regulatory flaw. These investments include additional resourcing in: (1) support of the workforce, (2) locally directed quality improvement funds; and (3) a continued commitment to extending the duration of services. Unique to this year, NHSA also requests needed funds (\$250,000,000) to support programs grappling with opioid and substance abuse. Finally, while the Head Start Program Performance Standards (HSPPS) have ushered in many excellent changes, a flaw in the evaluation process for Designated Renewal System (DRS) has unfortunately snagged and crippled solid, well-performing programs. Each of these priorities is further discussed below:

(1) *Support Quality Workforce:* Within the sum provided, NHSA recommends the allocation of \$233,600,000 (including \$16,600,000 for Early Head Start-Child Care Partnership grantees) in fiscal year 2019 for Workforce Investments through a cost-of-living adjustment in line with the Consumer Price Index-Urban.

The Head Start workforce is at the core of Head Start's success. Without home visitors, teachers, family service workers, education coordinators, and all those who create the vibrant, successful programs within communities across the country, Head Start simply would not thrive. Without adequate investment in our workforce, Head Start will continue to suffer from detrimental rates of staff turnover as quality, dedicated staff leave for jobs that can better support their families. The outcomes that Head Start creates for children and families is inextricably tied to programs' ability to retain and develop quality staff, and it is the Head Start community's hope that this importance is reflected by the Subcommittee's fiscal year 2019 funding decisions.

(2) *Promote Quality Improvement:* To complement workforce investments and the expansion of services and duration, NHSA recommends that \$339,500,000 be allocated for Quality Improvement Funds (QIF) in fiscal year 2019.¹ As outlined in the 2007 Head Start Act, these funds may be used for increasing duration of services to better support working families, train staff, improve community-wide coordination, enhance classroom environments, and strengthen transportation safety. In fiscal year 2019, these funds would serve to meet the already existing needs of Head Start programs across the country while providing the flexibility to address local priorities.

While programs must meet the same rigorous bar of quality and common threads of continuous quality improvement run throughout the community, no two Head Start programs are alike. Each program must adapt its services to meet the unique needs of its communities and families. Similarly, Federal support and funds must also include adequate flexibility for programs to invest in critical, local priorities. QIF was authorized with this exact purpose in mind. In Alabama, for example, St. Clair County Head Start seeks to use QIF to support infrastructure investments. In addition to the stellar services it provides directly to children and families, this rural Head Start program offers significant support to the surrounding area, such as their partnership with a local automotive plant to provide certification classes to parents to meet employment eligibility. However, inadequate facility space limits success and keeps over 60 children on a waitlist for Head Start participation. In unique instances such as these, to meet an acute need, QIF dollars could go a long way.

(3) *Extend Duration:* For programs to meet the needs of working families and fulfill the duration mandate by 2021, additional funding will be needed in fiscal years 2019 and 2020.² Based on the information offered in the regulatory impact analysis done by the Office of Management and Budget, NHSA recommends an increase of \$374,000,000 in fiscal year 2019 to make necessary progress towards meeting the requirement. In 2016, revised HSPPS called for the extension of the duration of classroom hours, based on strong research evidence. In fiscal year 2016 and fiscal year 2018, Head Start received increased funding to better serve working families through extended duration of services. The fiscal year 2016 extended duration funds (\$294,000,000) were met with overwhelming interest and appreciation by programs across the Nation, as is expected when the fiscal year 2018 extended duration grants become available.

¹Per the Head Start Act, funds appropriated to Head Start should include no less than 4.5 percent set aside for Migrant and Seasonal programs, and no less than 3 percent for American Indian/Alaska Native programs.

²45 CFR Chapter XIII RIN 0970-AC63 Head Start Program Performance Standards, Preamble Part II.

(4) *Addressing Substance Abuse and Addiction:* Separate and apart from the NHSA fiscal year 2019 Head Start Recommendation is an fiscal year 2019 request for specific assistance to respond to the tremendous challenge of opioid, methamphetamine, and prescription drug abuse. Because of Head Start's unique whole family and multi-generational model, Congress should leverage the interwoven relationship between families and Head Start staff, the current on-the-ground efforts, and long-trusted embedded services, with an fiscal year 2019 Office of Head Start investment of \$250,000,000 to combat the scourge of opioid, addiction, substance abuse, and Neonatal Abstinence Syndrome (NAS)—affecting children and families across the Nation. These funds will provide additional resources for more than 20,000 children and their families in existing Head Start programs.

Head Start grantees, particularly those in severely impacted opioid regions, need training and programming support to identify signs of home drug use, respond to children exhibiting increased developmental and behavioral challenges, and skills to intervene with families and children grappling with the many dimensions and tragedies of opioid addiction. Examples of successful interventions and partnerships led by Head Start exist in communities across the country—such as the targeted home-visiting program at Meeting Street in Boston or the Allentown, Pennsylvania based SafeStart which serves children who are born suffering from NAS and their families by providing high-impact child-teacher ratios, treatment transportation, routine home visits, and specialized mental health and addiction counseling for the whole family.

Other Head Start programs have seen similar impacts of opioids and addiction on their communities, but lacking local or philanthropic resources are unable to recreate similar models. Central Missouri Community Action in Osage County, is a prime example of this. This highly-regarded, rural area Head Start program serves children and families impacted by substance misuse and addiction, but currently is unable to tailor care to adequately respond. With additional funds, however, they would be able to expand trainings and supports for home visitors to spot the signs of substance abuse and follow reporting protocols. Further, additional funds could be used to establish a family-focused, trauma-informed mental health program.

With such targeted funding, Head Start can help reduce the societal costs of drug abuse by supporting the healthy development of drug-exposed children, helping these children “catch-up” to their peers while providing interventions for parents and families. Intervention at these early stages can provide real opportunities for these children and their families to succeed while simultaneously resulting in monumental societal cost savings in the judicial, child welfare, and education systems. Based on input and insight from Head Start programs across the Nation, NHSA will be releasing a report later this summer that details the role Head Start is currently playing and with additional supports and resources, could play in supporting children victimized by opioids. We look forward to sharing this document with Congress soon.

Head Start programs in communities across the country routinely face hard choices, pitting necessary investment in staff against increasing enrollment against implementing further quality improvements. These investments in fiscal year 2019 will allow local programs to make critical improvements while also expanding services to more children and extending hours based on community needs.

(5) *DRS Ten Percent Provision Reform:* Authorized in 2007 and first implemented in 2011, the Designated Renewal System (DRS) was intended to strengthen Head Start. While DRS overall has been welcomed by the Head Start community and is considered to be successful, one specific provision—the lowest 10 percent provision of the CLASS condition—has been found to be ineffective and continues to unfairly burden Head Start programs. Following the previous Administration's report in November 2016 detailing flaws in the ‘lowest ten percent’ provision of the CLASS condition, the current Administration released a December 2017 “Request for Comments” to adjust the condition. NHSA submitted comments, which were signed by more than 3,250 programs, organizations, and individuals, encouraging the Administration to quickly amend DRS before any additional grantees are unfairly impacted. While the Head Start community appreciates the Administration's leadership in recognizing flaws in the DRS rubric, the pace of correction is worrisome. NHSA encourages the Congress to continue to pressure the Administration to resolve this issue before additional programs are evaluated using a flawed system.

In closing, the Head Start community understands the challenges that the Subcommittee faces in the fiscal year 2019 appropriations process, and we are deeply grateful for the commitment shown by Congress to keep early learning, and Head Start in particular, a priority. fiscal year 2018 provided remarkable funding, support, and stabilization and the Head Start community is grateful. We agree that sound investment in children today will lead to the success and betterment of our

Nation for generations to come. As an established vehicle of change for entire families, Head Start represents an unparalleled opportunity for Congress to invest in our country's children, families, and future, and NHTA looks forward to working closely with the Subcommittee to realize this opportunity.

Sincerely,

[This statement was submitted by Yasmina Vinci, Executive Director, National Head Start Association.]

PREPARED STATEMENT OF THE NATIONAL INDIAN CHILD WELFARE ASSOCIATION

The National Indian Child Welfare Association (NICWA), located in Portland, Oregon, has over 35 years of policy experience advocating on behalf of American Indian and Alaska Native (AI/AN) children in child welfare and children's mental health systems. Thank you for the opportunity to provide fiscal year 2019 budget recommendations for child welfare and children's mental health programs administered by the Department of Health and Human Services (DHHS). Our full recommendations appear in the charts below with our priority recommendations described in more detail underneath the charts.

Child Welfare

| Agency | Program | Fiscal year 2018 enacted | Fiscal year 2019 recommended |
|----------------|---|--|---|
| DHHS ACF/CB | Promoting Safe and Stable Families— Discretionary (Tribal) Tribal Court Improvement Program | \$99 million ¹ (\$1.8million) (\$1.0 million) | \$110 million ² (\$2.1million) (\$3.0 million) |
| DHHS ACF/CB | Child Abuse Discretionary Activities (Tribal) | \$33.0m (unknown) | \$38.0m (unknown) |
| DHHS ACF/CB | Community-Based Child Abuse Prevention (Tribal) | \$39.7m (\$416k) | \$50m (estimated \$500k) |
| DHHS ACF/CB | Child Welfare Services (Tribal) | \$268.7m (\$6.3m) | \$268.7m (estimated \$6.3m) |
| DHHS HRSA | Maternal Infant & Early Childhood Home Visiting Program (Tribal) | \$400m (\$12m) | \$420m (\$12.6m) |

¹ Includes \$40 million of new funds with \$20 million designated for Kinship Navigator Programs and \$20 million for Substance Abuse Grants (competitive grants for Tribes and States). Discretionary funding for Promoting Safe and Stable Families programs remains at fiscal year 2017 level of \$59 million (\$1.8 million for tribes).

² Recommended increase for fiscal year 2019 is dedicated to Promoting Safe and Stable Families discretionary funding for States and Tribes (not Kinship Navigator and Substance Abuse grants). Only by increasing discretionary funds does tribal funding increase under this program.

PRIORITY RECOMMENDATIONS

Promoting Safe and Stable Families recommendation (Title IV-B, Subpart 2-Discretionary Portion): Increase discretionary funding under this program to \$70 million (not including Kinship Navigator and Substance Abuse grants at \$40 million) to provide additional access to tribes who are currently not eligible to apply for these funds based upon the current eligibility criteria that are tied to the funding formula, and increase tribal court improvement funding to \$3 million.

The Promoting Safe and Stable Families Program provides funds to tribes for coordinated child welfare services that include family preservation, family support, family reunification, and adoption support services. This program has a mandatory capped entitlement appropriation as well as a discretionary appropriation. There is a 3 percent set-aside for tribes under each program. All tribes with approved plans are eligible for a portion of the set-aside that is equal to the proportion of their member children compared to the total number of member children for all tribes with approved plans. Based on this formula, tribes who would qualify for less than

¹Hill, R. B. (2008). An analysis of racial/ethnic disproportionality and disparity at the national, State, and county levels (p. 9). Seattle, WA: Casey Family Programs, Casey-CSSP Alliance for Racial Equity in Child Welfare, Race Matters Consortium Westat.

²National Child Welfare Resource Center for Tribes. (2011). Findings from the national needs assessment of American Indian/Alaska Native child welfare programs (p. 23). Retrieved from nrc4tribes.org/files/NRCT%20Needs%20Assessment%20Findings_APPROVED.pdf.

\$10,000 are not eligible to receive any funding. This means that many tribes, typically those tribes that are most in need, cannot access it because the overall appropriation is currently too low. Out of the 567 federally recognized tribes, over 100 tribes have no access to these funds.

Tribal systems endeavor to reduce out-of-home placements whenever possible, saving children and their families additional trauma and helping States with services to Native families under their jurisdiction. Native children in State child welfare systems are three times more likely to be removed from their homes-as opposed to receiving family preservation services-than their non-Native counterparts.¹ Tribes are providing intensive family preservation and family reunification services in spite of inadequate funding and insufficient staffing, which is putting incredible strain on individual workers and programs.² New prevention services funding under Title IV-E will help a small portion of tribes, typically those that already receive Promoting Safe and Stable Funding, but many smaller tribes do not have access to Title IV-E and rely on these kinds of funds to reduce out of home placements and stabilize families.

The Promoting Safe and Stable Families Program offers support for culturally based services that tribes already have experience with, such as parenting classes, home visiting services, and respite care for caregivers of children. This program is vital to the tribes that depend on it to support efforts to prevent the unnecessary removal of AI/AN children from their homes.

Tribes are also eligible to apply for the Tribal Court Improvement Program, a competitive grant program authorized under Promoting Safe and Stable Families. This program is authorized for \$30 million of mandatory funding plus 3.3 percent of all discretionary funds. A \$1 million tribal set-aside was created in the 2011 Child and Family Services Improvement and Innovation Act, Public Law No. 112-34 (2011). Five tribal court improvement project grantees are currently funded under this program. They are using these funds to strengthen their family courts and better integrate the work of their courts with their child welfare systems and with their State court partners who serve Native children and families under their jurisdiction.

Child Abuse Discretionary Activities, Innovative Evidence-Based Community Prevention Program: Increase overall appropriations to \$38 million to account for tribes' recent eligibility for these funds through a competitive grant process.

Child Abuse Discretionary Activities, including the Innovative Evidence-Based Community Prevention Program, support a variety of activities including research and demonstration projects on the causes, prevention, identification, assessment, and treatment of child abuse and neglect, and the development and implementation of evidence-based training programs. In 2010, tribes were provided access to this program through a competitive grant process that includes States and other entities, but appropriation levels did not increase to account for the expanded pool of grant applicants. The majority of entities that have historically received funding are universities and research hospitals, rather than tribes or entities with tribal partners.

An accurate understanding of successful child abuse and neglect interventions for Native families allows child abuse prevention programs to target the correct issues, provide the most effective services, and allocate resources wisely. Although promising practices for child protection, child abuse prevention, and trauma-informed child welfare services exist throughout Indian Country, not enough information is available on the implementation and effectiveness of these programs to make them easily replicable.³

The Child Abuse Discretionary Activities Program is the only funding available to help tribes engage in the research necessary to test treatment and interventions. The surest way to effectuate this recommendation is to provide funding under the Child Abuse Discretionary Activities Program that supports tribal access to these funds.

¹Hill, R. B. (2008). An analysis of racial/ethnic disproportionality and disparity at the national, State, and county levels (p. 9). Seattle, WA: Casey Family Programs, Casey-CSSP Alliance for Racial Equity in Child Welfare, Race Matters Consortium Westat.

²National Child Welfare Resource Center for Tribes. (2011). Findings from the national needs assessment of American Indian/Alaska Native child welfare programs (p. 23). Retrieved from nrc4tribes.org/files/NRCT%20Needs%20Assessment%20Findings_APPROVED.pdf.

³U.S. Department of Justice, Office of Justice Programs, Office of Juvenile Justice and Delinquency Prevention. (2014). Attorney General's Advisory Committee on American Indian/Alaska Native Children Exposed to Violence: Ending violence so children can thrive (p. 81). Retrieved from www.justice.gov/sites/default/files/defendingchildhood/pages/attachments/2014/11/18/finalaianreport.pdf.

Children's Mental Health

| Agency | Program | Fiscal year 2018 enacted | Fiscal year 2019 recommended |
|----------------|---|---|--|
| DHHS SAMHSA | Programs of Regional and National Significance—Children and Family Programs (includes Circles of Care) | \$7.2 million (no funds reserved for Circles of Care) | \$7.2 million (Reserve \$6.5m for Circles of Care) |
| DHHS SAMHSA | Children's Mental Health Services Program— Systems of Care | \$125m (no funding reserved for State or Tribal System of Care grants) | \$125m (Reserve funding for State and Tribal children's mental health grants) |
| DHHS SAMHSA | GLS State/Tribal Youth Suicide Prevention (Tribes receive portion of grant funds) | \$35.4m | \$40.5m |
| DHHS SAMHSA | GLS Campus Suicide Prevention Program | \$6.5m | \$9.1m |
| DHHS SAMHSA | AI/AN Suicide Prevention | \$2.9m | \$4.0m |
| DHHS SAMHSA | Tribal Behavioral Health Grant (divided between substance abuse prevention and mental health services) | \$30m | \$50m |

Programs of Regional and National Significance, Children and Family Programs (includes Circles of Care): Ensure that \$6.5 million under this line item continues to be reserved specifically for the tribal and urban Indian community Circles of Care program in fiscal year 2019.

The Children and Family Programs under Programs of Regional and National represents funds allocated to support the tribal Circles of Care program. Circles of Care is a competitive grant program exclusively for Tribal communities. It is the cornerstone of tribal children's mental health programming.

Circles of Care is a 3-year planning grant that helps communities design programs to specifically serve AI/AN children with serious behavioral health issues. Specifically, Circles of Care funds the development of the tribal capacity and infrastructure necessary to support a coordinated network of holistic, community-based, mental and behavioral health interventions in tribal communities.

Circles of Care is one of only two SAMHSA programs that allow tribes and tribal organizations to apply for funding without competing with other governmental entities (States, counties, or cities). There are currently 11 communities receiving Circles of Care funding.

AI/AN children and youth face a "disproportionate burden" of mental health issues while simultaneously facing more barriers to quality mental healthcare.⁴ Since its inception in 1998, the Circles of Care program has affected 49 different tribal and urban Indian communities. These programs have been incredibly successful. The majority of tribes who have received these grants have created long-term, sustainable systems of care for their children.

Of the 31 total graduated Circles of Care grantees, 12 have obtained direct funding to implement their system change efforts through System of Care (SOC) grants, and four others have partnered with other SOC grantees to implement their models. The others have developed various alternative strategies to operationalize and sustain their system change plans to care for youth with mental health challenges.

Children's Mental Health Initiative (Systems of Care): Continue funding at \$125 million to allow for continued support of the current 4-year grantees and funding of new grantees in fiscal year 2019. We are asking for Congress to specify that these funds must be used for System of Care grants for States and Tribes.

The children's mental health initiative supports the development of comprehensive, community-based "systems of care" for children and youth with serious emotional disorders. This includes funding for 1 year System of Care Expansion Planning Grants, 4-year System of Care Expansion Implementation Grants, and 6-year

⁴ American Psychiatric Association. (2010). Mental health disparities factsheet: American Indians and Alaska Natives (p. 4).

Children's Mental Health Initiative System of Care Grants. AI/AN communities are eligible for, and recipients of, each of these grants, but must compete with non-tribal applicants to receive these funds.

Children's Mental Health Initiative System of Care Grants support a community's efforts to further plan and implement strategic approaches to mental health services. These approaches are based on important principles: they must be family-driven; youth-guided; and meet the intellectual, emotional, cultural, and social needs of children and youth. Since 1993, 180 total projects have been funded, dozens of which have been in tribal communities. Currently, 12 tribal communities are funded.

Evaluation studies of System of Care have indicated return on investment from cost-savings in reduced use of in-patient psychiatric care, emergency room care, and residential treatment even when other community- or home-based care is provided. There are also cost savings from decreased involvement in juvenile justice systems, fewer school failures, and improved family stability.⁵

Programs of Regional and National Significance, Tribal Behavioral Health Program: Increase funding for the Tribal Behavioral Health program (mental health and substance abuse prevention programs) to \$50 million in fiscal year 2019.

In the fiscal year 2018 Consolidated Appropriations Act, Tribal Behavioral Health Grants were funded at \$30 million (\$15 million in the Mental Health appropriation and \$15 million in the Substance Abuse Prevention appropriation). NICWA recommends \$50 million in fiscal year 2019 to continue to address the expansion of suicide prevention, mental health, and substance abuse activities for Native communities.

These are to be competitive grants designed to target tribal entities with the highest rates of suicide per capita over the last 10 years. These funds must be used for effective and promising strategies to address the problems of substance abuse and suicide and promote mental health among AI/AN young people.

AI/AN young people are more likely than other youth to have an alcohol use disorder. In 2007, 8.5 percent of all AI/AN youth struggled with alcohol use disorders compared to 5.8 percent of the general youth population.⁶ Although these statistics are troubling, with adequate resources tribes are best able to serve these young people and help them heal before they reach adulthood:

There is growing evidence that Native youth who are culturally and spiritually engaged are more resilient than their peers. Research has revealed that 34 percent of Native adolescents preferred to seek mental or substance abuse services from a cultural- or religious-oriented service provider. In other research, American Indian caregivers preferred cultural treatments (e.g., sweat lodge, prayer) for their children and found the traditionally based ceremonies more effective than standard or typical behavioral health treatment.⁷

PREPARED STATEMENT OF THE NATIONAL INDIAN EDUCATION ASSOCIATION

Dear Chairman Blunt:

On behalf of the National Indian Education Association (NIEA), I respectfully submit the following comments in response to the President's fiscal year 2019 Budget Request for programs that impact Native students.

NIEA is the most inclusive national organization advocating for improved educational opportunities for American Indian, Alaska Native, and Native Hawaiian students. Our mission is to ensure that Native students have access to a high-quality academic and cultural education, a goal that is only possible if Congress upholds the Federal trust responsibility to tribes.

THE FEDERAL TRUST RELATIONSHIP

Congress has a Federal trust responsibility for the education of Native students. Established through treaties, Federal law, and U.S. Supreme Court decisions, the

⁵Stroul, B. (2015). Return on investment on System of Care for children with behavioral health challenges: A look at wraparound. *The TA Telescope*, 1(2), pp. 1–2.

⁶U.S. Department of Justice, Office of Justice Programs, Office of Juvenile Justice and Delinquency Prevention. (2014). Attorney General's Advisory Committee on American Indian/Alaska Native Children Exposed to Violence: Ending violence so children can thrive (p. 81). Retrieved from www.justice.gov/sites/default/files/defendingchildhood/pages/attachments/2014/11/18/finalaianreport.pdf.

⁷Novins, D. K., & Bess, G. (2011). 10. Systems of mental healthcare for American Indian and Alaska Native children and adolescents. In P. Spicer, P. Farrell, M. C. Sarche, & H. E. Fitzgerald (Eds.), *American Indian and Alaska Native children and mental health: Development, context, prevention, and treatment*. Santa Barbara, CA: SABC-CLIO, LLC.

Federal Government's trust responsibility to tribes includes the obligation to provide parity in access and equal resources to all American Indian and Alaska Native students, regardless of where they attend school. The Federal trust responsibility is an obligation shared between the Congress and the Administration for federally-recognized tribes.

NIEA'S SPECIFIC REQUESTS

NIEA's budget requests for 2019 are outlined below:

ESSA Title VI: Indian Education Formula Grants

Provide \$198 million for Title VI, Part A. An increase of \$92.7 million above fiscal year 2018 enacted. Authorized funding for Title VI, Part A for fiscal year 2018 is \$105.3 million. Increases are needed as this critical grant funding is designed to supplement the regular school program and assist Native students so they have the opportunity to achieve the same educational standards and attain parity with their non-Native peers.

—Title VI funds support early-childhood and family programs, academic enrichment programs, curriculum development, professional development, and culturally-related activities.

ESSA Title VI, Part A, Subpart 2: Special Programs and Projects to Improve Educational Opportunities for Indian Children

Provide \$67.9 million for Title VI, Part A, Subpart 2: Special Programs and Projects to Improve Educational Opportunities for Indian Children. An increase of \$10 million above fiscal year 2018 enacted.

—ED's Native Youth Community Projects initiative provides better comprehensive, community-driven strategies to improve college and career-readiness of Native youth.

ESSA Title VI, Part A, Subpart 3: Language Immersion and National Activities

Provide \$10 million for Title VI, Part A, Subpart 3. An increase of \$3.1 million above fiscal year 2018 enacted.

—Native language funding is critically important to tribes and Native communities across the country. The research supporting Native language funding is clear and the investment in the National Activities fund will support the critical building block of Native languages for our students.

ESSA Title VI, Part B: Native Hawaiian Education Program

Provide \$36.4 million Title VI, Part B. Level with the fiscal year 2018 appropriation.

—The Native Hawaiian Education program empowers innovative culturally appropriate programs to enhance the quality of education for Native Hawaiians. When establishing the Native Hawaiian Education Program, Congress acknowledged the trust relationship between the Native Hawaiian people and the United States.

ESSA Title VI, Part C: Alaska Native Education Equity Assistance Program

Provide \$36.4 million for Title VI, Part C. An increase of \$1.1 million over the 2018 enacted.

—This funding is crucial to closing the gap between Alaska Native students and their non-Native peers as eligible activities include professional development for educators, activities carried out through Even Start programs and Head Start programs, family literacy services, and dropout prevention programs.

ESSA Title VII: Impact Aid

Provide \$2 billion for Title VII. An increase of \$589 million above fiscal year 2018 enacted.

—Impact Aid provides direct payments to public school districts as reimbursement for the loss of traditional property taxes due to a Federal presence or activity, including the existence of an Indian reservation.

—With nearly 93 percent of Native students enrolling in public schools, Impact Aid provides essential funding for schools serving Native students.

HEA Title III: Tribal Colleges and Universities: Supporting Financially Disadvantaged Students

Provide \$65 million (\$35 million in discretionary funding and \$30 million in mandatory funding) for Title III-A grants under the Higher Education Act for Tribal Colleges and Universities. An increase of \$5.3 million above the fiscal year 2018 enacted.

- Titles III and V of the Higher Education Act, known as Aid for Institutional Development programs, support institutions with a large proportion of financially disadvantaged students and low cost-per-student expenditures.
- Tribal Colleges and Universities (TCUs) clearly fit this definition. The Nation's 36 accredited TCUs serve Native and non-Native students in some of the most impoverished areas in the Nation.

HEA Title III: Tribal Colleges and Universities: Adult/Basic Education

Provide \$8 million for American Indian Adult/Basic Education at Tribal Colleges and Universities, from existing funds appropriated for State block grant funding. No such set-aside from existing funds included in fiscal year 2018 enacted.

- Despite an absence of dedicated funding, TCUs must find ways to continue to provide basic adult education classes for those American Indians that the present K–12 Indian education system has failed.

Perkins: Tribally Controlled Post-Secondary Career and Technical Institutions

Provide \$10 million for postsecondary career and technical institutions program funds under Carl Perkins Technical and Career Education Act. An increase of \$1.7 million above fiscal year 2018 enacted.

- Section 117 of the Carl Perkins Career and Technical Education Improvement Act authorizes funding for operations at tribally-controlled postsecondary career and technical institutions.
- Vocational education/training programs are very expensive to conduct, but are vital to preparing a future workforce that will operate safely and efficiently contributing greatly to the global economy.

CONCLUSION

Through these recommendations on the fiscal year 2019 Budget Request for Indian programs, NIEA looks forward to working with the Chairman to pass a budget that serves the unique needs of the only students that the Federal Government has a direct responsibility to educate—Native students. If you have any questions, please contact Matt de Ferranti, NIEA's Legislative Director, at mdferranti@niea.org.

Sincerely,

[This statement was submitted by Ahniwake Rose, Executive Director, National Indian Education Association.]

PREPARED STATEMENT OF THE NATIONAL INDIAN HEAD START DIRECTORS ASSOCIATION AND THE NATIONAL MIGRANT AND SEASONAL HEAD START ASSOCIATION

Dear Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee:

On behalf of the National Indian Head Start Directors Association (NIHSDA) and the National Migrant and Seasonal Head Start Association (NMSHSA), we are writing to urge you to provide increased funding for Indian Head Start and Migrant and Seasonal Head Start in fiscal year 2019. With the \$2.2 billion increase allocated for the Labor-HHS-Education account in fiscal year 2019, the Senate Appropriations Committee has the opportunity to provide urgently needed investment in these programs.

Background.—Congress authorized Indian Head Start and Migrant and Seasonal Head Start in response to the unique needs of American Indian families and farmworker families. In so doing, Congress committed the Federal Government to ensuring that Head Start benefits are extended to all of our Nation's children. Both Indian Head Start and Migrant and Seasonal Head Start were established as national programs and to this day both are administered by the Office of Head Start within the Department of Health and Human Services.

Since its inception in 1965, Indian Head Start has played a critical role in providing American Indian and Alaska Native children with a strong foundation for life-long academic achievement and personal resiliency. Its strength is rooted in a two-generational model of early childhood development that responds to the unique needs of children and their families. It does this through a highly effective program model that encompasses the whole child, family, and community—through education, health, language, and culture—to create a vibrant and nurturing learning environment. Because of this holistic approach, Indian Head Start is currently the most successful Federal program focused on Native early childhood education.

Similarly, since 1969, Migrant and Seasonal Head Start programs have delivered comprehensive, high-quality Head Start to farmworker families using a unique serv-

ice delivery model that addresses the demands of the agriculture labor market. This unique design allows programs to operate seasonally to accommodate parents working in the fields and packing houses. During peak agricultural seasons, for example, programs operate up to 7 days a week for 8–14 hours per day. Migrant Head Start is the only Head Start program that requires parents to work in order to be eligible for services and about 80 percent of the enrolled households have both parents working in agriculture. Local childcare resources are often not available when farmworker families arrive to new worksites. Parents have few choices in these situations, oftentimes arranging for unlicensed childcare or taking their children with them to the fields, where they may be exposed to pesticides, hazardous equipment, extreme heat, and other health dangers. Despite working long hours in labor-intensive jobs, our parents are actively engaged in their children's education and the operation of their Head Start centers, which has contributed to the success of Migrant and Seasonal Head Start programs.

Despite its documented accomplishments, only about 16 percent of the age-eligible Native child population is enrolled in Indian Head Start; and only 188 of 573 federally recognized tribes operate Indian Head Start programs. This means that approximately 385 tribal nations do not have direct access to these critical services. The numbers are equally startling for Migrant and Seasonal Head Start programs working to reach and serve families working in various sectors of agriculture and often living in remote rural areas. Of the Native and farmworker communities that do have Head Start programs, many are plagued by inadequate classroom facilities, high staff turnover, cost-prohibitive Federal in-kind contribution requirements, and culturally inappropriate evaluation metrics. Strengthening and expanding programs through increased Federal support is, therefore, paramount to continuing our programs' success.

Base Funding of Head Start and Early Head Start Programs.—Together with the National Head Start Association, we would like to express our appreciation for Congress' commitment to providing all children with a head start in life through the provision of high-quality early childhood education. To continue to serve the dire and ever-increasing needs of American working and low-income families, we recommend funding Head Start and Early Head Start at \$10,810,095,000 in fiscal year 2019. Within this amount, we recommend the allocation of \$339,500,000 for Quality Improvement funding to support the implementation of the Head Start Program Performance Standards issued in 2016. It is essential that these funds be provided with flexibility, so programs are empowered to address areas of greatest need, such as staff training, integrating culturally and linguistically appropriate classroom practices, increasing duration of services to support working families, and strengthening transportation safety.

We also recommend the allocation of \$233,600,000 for Workforce Investments through a cost of living adjustment. Recruiting and training qualified teachers is a persistent challenge for Indian Head Start and Migrant and Seasonal Head Start programs, which are generally located in remote or rural communities with limited economic development opportunities. A cost of living adjustment is sorely needed to retain qualified staff and effectively serve the children and families enrolled in our programs.

Full Funding of the 3 Percent Set Aside for Indian Head Start and the 4.5 percent Set Aside for Migrant and Seasonal Head Start.—Prior to the reauthorization of the Head Start Act in December 2007, the Act had a funding formula that established a 12 percent set aside for five priority programs, including Indian Head Start. During the 2007 reauthorization process, the Department of Health and Human Services, under questioning from congressional staff, divulged that 3–4 percent of the 12 percent (essentially one-third of the set aside amount) had been transferred away from the priority programs to supplement regional Head Start programs. Congress's express set aside was effectively reduced to 8–9 percent by unilateral and undisclosed administrative action and, necessarily, the funding of the priority programs was reduced as well.

To address this irregularity and assure that our programs could recover financial ground, the 2007 Act provided for special expansion funds for Indian Head Start and for Migrant and Seasonal Head Start. 42 U.S.C. § 9835. The formula is very complicated and difficult to parse, however, it essentially provided that both of our programs would receive increases of up to \$10 million per year for fiscal years 2008–2010 for expanded enrollment so long as there was sufficient funding to ensure that all Head Start programs received cost of living increases (this was to ensure that there would be no loss of slots in regional programs to make up for the unseen losses in our programs). Because of flat funding in fiscal years 2008 and 2010, we only received special expansion funds in fiscal year 2009. As a result, there

has never been real mitigation of Indian Head Start and Migrant and Seasonal Head Start losses arising from the earlier diversion of priority program funds.

All of this could change, however, if Congress acts now to provide Indian Head Start with the full 3 percent set aside and Migrant and Seasonal Head Start the full 4.5 percent set aside of Head Start funding in fiscal year 2019. Section 640(a)(4)(D)(ii) of the 2007 Act provides for special expansion funds of not less than 3 percent for Indian Head Start programs, and not less than 4.5 percent for Migrant and Seasonal Head Start programs, with an additional percentage increase available at the Secretary's discretion. We have never received our full set aside amounts. Taking advantage of the current budget deal to fully fund the Indian Head Start and Migrant and Seasonal Head Start set asides would help fulfill Congress's unfunded mandate and set our programs on the long-overdue path towards parity with our colleagues in regional Head Start.

Unique Challenges Facing Our Programs Warrant Additional Funding.—Indian Head Start programs are deeply committed to serving Native children, families, and communities who on a daily basis must deal with depression-era economics, high rates of crime, limited educational resources, and poor health outcomes. Migrant and Seasonal Head Start programs are equally committed to ensuring that farm-worker children and families have access to first-rate, consistent educational services as parents work to ensure that families across the country have access to safe, secure and affordable food.

Both of our programs desperately need facilities and quality improvement funds for staff training and development, staff retention, improved classroom facilities, increased services, and other program needs. We, thus, urge Congress to take advantage of this unique opportunity in the Federal budgeting process to fully fund the 3 percent and 4.5 percent set asides for Indian Head Start and Migrant and Seasonal Head Start, respectively, so that our programs can continue to fulfill their critical role in developing youth resiliency and strengthening entire families and communities.

On behalf of NIHSDA and the NMSHSA, we thank you for your continued leadership in the Federal appropriations process. The members and staff of the Senate Labor—HHS Appropriations Subcommittee have been and continue to be strong allies of early childhood education. Please know that NIHSDA and the NMSHSA stand ready to serve as a resource to you and your staff on the unique needs of Indian Head Start and Migrant and Seasonal Head Start. Thank you for your time and consideration of this critical request.

Sincerely,

[This statement was submitted by Lee Turney, President, National Indian Head Start Directors Ass'n, and Delia Garcia, Executive Director, National Migrant & Season Head Start Ass'n.]

PREPARED STATEMENT OF THE NATIONAL INDIAN HEALTH BOARD

Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee, thank you for the opportunity to offer this written testimony. On behalf of the National Indian Health Board (NIHB) and the 573 Tribal Nations we serve, I, Stacy A. Bohlen, CEO of NIHB, submit this testimony on the fiscal year 2019 budget for the Department of Health and Human Services (HHS).

Since the earliest days of the Republic, all branches of the Federal Government have acknowledged the Nation's obligations to the Tribes and the special trust relationship between the United States and Tribes. In 2010, as part of the Indian Health Care Improvement Act, Congress reaffirmed the duty of the Federal Government to American Indians and Alaska Natives (AI/ANs), declaring that "it is the policy of this Nation, in fulfillment of its special trust responsibilities and legal obligations to Indians—to ensure the highest possible health status for Indians and urban Indians and to provide all resources necessary to effect that policy."¹ Though the Indian Health Service (IHS) was established to help the Federal Government fulfill the trust responsibility for health, Congress has never provided IHS with enough funding to meet the needs of Indian Country. As a result of this underfunding, historical trauma, and a Federal-State centric public health system, AI/ANs suffer some of the worst health disparities in almost every category. The Federal trust responsibility is the responsibility of all government agencies, including others within HHS. Agencies like the Centers for Disease Control and Prevention (CDC); Substance Abuse and Mental Health Services Administration (SAMHSA); and Cen-

¹25 U.S.C. 1602

ters for Medicare and Medicaid Services (CMS) all must ensure that Tribes have access to preventative and direct health services.

NIHB would first like to thank the subcommittee for the efforts to improve health for AI/ANs over the last several years. The inclusion of a \$50 million Tribal set aside in the State Targeted Response to Opioid Grants as well as the \$5 million Tribal set aside for the Medication Assisted Treatment Program in the fiscal year 2018 Omnibus Appropriations Act are critical investments that will enable Tribal communities to make important progress when it comes to opioid use disorder, prevention and treatment.

However, there is much work to be done. Generally speaking, Tribal health systems are simply left out of many funding streams within HHS for a variety of reasons. Federal block grants flow to States, leaving little opportunity for Tribal governments to receive this funding. Tribes are eligible to apply for many other Federal grants that address public health and other issues, however, many of these programs have little penetration into Indian Country because Tribes have difficulty meeting the service population requirements, match requirements, or are under resourced to apply for the grants. Generally speaking, funding should flow through to Tribes on a recurring, formula basis, so that Tribal health programs have funds they can count on from year to year.

CENTERS FOR DISEASE CONTROL AND PREVENTION

Preventive Health and Health Services (PHHS) Block Grant:

Public health infrastructure in Indian Country is one of the most severely underfunded and under developed areas of the health service delivery system. Like State and territorial governments, Tribes have both the rights and responsibilities to provide vital public health services for their communities. To do this, they must also have the tools to carry out these functions. Establishing Tribal-specific funding streams, scaled for impact, will allow Tribes to secure needed funding and design and implement public health programs that meet the specific needs of their Tribal citizens. Therefore, NIHB requests that, in fiscal year 2019, Congress create base funding for Tribal communities through the PHHS grant program by allocating at least 5 percent to Indian Tribes directly, annually.

Good Health and Wellness in Indian Country:

The President's fiscal year 2019 Budget request eliminated funding for the Good Health and Wellness in Indian Country (GHWIC) program (currently funded at \$16 million). GHWIC is CDC's largest investment in the wellbeing of American Indian and Alaska Natives. The twelve Tribes and eleven Tribal organizations in the program have utilized community-driven, culturally adapted strategies to improve public health in their communities. GHWIC is a lifeline for these communities who would otherwise have no public health investment. CDC has told Tribal leaders on March 1, 2018 that they are replacing GHWIC with the proposed "America's Health Block Grant." That funding has no indicated set aside for Tribes or Tribal epi-centers so there is zero guarantee that this funding would reach AI/AN communities. Instead, the Committee should reject this elimination of GHWIC and double the size of the program to \$32 million in fiscal year 2019.

Public Health Emergency Preparedness:

The Public Health Emergency Preparedness (PHEP) Cooperative Agreements at CDC provide base funding to States, territories and major cities to upgrade their ability to respond to a public health crises. But again, Tribal communities do not receive this funding directly, and few, if any, see any support from their State programs. Failure to fund Tribal communities will mean that large land areas of this country are not covered for emergency infrastructure support, causing a domino effect throughout the rest of the Nation when it comes to pandemics or natural disasters. NIHB requests that Congress direct at least 5 percent of PHEP funds to Tribes so that they can develop comprehensive and achievable response plans for public health crises.

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

Nowhere is the issue of lack of solid infrastructure support more acute than when it comes to mental and behavioral health services. AI/AN children and communities grapple with complex behavioral health issues at higher rates than any other population. Destructive Federal Indian policies and unresponsive or harmful human

service systems have left AI/AN communities with unresolved historical and generational trauma, leading to contemporary trauma.²

State Targeted Response to Opioid Grants (STR):

As noted above, Tribes were glad to see a \$50 million Tribal set-aside for the State targeted response to opioid grants in the fiscal year 2018 Omnibus Appropriations Act. We request that the Committee expand and improve this set-aside for fiscal year 2019. The CDC reports that AI/ANs consistently had the highest drug overdose death rate by race every year from 2008–2015, and the highest percentage increase in drug overdose deaths from 1999–2015 at 519 percent.³ Therefore, we believe that it is critical to provide at least a 10 percent Tribal set aside for STR grants. With a larger pool of money, funding could also be distributed in a formula basis, instead of competitive grants which force Tribes to compete against each other.

Mental Health Service Block Grant:

Access to behavioral health services for AI/ANs would be improved if Tribes had access to the Mental Health Service Block Grant. Without this critical funding, comprehensive mental health services are not reaching Tribal communities, though States are awarded these funds. IHS has limited mental health funding, but has always been underfunded to provide sustained mental health infrastructure. Congress should dedicate funding to Tribes directly for the Mental Health Services Block Grant.

Tribal Behavioral Health Grants (TBHG):

At SAMHSA, several programs specifically target Tribal communities. TBHG is designed to address the high incidence of substance use and suicide among AI/AN populations and it is a vital component of ensuring that behavioral health challenges are addressed across Indian Country. In fiscal year 2019, NIHB requests funding of \$50 million for the TBHG program.

Circles of Care:

The SAMHSA Circles of Care Program offers 3-year infrastructure/planning grants and seeks to eliminate mental health disparities by providing AI/AN communities with tools and resources to design and sustain their own culturally competent system of care approach for children. In fiscal year 2019, we recommend increasing Circles of Care funding to \$8.5 million.

Substance Abuse Block Grant:

The purpose of the SAMHSA Substance Abuse Block Grant (SABG) is to implement activities to treat and prevent substance abuse throughout the country. Few places have greater need than Indian Country when it comes to these issues. However, SABG is operated by State governments, which means that Tribal communities are often left out. We recommend that the Committee allocate specific funding for SABG directly to Tribal communities so that there can be sustained funding to help address long-term substance abuse issues in Tribal communities.

CENTERS FOR MEDICARE AND MEDICAID SERVICES

The Medicaid system is a critical lifeline in Tribal communities. Moving Medicaid to a block grant system, as proposed in the President's fiscal year 2019 Budget Request, will have major fiscal impacts on Tribal health reimbursements, and would devastate Tribal health. This puts an unequal burden on the IHS budget which is reliant on these resources to make up for chronic funding shortfalls. We also urge Congress to reinforce the trust responsibility of the Federal Government and the unique political relationship between Tribes and the Federal Government by exempting AI/ANs from any new burdens put on Medicaid like work requirements. AI/ANs already have access to healthcare through the IHS, so work requirements only serve to inhibit the use of Medicaid in Tribal communities, and thereby increase pressure on the IHS, which already is strained by chronic underfunding.

²Braveheart, M. Y. A., & DeBruyn, I. M. (1998). The American Indian Holocaust: healing historical unresolved grief. *American Indian and Alaska Native Mental Health Research*, 8(2).

³Mack KA, Jones CM, Ballesteros MF. Illicit Drug Use, Illicit Drug Use Disorders, and Drug Overdose Deaths in Metropolitan and Nonmetropolitan Areas—United States. *MMWR Surveill Summ* 2017;66(No. SS-19):1–12. DOI: <http://dx.doi.org/10.15585/mmwr.ss6619a1>.

SECRETARY'S MINORITY AIDS INITIATIVE FUND

AI/AN communities face the lowest survival rates after an AIDS diagnosis among all demographics, and one of the lowest rates of viral suppression. SMAIF (Secretary's Minority AIDS Initiative Fund) is a vital source of funding to improve HIV/AIDS prevention and treatment initiatives in American Indian and Alaska Native (AI/AN) communities. SMAIF dollars are the only source of HIV specific funding to the IHS, supporting fifteen critical projects across Indian Country and accounting for nearly 99 percent of all IHS HIV initiatives. From 2005 to 2016, IHS successfully increased prenatal HIV screening to 87 percent, and expanded its reportable quality of care metrics which led to 80,000 AI/AN individuals receiving HIV screening for the first time. Overall, IHS has improved HIV screening by 22 percent. These statistics demonstrate the vital role that SMAIF dollars play in improving IHS' HIV initiatives.

In fiscal year 2016, SMAIF was funded at \$53.9 million, of which \$3.6 million was awarded to IHS via competitive grants. This funding provided technical assistance and training to improve delivery of HIV services at IHS, Tribal, and Urban Indian facilities, improved clinical support for HIV care coordination, expanded HIV screening services, bolstered HIV and sexually transmitted infection outreach and education initiatives for AI/AN youth, and built the capacity of Tribal communities to respond to new HIV infections and improve linkage to care.

Currently, there is no guarantee that Indian Country receives SMAIF dollars because IHS must compete with other Federal agencies for awards. This poses a significant barrier for IHS, as unlike other Federal agencies, it does not receive funds via congressional appropriations from the separate Minority AIDS Initiative. NIH strongly urges the Committee to reauthorize SMAIF for fiscal year 2019 and establish a \$5 million set aside for IHS to ensure that critical HIV/AIDS prevention and treatment initiatives continue, and to ensure that IHS is not forced to compete on an unfair playing field for these vitally important dollars.

EXPANSION OF SELF-GOVERNANCE AT HHS

For over a decade, Tribes have been advocating for expanding self-governance authority to programs at HHS. Self-governance represents efficiency, accountability and best practices in managing and operating Tribal programs and administering Federal funds at the local level. This proposal was deemed feasible by a Tribal/Federal HHS workgroup in 2011. Therefore, we request that the Appropriations Committee direct HHS to enter into pilot projects for self-governance at the agency in fiscal year 2019.

Thank you again for the opportunity to offer to participate in the Public Witness Hearing for fiscal year 2019. As noted above, the Federal trust responsibility for health extends beyond the IHS to all agencies of the Federal Government. We thank the committee for the efforts it has put forward to prioritize this issues at the Department of Health and Human Services. Please do not hesitate to contact our offices directly if you have any questions or if you require additional information.

PREPARED STATEMENT OF THE NATIONAL INDIAN YOUTH COUNCIL, INC.

The National Indian Youth Council, Inc. (NIYC) is grateful for this opportunity to submit this statement urging the continuation of funding for American Indians and Alaska Natives via the U.S. Department of Labor's Division of Indian and Native American Program (DINAP) grants under Section 166 of the Workforce Innovation and Opportunity Act (WIOA). NIYC also would advocate that all WIOA programs receive the same, at a minimum, funding amounts as they did in fiscal year 2018.

NIYC, a national nonprofit with 501(c) (3) tax status, has served the interests of American Indians and Alaska Natives in this country since the early 1960's. In 1974, NIYC began to focus a large part of its programming efforts on ensuring that Native Americans, specifically off-reservation Native people living in the State of New Mexico, had access to employment and training services in order to fully participate in the American workforce and provide economic security for themselves and their families. Since the 70's, NIYC has received employment and training program funding from the U.S. Department of Labor's (DOL), Employment and Training Administration, beginning with the former Comprehensive Employment and Training Act (CETA) program. NIYC has continued to receive similar funding through the subsequent programs, including the Job Training and Partnership Act, the Workforce Investment Act, and now the Workforce Innovation and Opportunity Act. Throughout all these changes, NIYC has been a top performing grantee serving

off-reservation Native Americans. The purpose of this program is to “support employment and training activities for Indian, Alaska Native, and Native Hawaiian individuals in order to: (A) develop more fully the academic, occupational, and literacy skills of such individuals; (B) make such individuals more competitive in the workforce and equip them with the entrepreneurial skills necessary for successful self-employment; and (C) promote the economic and social development of Indian, Alaska Native, and Native Hawaiian communities in accordance with the goals and values of such communities.”

According to the 2000 U.S. Census, 64,434 off-reservation/urban American Indian, Alaska Native, and Native Hawaiians live directly within NIYC’s designated WIOA service areas (which covers 31 of New Mexico’s 33 counties), with a total statewide population of approximately 195,000 American Indian, Alaska Native, and Native Hawaiians, roughly equivalent to 10 percent of the entire State’s population. Nationally, over 75 percent of the American Indian, Alaska Native, and Native Hawaiian population lives outside of reservation lands, with the higher concentrations occurring in cities and other urban areas. This is largely a result of U.S. Government policy, namely the Indian Relocation Act of 1956 (also known as Public Law 959), which relocated many Native peoples to the cities. Prior to the 1950’s, less than 6 percent lived in urban areas. These relocation programs provided up to four (4) weeks of support for people who agreed to relocate. Not surprisingly, the programs were not successful. Relocated tribal members became isolated from their communities and faced racial discrimination and segregation. Many found only low-paying jobs with little advancement potential, and suffered from the lack of community support, and the higher expenses typical for urban areas.

In 2015, according to the New Mexico 2017 State of the Workforce Report, “Native Americans in New Mexico had a 16 percent unemployment rate, compared to the overall State unemployment rate of 7.4 percent, the highest of all racial and ethnic groups. As with all of New Mexico’s populations, American Indians faced large job losses during the recession. What is more unique to American Indians is that unemployment has been consistently high, even prior to the recession.” Further, the report indicated that Native Americans in New Mexico had the lowest labor force participation rate of any racial group in the State, at just 56.1 percent compared to the overall State participation rate of 58.4 percent. Statewide, the percentage of people living below the poverty level in New Mexico, in 2015, was 20.4 percent, down from 21.3 percent in 2014, but still 5.7 percentage points higher than the national average (14.7 percent). Among all States, only Mississippi had a larger share of people living below the poverty level. In New Mexico, approximately one-third (33 percent) of all Native Americans were living below the poverty level.

WORKFORCE INNOVATION AND OPPORTUNITY ACT

The DOL’s Training and Employment Services (TES) programs exist to provide employers with skilled and qualified workers to fill their current and future openings and help Americans get and keep family-sustaining jobs. The majority of the program activities are authorized by the WIOA. Under TES, all WIOA programs serve as the primary vehicle for helping adults with barriers to employment gain new skills and find in-demand jobs in sectors that are projected to grow.

State operated WIOA Adult programs serve as the primary vehicle to help adults with barriers to employment gain new skills and find in-demand jobs in sectors that are projected to grow. However, these programs are not culturally-sensitive, nor are they as successful in reaching out to the Native populations with their multiple barriers to employment.

Because of this, WIOA programming under Section 166, Indian and Native American Programs, supports underemployed and unemployed Native Americans pursuing improved job skills. Improving employees’ skillsets builds stronger workforces and ensures sustainable employment over time. Programs funded by WIOA via DINAP offer training opportunities for American Indian and Alaska Natives to earn a GED, learn computing skills, and obtain certificates in specialized areas of various fields. The training offered to participants is based on the current labor market information determined by the various States and is designed to satisfy future job opportunities. Like the programs operated by the States, all qualifying U.S. Armed Services veterans and their spouses are given priority in the services offered. WIOA’s Section 166 program supports employment and training activities specifically for American Indians and Alaska Natives, serving over 32,000 unemployed, underemployed, and under-skilled, low-income Native people annually. Given the employment challenges and growing population in Indian Country, targeted programs are essential to meeting the challenges of today’s economy.

FISCAL YEAR 2019 BUDGET IMPACT

Nationally, DOL's Indian and Native American Employment and Training Program (section 166 grantees) currently funds 176 grants with funding amounts ranging from \$14,803 to \$5,525,686 for the Comprehensive Services Program (CSP) and \$1,006 to \$2,885,909 for the Supplemental Youth Services Program (SYSP). For 2018, the DOL allocated almost \$50 million to Indian and Native American Programs and almost \$815 million for State WIOA Adult programs. Thus, the 176 Indian and Native American grantees, under Section 166, were receiving funding equivalent to 6 percent of the Adult workforce programs.

This year, the DOL, in response to President Trump's proposed fiscal year 2019 budget which would substantially underfund DOL and WIOA compared to prior administrations, has prepared a proposed budget that would allocate just \$490 million to fund State Adult WIOA programs for fiscal year 2019, compared to the nearly \$815 million in fiscal year 2018, a 40 percent cut in funding. Even more alarming, to NIYC and other current Section 166 grantees, the Department's proposed budget would eliminate, entirely, the Division of Indian and Native American Programs and create a set-aside of just 1.5 percent of that budget for adult employment and training services under the Adult WIOA programs to American Indians, Alaska Natives, and Native Hawaiians, equivalent to \$7.35 million, which when compared to fiscal year 2018's \$49 million, is a reduction of 85%! This makes no sense. Native programs place people into employment, often with less money per person than the States, while serving a population that is harder to serve due to substantially heavier obstacles to overcome. Section 166 grantees know how to get results with this population.

With the proposed budget cuts to TES and WIOA, NIYC and the other off-reservation, nonprofit WIOA grantees serving America's off-reservation (again, over 75 percent of Native people live off-reservation) Native population will be unable to continue their services. WIOA funding is often all that is available for these activities. According to the organization, Native Americans in Philanthropy's website, "...despite Native Americans accounting for nearly 2 percent (5.4 million) of the U.S. population, philanthropic funding for the population remains less than 0.5 percent of annual foundation grant dollars. Most philanthropic efforts to improve the lives of men and women of color overlook the distinctive needs of Native Americans." Thus, looking to private foundations for funding is not a viable option. Without access to WIOA funds, our ability (and that of other Native organizations) to serve our urban Native community is essentially wiped out. Likewise, the reduction to the States' adult programs means even less funding to go around, with an increase in demand, as Native peoples have to turn to the States for employment and training services. Native people, who already are discriminated against and leery of Federal and State programs are likely to suffer in such a scenario.

NIYC—A WIOA GRANTEE

With WIOA funding, NIYC is able to enroll over 325 low income adults in its three field offices. It will also serve an additional 1,100 who are not enrolled into a particular program, but who access "self-services." NIYC's average cost per participant in its last program year \$4,291.00. Sixty-one (61) were still employed in the 4th quarter after exiting the program, with the total median earnings (unsubsidized) of the participants at \$8,523.31, in just their second quarter after exiting.

One of many success stories of WIOA participants funded by DINAP/WIOA, in her own words, follows:

My name is Tashina S., I am an enrolled Tribal member of the Navajo Nation and currently live in Albuquerque, NM. I'm employed with the American Indian Chamber of Commerce of NM as the Membership Manager. Before this job, I was a young unemployed Native American woman trying to make ends meet on unemployment benefits and food stamps for over half a year until I realized those benefits weren't enough for me to continue relying on. That's when I applied for the National Indian Youth Council's Employment and Training Program. ... [T]here were times when I wanted to throw in the towel, but I did not want to label myself as a quitter because I knew I could not rely on my unemployment benefits much longer. I had several interviews but never seemed to have met the qualifications, so I pushed myself to try harder and not to give up. I applied for the Employment program at NIYC and the staff there were very helpful and understanding.

I got approved for NIYC's Employment program...then, a position was available with the American Indian Chamber of Commerce of New Mexico as an Office Clerk and I was recommended to AICCNM by my job developer, Tera Frank. She knew that I was dedicated to finding a job and seen the opportunity for me

to potentially get hired on with them; in which, AICCNM took me in as an Intern through the program. Upon successfully completing my Employment program with NIYC, I was hired on as a Full-Time employee with the American Indian Chamber of Commerce and took the position as the Membership Manager. A year after being employed with AICCNM, another opportunity was offered to me as the Administrative Assistant for the Santa Fe Minority Business Development Agency which is currently operated by AICCNM under the U.S Department of Commerce. I now hold multiple job responsibilities within AICCNM and MBDA which keeps me busy throughout the day and I've had the opportunity to travel to various cities for business trips, meet some wonderful people and learn from my experiences throughout the process.

NIYC has helped me tremendously by getting me back on my feet, not once but twice. I know there are several other temporary work services around but they don't give the dedication and 1-to-1 attention that NIYC Employment & Training program offers. I know for a fact that NIYC wants their participants to come out successful from the program and is willing to help participants who work hard enough for it. I am very grateful for the National Indian Youth Council Program and all that they do to help our Native community and Youth.

Continued full funding of WIOA and the Division of Indian and Native American Programs by the U.S. and its Department of Labor ensures that there will be more success stories such as Tashina's. Leaving Native Americans with just a 1.5 percent set-aside of a decimated WIOA budget will not be enough, we respectfully ask that you maintain the current levels of funding to both.

NIYC stands ready to support the Committee in any way as it develops funding priorities for the DOL. If you have any questions, please contact Tina Farrenkopf via email or the telephone number listed above.

[This statement was submitted by Tina M. Farrenkopf, Executive Director, National Indian Youth Council, Inc.]

PREPARED STATEMENT OF THE NATIONAL INSTITUTE ON DISABILITY, INDEPENDENT LIVING AND REHABILITATION RESEARCH

Smith-Kettlewell, an Independent Eye Research Institute, thanks Congress for continuing to support both the National Institutes of Health and the Administration for Community Living, and their different missions.

We would like to express our strong support for keeping the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR) under the aegis of ACL, with whose mission it is most compatible. We understand there has been a proposal to move this agency to NIH, which we believe would be a mistake. Reconstituting NIDILRR as just another research institute within the NIH model would have very negative consequences, since the NIDILRR mission, goals, sub-components, organization, culture, target population, and practical impact are so different and incompatible with the more homogeneous and narrowly focused basic research structure and organization of the NIH and its component Institutes. We therefore believe many of the goals and beneficial impacts of NIDILRR would inevitably be lost in such a move.

The NIH is organized specifically to foster basic research in the various areas of medical focus of its component Institutes (Eye, Heart Lung and Blood, Allergy, etc) which are tightly integrated within the NIH structure with staff, rules and procedures geared towards the basic medical research mission. Even the review panels are controlled directly by the overarching NIH administration, are shared between the different Institutes, and have an ingrained tradition of basic science focus and membership.

NIDILRR, on the other hand, has a much more applied research focus and a mission to maximize practical impacts. It is oriented towards research and model programs to address and help the population of people with existing disabilities, rather than pushing back the frontiers of medical science in order to prevent others developing such disabilities in the future. In addition, NIDILRR incorporates other important activities and mechanisms such as demonstration systems, centers of excellence, training and technical support programs which would not easily fit into the NIH structure.

Overall, this different focus, target population and program structure is fundamentally incompatible with the NIH model, and the practical impacts on people with disabilities would inevitably be diluted if not lost altogether if a merger with NIH were to be forced upon it.

Many thanks for the opportunity to comment upon this proposal.

Sincerely.

[This statement was submitted by John Brabyn Ph.D, Executive Director, National Institute on Disability, Independent Living and Rehabilitation Research.]

PREPARED STATEMENT OF THE NATIONAL KIDNEY FOUNDATION

The National Kidney Foundation (NKF) is pleased to submit testimony regarding the impact of Chronic Kidney Disease (CKD) and funding necessary to build upon the successes of the existing programs at the CDC National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), \$2.165 billion for the National Institute of Diabetes, Digestive and Kidney Diseases, and the HRSA Division of Transplantation (DoT) and increases necessary for the HRSA Bureau of Primary care to fight kidney disease.

ABOUT CKD

CKD impacts 30 million American adults, while 1 in 3 adults (73 million) are at risk. Diabetes and high blood pressure are responsible for up to two-thirds of all cases of irreversible kidney failure (end stage renal disease) which requires dialysis or a kidney transplant to maintain life. Kidney disease can be detected through simple blood and urine tests yet can go undetected until very advanced because kidney disease often has no symptoms. African Americans develop ESRD at a rate of 4:1 compared to Whites and Hispanic Americans develop it at a rate of 2:1 compared to Whites.

Over 700,000 Americans have ESRD, nearly 500,000 of whom receive dialysis at least 3 times per week to replace kidney function, and over 200,000 Americans live with a kidney transplant. Medicare spends nearly \$100 billion annually on the care of people with CKD, \$64 billion of which is for individuals who do not have kidney failure.

Astonishingly, 90 percent of individuals with CKD are unaware they have it. Many people are not diagnosed until they have reached ESRD and must begin dialysis immediately. The impact of CKD is further amplified as the disease burden is growing. A study published by researchers leading the CDC's CKD surveillance program shows that over half of U.S. adults age 30–64 are likely to develop CKD. Many with CKD also have cardiovascular disease, bone disease, and other chronic conditions, contributing to poor outcomes and increased health spending for this population. In fact, CKD is an independent risk predictor for heart attack and stroke.

Intervention at the earliest stage is vital to improving outcomes, lowering healthcare costs, and improving patient experience, yet nationally only 6 percent of patients with high blood pressure and 40 percent with diabetes are receiving necessary testing for CKD. To improve awareness, early identification, and optimal treatment for kidney disease, the National Kidney Foundation calls on the Committee to sustain or increase funding for several agencies that are contributing substantially to these improvements.

CDC NCCDPHP

NCCDPHP is at the forefront of our Nation's efforts to promote and control chronic diseases. To address the social and economic impact of kidney disease, in fiscal year 2006 NKF worked with Congress to launch the CKD Surveillance Project. This program has provided information to the public on the scope of CKD and has illuminated gaps in care as well as successful targeted efforts to reduce new cases of ESRD. The National Kidney Foundation is extremely appreciative of Congress's funding increase for the program in fiscal year 2018 and we encourage the Committee to sustain funding in fiscal year 2019. Also, key to improving public health is addressing the link between kidney disease and cardiovascular disease. The National Kidney Foundation has been pleased to collaborate with Million Hearts to improve assessment for CKD among those with hypertension. We urge Congress to continue funding to support Million Hearts in its goal to reduce heart attack and stroke by 1 million by 2022. While both efforts are helpful in moving forward improvements in earlier identification and treatment, we urge Congress to do more to address this largely silent public health problem by increasing funding for NCCDPHP to promote increased awareness of the important role kidneys have in overall health.

NIH NIDDK

NKF supports the Friends of NIDDK request of \$2.165 billion for fiscal year 2019. Despite Medicare spending of nearly \$100 billion for CKD, NIH funding for kidney

disease research is only about \$600 million annually. America's scientists are at the cusp of many potential breakthroughs in improving our understanding of CKD and providing new therapies to delay and treat various kidney diseases. With the unique status of ESRD in the Medicare program, CKD research has the potential to provide cost savings to the Federal Government like that of no other chronic disease. We urge Congress to again provide strong bipartisan support for NIH to continue building on the success of the previous commitments and fund NIDDK at this requested level.

HRSA BUREAU OF PRIMARY CARE

The HRSA Bureau of Primary Care supports a national network of more than 9,800 health clinics for 1 in 13 people in underserved communities who otherwise would have little or no access to care. Community Health Centers can serve as a first line of detection and care for people at risk and with CKD. NKF urges the Committee to increase funding for federally Qualified Community Health Centers to improve testing of CKD among those with diabetes and hypertension by including, in the Uniform Data System (UDS), laboratory values for estimated Glomerular Filtration Rate (eGFR) and urine albumin to creatinine ratio (ACR), which provide vital information on kidney function and the risk of progression and cardiovascular complications and CKD diagnosis. This would align with Healthy People 2020 objectives related to CKD detection and provide a critical data source for CKD surveillance.

HRSA DOT

The Division of Transplantation supports initiatives to increase the number of donor organs, including the National Donor Assistance Program which helps offset living organ donors' expenses that are not reimbursed by insurance or other programs. We appreciate the increase in fiscal year 2018 funding and urge Congress to continue this funding to ensure more ESRD patients have access to the therapy associated with the best outcomes.

The National Kidney Foundation is not asking the Government to bear the responsibility CKD on its own and we have undertaken initiatives to drive forward improvements in kidney care. Our CKDIntercept initiative aims to transform Primary Care Practitioners (PCP) detection and care of the growing numbers of Americans with CKD by deploying evidence based clinical guidelines into primary care settings through education programs, symposia and practical implementation tools. Through this initiative, we have collaborated with the American Society for Clinical Pathology (ASCP) and the Nation's leading commercial laboratories and clinical laboratory societies to help remove barriers to CKD testing. A component of this new collaboration is the recommendation of a new test profile for CKD assessment and diagnosis. The new "Kidney Profile" combines the blood and urine testes needed to calculate the eGFR, which assesses kidney function, and urine ACR, which assesses kidney damage. We also developed recommendations for a patient-focused alternative payment model that will foster collaboration among PCPs and nephrologists to slow progression of CKD and ease transitions for those that progress to ESRD. In support of this effort, NKF is advocating for Congress to enact legislation (H.R. 3867) that directs the Secretary of Health and Human Services to design a voluntary pilot program that ties payments to clinicians with improvements in the early detection of chronic kidney disease and the care these patients receive. The pilot will be practitioner-led and supported by a multidisciplinary healthcare team. In addition, it will provide primary care practitioners and nephrologists with the resources they need to better care for people with CKD, while also ensuring they are accountable for measurable improvements in care. Practitioners will be rewarded for identifying kidney disease early so that the progression of the disease can be slowed resulting in better, long-term patient outcomes, such as a reduction in the number of patients dying early, requiring dialysis or needing kidney transplantation.

To foster increased access to kidney transplantation, the National Kidney Foundation hosted the Organ Discard Conference in May 2017, which brought the transplant community, researchers, and government agencies together to address this phenomenon. At our 2018 Spring Clinicals Meeting this month, we announced the results of a study of transplanted kidneys that were previously deemed unfit for transplant. This first-ever study showed a graft survival rate for these kidneys exceeding 90 percent 1 year after transplant. We also have launched the Big Ask, Big Give, an educational program to help transplant recipients identify willing living kidney donors.

Thank you for your past support and your consideration of our requests for fiscal year 2019.

PREPARED STATEMENT OF THE NATIONAL LEAGUE FOR NURSING

As the oldest nursing organization in the United States, the NLN promotes excellence in nursing education to build a strong and diverse nursing workforce to advance the health of the Nation and the global community. The League represents more than 1,200 nursing schools, 40,000 members, and 25 regional constituent leagues. The NLN thanks the subcommittee for the increase in fiscal year 2018 funding for these vital programs at HRSA. The NLN urges the subcommittee to fund the Health Resources and Services Administration's (HRSA) Title VIII nursing workforce development programs at \$266 million in fiscal year 2019. Your ongoing support for these programs ensures a strong nursing workforce able to meet the health demands of an aging population as well as the current opioid epidemic.

NURSING EDUCATION AND WORKFORCE

The changing landscape of patient care, driven by greater consumer engagement, practice-driven technologies, and virtual healthcare, provides a unique context for teaching and learning. Teaching with and about emerging technology is the future of nursing education. Providing nursing care in a highly technological, connected work environment is the future of nursing practice (NLN 2015).

A high quality-nursing workforce equals high quality care for the Nation. With 4.8 million active, licensed vocational/practical nurses (LVNs/LPNs) and registered nurses (RNs), nurses are the primary professionals delivering quality healthcare in the Nation (NCSBN 2018). According to the Bureau of Labor Statistics (BLS), the RN workforce is projected to grow by 15 percent from 2016 to 2026. The BLS also estimates the LVN/LPN workforce will grow by 12 percent, the advanced practice registered nurses (APRNs) workforce will grow by 31 percent, and the need for nursing faculty will grow 24 percent during the same period (BLS 2017).

This increase is fueled by the opioid epidemic, demand for healthcare services for our aging population; for patients with various chronic conditions, such as arthritis, dementia, diabetes, and obesity; and for staffing facilities that provide long-term rehabilitation for stroke and head injury patients and those that treat people with Alzheimer's. In addition, because many older people prefer to be treated at home or in residential care facilities, nurses will be in demand in those settings.

DIVERSITY IN NURSING

Diversity and quality healthcare are inseparable. Diversity signifies that each individual is unique and recognizes individual differences—race, ethnicity, gender, sexual orientation and gender identity, socio-economic status, age, physical abilities, religious beliefs, political beliefs, or other attributes. It encourages self-awareness and respect for all persons, embracing and celebrating the richness of each individual. It also encompasses organizational, institutional, and system-wide behaviors in nursing, nursing education, and healthcare (NLN 2016).

There is a great need for diversity in the nurse workforce, student population, and faculty in order for nursing to achieve excellent care for all. Diversity in nursing is essential to a market-driven healthcare system that understands and addresses cultural challenges and social determinants of health in our rapidly changing population. Our Nation is enriched by cultural complexity—37 percent of our population identify as racial and ethnic minorities. Yet diversity eludes the nursing student and nurse educator populations. Minorities only constitute 27 percent of the student population and males only 14 percent of pre-licensure RN students (NLN 2016). Workforce diversity is especially needed where research indicates that factors such as societal biases and stereotyping, communication barriers, limited cultural sensitivity and competence, and system and organizational determinants contribute to healthcare inequities.

HRSA'S TITLE VIII NURSING WORKFORCE DEVELOPMENT PROGRAMS

For over 50 years, the Title VIII nursing workforce development programs have provided training for entry-level and advanced practice registered nurses (APRNs) to improve the access to, and quality of, healthcare in underserved communities. These programs provide students and schools of nursing with grants to strengthen education programs, including faculty recruitment and retention efforts, facility and equipment acquisition, clinical lab enhancements, loans, scholarships, and services that enable students to overcome obstacles to completing their nursing education programs. Many of the Title VIII grantees collaborate with health delivery sites in medically underserved communities, which is especially important as the opioid epidemic continues to ravage the country. Your ongoing support of HRSA's Title VIII nursing programs will help build the workforce needed to battle this epidemic.

Information from HRSA's Title VIII programs listed below provides a perspective on current Federal investments.

The *Advanced Nursing Education (ANE)* programs increase the number of qualified nurses in the primary care workforce by improving advanced nursing education through traineeships as well as curriculum and faculty development. The programs include a preference for supporting rural and underserved communities. In academic year 2016–2017, grantees of the ANE Program trained 5,942 nursing students and produced 1,541 graduates. ANE grantees partnered with 2,304 healthcare delivery sites to provide clinical and experiential training. Approximately 40 percent of sites used by ANE grantees were located in a medically underserved community, and 59 percent were primary care settings.

The *Nursing Workforce Diversity (NWD)* program increases nursing education opportunities for individuals from disadvantaged backgrounds, including racial and ethnic minorities who are underrepresented among registered nurses. The program supports disadvantaged students through student stipends and scholarships, and a variety of pre-entry preparation, advanced education preparation, and retention activities. In academic year 2016–2017, the NWD Program supported 57 college-level degree programs as well as 38 training programs and activities designed to recruit and retain health professions students. These programs trained 4,416 students including 2,637 students who graduated or completed their programs. NWD grantees partnered with 571 training sites during the academic year to provide 7,800 clinical training experiences to trainees across all programs. Approximately 49 percent of training sites were located in medically underserved communities and 37 percent were in primary care settings.

The *Nurse Education, Practice, Quality, and Retention Programs (NEPQR)* address national nursing needs and strengthen the capacity for basic nurse education and practice under three priority areas: Education, Practice and Retention. The NEPQR Programs support the development, distribution and retention of a diverse, culturally competent health workforce that can adapt to the population's changing healthcare needs and provide the highest quality of care for all. Woven throughout the programs is the aim to increase the number of Bachelor of Science in Nursing (BSN) students exposed to enhanced curriculum and with meaningful clinical experience and training in medically underserved and rural communities, who will then be more likely to choose to work in these settings upon graduation.

The *Nurse Faculty Loan Program (NFLP)* seeks to increase the number of qualified nurse faculty by awarding funds to schools of nursing who in turn provide student loans to graduate-level nursing students who are interested to serve as faculty. Upon graduation, student borrowers are eligible to receive partial loan cancellation (up to 85 percent of the loan principal and interest over 4 years) in exchange for serving as full-time faculty at an accredited school of nursing. In academic year 2016–2017, 84 schools received new NFLP grant awards and supported 1,998 nursing students pursuing graduate level degrees as nurse faculty. The majority of students (83 percent) who received loans during the academic year were pursuing doctoral-level nursing degrees (e.g., PhD, DNP, DNSc/DNS, or EdD). By the end of the academic year, 568 trainees graduated; 92 percent of whom intend to teach nursing.

The *NURSE Corps Scholarship and Loan Repayment Program (NURSE Corps)* helps to improve the distribution of nurses by supporting nurses and nursing students committed to working in communities with inadequate access to care. In exchange for scholarships or educational loan repayment, NURSE Corps members fulfill their service obligation by working in Critical Shortage Facilities (CSFs) located in health professional shortage areas and medically underserved communities around the Nation, which include rural communities and other identified geographic areas with populations that lack access to primary care services. In fiscal year 2018, the NURSE Corps loan repayment program made 671 loan repayment awards and 326 continuation awards. The NURSE Corps scholarship program made 203 new scholarship awards and 22 continuation awards during the same time period.

The NLN urges the subcommittee to fund the Title VIII nursing workforce development programs at \$266 million in fiscal year 2019.

[This statement was submitted by G. Rumay Alexander, EdD, RN, FAAN, President, and Beverly Malone, PhD, RN, FAAN, Chief Executive Officer, National League for Nursing.]

PREPARED STATEMENT OF THE NATIONAL MINORITY CONSORTIA

The National Minority Consortia (NMC) submits this statement on the fiscal year 2021 advance appropriations for the Corporation for Public Broadcasting (CPB). We represent a coalition of five national organizations, who, with modest support from

CPB, bring authentic and unique stories of diversity to all of America's communities via public broadcasting and other media, including content transmitted digitally over the Internet. Our requests are two: (1) That at least \$445 million be provided in advance fiscal year 2021 funding for CPB; and (2) that Congress direct CPB to meaningfully increase its commitment to diverse programming and serving underserved communities. We ask the Committee to:

—*Provide fiscal year 2021 advance appropriation for CPB of \$445 million*, to continue a service that provides 98 percent of Americans, including those in rural areas with free, unique local and national community resources that would otherwise not be available.

Public broadcasting upholds strong ethics of responsible journalism and thoughtful examination of American history, life and culture. In America today, where minorities comprise over 36 percent of the population, and where racial and ethnic minorities make up more than half of all children born in the United States today, it is particularly important that Congress support continued funding of CPB so that our public media system can continue to deliver well-researched and authentic stories about America's unique and rapidly diversifying populace.

From children's educational content to public safety awareness, America's public media broadcasting system is a necessary tool to ensure a well-educated, well-informed, and cultured civil society capable of meeting the responsibilities of self-government in the world's most important democracy.

—*Direct CPB to increase its efforts for diversity to meet the demands of a growing and diverse public*. We appreciate that the House Appropriations Committee last year included in its Report 115–224 the statement that “Programming that reflects the histories and perspectives of diverse racial and ethnic communities is a core value and responsibility of public broadcasting, therefore the Committee supports continued investment in the National Minority Consortia to help accomplish this goal.” We urge the Senate Committee to likewise in bill and/or report language to include language that recognizes the five members of the National Minority Consortia, and the need to rapidly increase and expand efforts across programming, content creation, and work-force, to meet the demands of an increasingly diverse public. We suggest language such as:

The Committee recognizes the importance of the partnership CPB has with the National Minority Consortia, which helps develop, acquire, and distribute diverse content to Public Media entities to serve underrepresented communities. These stories of diversity transcend statistics and bring universal American stories to all U.S. citizens. As populations of diverse ethnic backgrounds are increasing in cities and towns across the Nation, Public Media entities, TV and Radio stations and digital platforms must strive to meet this audience's needs. The Committee encourages CPB to support and expand this critical partnership, including instituting funding guidelines that encourage and reward public media that represent and reach a diverse American public.

The five NMC organizations combined receive only \$6.5 million in discretionary funds from CPB, an amount less than 2 percent of the CPB budget. A modest increase of 10 percent or \$7.5 million for the NMC will go a long way in supporting the continued development of diverse content and diverse media makers.

ABOUT THE NATIONAL MINORITY CONSORTIA

The NMC is made up of five separate and distinct organizations that address the need for programing that reflects American's growing ethnic and cultural diversity. By developing and funding diverse content, training and mentoring the next generation of minority media makers, as well as brokering relationships between content creators and content aggregators, the NMC helps to ensure the future strength and relevance of Public Media content from and to diverse communities.

Black Public Media (BPM) is committed to a fully realized expression of democracy by supporting diverse voices in public media. NBPC develops, produces, and funds media content about the African American and global black experience that is distributed across public media platforms. It has invested over \$12 million dollars in iconic documentary productions such as *Maya Angelou: And Still I Rise*; trained, mentored, and supported diverse producers through programs such as 360 Incubator; and is the Executive Producer of the public media series *AfroPoP: The Ultimate Cultural Exchange*, a showcase of independent documentaries about life, art and culture of African Americans and Africans of the diaspora.

The Center for Asian American Media (CAAM) is a nonprofit organization dedicated to presenting stories that convey the richness and diversity of Asian American experiences to the broadest audience possible. We do this by funding, producing, distributing and exhibiting works in film, television and digital media. Each year our

documentaries reach millions of viewers through our public television system. Since our founding in 1980 CAAM has awarded over \$5 million to independent film and video productions by and about Asian Americans, exposing audiences to new voices and communities, and advancing our collective understanding of the American experience.

Latino Public Broadcasting (LPB). Latino Public Broadcasting (LPB) is the leader in the development, production, acquisition and distribution of non-commercial educational and cultural media that is representative of Latino Americans. These programs are produced for dissemination to public broadcasting stations and other public telecommunication entities. Between 2009 and 2016, LPB programs won 85 awards, including the prestigious George Foster Peabody Award, two Emmys, two Imagen Awards and the Sundance Film Festival Award for Best Director, Documentary. In addition, LPB has been the recipient of the Norman Lear Legacy Award and the NCLR Alma Award for Special Achievement—Year in Documentaries.

Latino Public Broadcasting provides a voice to the diverse Latino community throughout the United States. Latinos have helped shape the Nation over the last 500-plus years and have become, with more than 50 million people, the largest minority group in the Nation.

Pacific Islanders in Communications (PIC). Since 1991, Pacific Islanders in Communications has pursued our mission of supporting, advancing, and developing Pacific Island media content and talent that results in a deeper understanding of Pacific Island history, culture and contemporary challenges. Pacific Islanders in Communications works with independent producers, specifically with Pacific Islander producers, by training, creating, and distributing programs with Pacific Islander content. Our overall goal is to bring authentic Pacific Islander stories to the world. We do this through funding support for productions, training and education, broadcast services and community engagement. In the next 3 years, we intended to reinforce our commitment to our communities, to preserve our relevance, and to build the organizational capacity we need to survive the forces of change.

Vision Maker Media (VMM) (formerly Native American Public Telecommunications) empowers and engages Native People to tell stories. They serve Native producers and Indian country in partnership with public television and radio by working with Native producers to develop, produce and distribute educational programs for all media including public television and radio. Vision Maker Media supports training to increase the number of American Indians and Alaska Natives producing quality public broadcasting programs. A key strategy for this work is the development of strong partnerships with tribal nations and Native communities. Reaching the general public and the global market is the ultimate goal for the dissemination of Native produced media that shares Native perspectives with the world.

PREPARED STATEMENT OF THE NATIONAL MULTIPLE SCLEROSIS SOCIETY

Mr. Chairman and Members of the Subcommittee, the National Multiple Sclerosis Society (Society) thanks you for this opportunity to provide testimony regarding funding of critically important Federal programs that impact those affected by multiple sclerosis (MS). We urge the Subcommittee to provide the following in fiscal year 2019:

- At least \$39.3 billion for the National Institute of Health (NIH), including funds provided to the agency through the 21st Century Cures Act (Public Law 114–255) for targeted initiative;
- \$8.445 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;
- \$150 million for the Patient Centered Outcomes Research Institute (PCORI);
- \$5 million for the Lifespan Respite Care Program;
- Robust support for Medicare and Medicaid and protection of Medicaid’s current financing structure; and
- An increase above fiscal year 2018’s funding level of \$12.9 billion for the Social Security Administration’s administrative budget
- \$454 million for the Agency for Healthcare Research and Quality (AHRQ)

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 addresses the challenges of each person affected by MS so that each person affected by MS can live their best life. We support all types of scientifically meritorious medical research that is conducted in accordance with Fed-

eral, State and local laws and with adherence to the strictest ethical and procedural guidelines that will help provide solutions for people affected by MS.

We believe that the President's fiscal year 2019 proposed budget would set back research and innovation and prevent people with MS from receiving the coverage and services they need to live their best lives. The Society urges the Committee to reject these proposed cuts and instead, adequately fund research and programs and health coverage and services important to people with MS.

NATIONAL INSTITUTES OF HEALTH

The NIH is the Nation's premiere biomedical research institution and directly supports jobs in all 50 States. More than 83 percent of the NIH's funding is awarded through almost 50,000 competitive grants to more than 325,000 researchers at over 3,000 universities, medical schools, and other research institutions in every State. We thank the Committee for its support of the NIH, which culminated in a \$3 billion dollar increase for the Agency in fiscal year 2018.

The NIH is a fundamental partner in the Society's mission to stop MS in its tracks, restore what has been lost, and end MS forever. Before 1993, there were no MS therapies or medications, now there are fifteen disease modifying therapies for relapsing MS, and the first therapy for progressive MS was recently approved by the Food and Drug Administration. Much work remains, and the NIH continues to provide the basic research necessary to facilitate the development of novel therapies. NIH scientists were among the first to report the value of MRI in detecting early signs of MS and have enhanced knowledge about how the immune system works and its role in the development of MS lesions. Initiatives such as Brain Research through Advancing Innovative Neurotechnologies® (BRAIN) and All of Us Research Program will improve our understanding of the anatomy and connectivity of the brain and ultimately aid researchers in the development of novel endpoints and biomarkers for all neurologic conditions, including MS.

The NIH is a fundamental partner in the Society's mission to stop MS in its tracks, restore what has been lost, and end MS forever. To date, the Society has invested \$1.082 billion to MS research to date, yet we rely on Congress to provide consistent and sustained investments to the Agency to cultivate an environment that is optimal for scientific discovery. NIH continues to provide the basic research necessary to facilitate the development of novel therapies. NIH spending on MS related research has decreased by more than \$10 million since fiscal year 2013, and that investment was projected to fall to approximately \$77 million in fiscal year 2018. People with MS rely on the NIH to fund the basic research that will lead to better treatments and a cure, and though much progress has been made, now is not the time to decrease much needed Federal investment in MS research. The Society urges Congress to provide at least \$39.3 billion for the NIH, including funds provided to the agency through the 21st Century Cures Act for targeted initiatives.

LIFESPAN RESPITE CARE PROGRAM

Up to one quarter of individuals living with MS require long-term care services at some point during the course of the disease. Often, a family member steps into the role of primary caregiver. According to a 2015 AARP report, about 40 million family caregivers provided care at some point during 2013 and the value of their uncompensated services was approximately \$470 billion per year. Family caregivers allow the person living with MS to remain home for as long as possible and avoid premature admission to costlier institutional facilities.

Family caregiving, while essential, can be draining and stressful. A 2012 National Alliance for Caregiving (NAC) survey of individuals providing care to people living with MS shows that on average, caregivers spend 24 hours a week providing care. Sixty 4 percent of caregivers were emotionally drained, 32 percent suffered from depression and 22 percent have lost a job due to caregiving responsibilities.

The Lifespan Respite Care Program, enacted in 2006 under President Bush, provides competitive grants to States to establish or enhance statewide lifespan respite programs that better coordinate and increase access to quality respite care. Respite offers professional short-term help to give caregivers a break from the stress of providing care and has been shown to provide family caregivers with the relief necessary to maintain their own health and bolster family stability. Perhaps the most critical aspect of the program for people living with MS is that Lifespan Respite serves families regardless of special need or age—literally across the lifespan. Much existing respite care has age eligibility requirements and since MS is typically diagnosed between the ages of 20 and 50, Lifespan Respite programs are often the only open door to needed respite services. For these reasons, the Society asks that Congress provide \$5 million for the Lifespan Respite Care Program in fiscal year 2019.

CENTERS FOR MEDICARE & MEDICAID SERVICES

Medicare: It is estimated that over 30 percent of the MS population relies on Medicare as its primary insurer. Many of these individuals are under the age of 65 and receive the Medicare benefit because of their disability. The Society supports ensuring appropriate reimbursement levels for Medicare providers; maintaining access to diagnostics and durable medical equipment including power and manual complex rehabilitation technology and related accessories; protecting access to needed speech, physical and occupational therapy services which will be aided by the recent repeal of the Medicare therapy cap; updating local coverage determinations to keep pace with advances in care; and affordable access to prescription drugs.

Medicaid: Medicaid provides comprehensive health coverage to over 10 million persons living with disabilities, plus six million persons with disabilities who rely on Medicaid to fill Medicare's gaps. The latest statistics show that about 5–10 percent of people with MS have Medicaid coverage. After years of paying to manage their disease, some people with MS have spent much of their earnings and savings, making their financial situation so dire that Medicaid becomes their only option for health coverage. People with MS also rely on Medicaid for access to long-term services and supports. The Society urges Congress to maintain funding for Medicaid and reject proposals to cap or block grant the program. Any of these proposals would merely shift costs to States, forcing States to shoulder a seemingly insurmountable financial burden or cut services on which our most vulnerable rely. The Society also urges Congress to protect and promote access to home- and community-based care in line with the 1999 U.S. Supreme Court decision *Olmstead*.

Social Security Administration (SSA).—Because of the unpredictable nature and sometimes serious impairment caused by the disease, SSA recognizes MS as a chronic illness or “impairment” that can cause disability severe enough to prevent an individual from working. During such periods, people living with MS are entitled to and rely on Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) benefits to survive. The National MS Society urges Congress to provide an increase above fiscal year 2018's funding level of \$12.9 billion for the Social Security Administration's administrative budget to ensure people with MS have timely access to benefits and the agency continues to make progress reducing the disability backlog.

Agency for Healthcare Research and Quality (AHRQ).—AHRQ is a small agency that is revolutionizing the healthcare system based on healthcare costs and quality. It provides evidence for healthcare providers to use to make healthcare safer, higher quality, more accessible, equitable, and affordable. In 2015, AHRQ produced the report, “Decisional Dilemmas in Discontinuing Prolonged Disease-Modifying treatment for Multiple Sclerosis” as a tool that captured the influence of patient values, beliefs and preferences of people affected by MS to support providers. Reports like these are vital in ensuring that the healthcare community has science and evidence-based information to aid in consultations on treatment decisions. The clinical evidence that AHRQ produces is a vital metric for the healthcare industry and government to utilize as the industry moves toward value-based care. While proposals have called for the Agency's elimination, the Society supports the work of AHRQ and recommends Congress provide \$454 million for the Agency in fiscal year 2019.

Patient-Centered Outcomes Research Institute.—The Patient-Centered Outcomes Research Institute (PCORI) serves a vital role in ensuring that the public and private healthcare sectors have valid and trustworthy data on health outcomes, clinical effectiveness, and appropriateness of different medical treatments by both conducting research and evaluating existing studies.

PCORI's 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. In 2016, PCORI approved over \$50 comparative effectiveness studies in MS. These studies will provide important evidence for the best ways to address symptoms like fatigue and the potential to use technology to deliver needed rehabilitation therapies to people in remote areas. We recommend that Congress reauthorize PCORI to continue its important mission, fully fund its work for fiscal year 2019, and ensure that it has reliable and sustainable funding to continue its work in the future.

CENTERS FOR DISEASE CONTROL AND PREVENTION

The CDC (Centers for Disease Control and Prevention) is tasked with protecting public health and safety through the control and prevention of disease, injury, and disability. Unfortunately, budgetary cuts and public health emergencies has limited its ability to collect data to track the incidence and prevalence of neurological diseases like MS. The 21st Century Cures Act authorized the creation of the National

Neurological Conditions Surveillance System (NNCSS) within the Agency, Congress has not yet funded the it. Having strong and reliable prevalence data is critical to protecting the public health and funding new and novel research to treat neurologic conditions. Congress must keep its commitments included in the 21st Century Cures act and fund the CDC at \$8.445 billion for fiscal year 2019—including \$5 million for the NNCSS.

The National MS Society thanks the Committee for the opportunity to provide written testimony on our recommendations for fiscal year 2019 LHHs appropriations. The agencies and programs we have outlined above are of vital importance to people living with MS. Please do not hesitate to contact the Society with any questions. 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, Senior Director, Federal Government Relations, National Multiple Sclerosis Society.]

PREPARED STATEMENT OF THE NATIONAL NETWORK TO END DOMESTIC VIOLENCE

Labor, Health and Human Services, Education, and Related Agencies Appropriations Subcommittee Chairman Blunt, Ranking Member Murray and distinguished members of the Appropriations Committee, thank you for this opportunity to submit testimony on the importance of investing in Family Violence Prevention and Services Act (FVPSA) and Violence Against Women Act (VAWA) programs. I sincerely thank the Committee for its ongoing support of these lifesaving programs.

I am the President and CEO of the National Network to End Domestic Violence (NNEDV), the Nation's leading voice for domestic violence survivors and their advocates. We represent the 56 State and territorial domestic violence coalitions, their nearly 2,000 member domestic violence and sexual assault programs, and the millions of victims they serve. Our direct connection with victims and victim service providers gives us a unique understanding of their needs and the vital importance of continued Federal investments. I am submitting this testimony to request a targeted investment of \$257.25 million in FVPSA, VAWA and related programs administered by the U.S. Department of Health and Human Services fiscal year 2019 Budget.

We appreciate the Committee's increased funding for FVPSA, including the increase to the dedicated tribal funding stream, and Rape Prevention Education (RPE), in the recently passed fiscal year 2018 Omnibus bill. These incremental increases help close gaps for survivors to access critical services.

Incidence, Prevalence, Severity and Consequences of Domestic and Sexual Violence.

The crimes of domestic and sexual violence are pervasive, insidious and life-threatening. Recently, the Centers for Disease Control and Prevention (CDC) released the first-ever National Intimate Partner and Sexual Violence Survey (NISVS) which found that domestic violence, sexual violence, and stalking are widespread. Domestic violence affects more than 12 million people each year and more than one in three women and one in four men have experienced rape, physical violence, or stalking in their lifetime. Survivors have detailed severe impacts of domestic violence such as fear, concern for their safety, need for medical care, injury, need for housing services, and missing work or school.

The terrifying conclusion of domestic violence is often murder, and every day in the United States, an average of three women are killed by a current or former intimate partner.¹ The cycle of intergenerational violence is perpetuated as children are exposed to violence. Unfortunately, 15.5 million children are exposed to domestic violence every year.² One study found that men exposed to physical abuse, sexual abuse and witnessing adult domestic violence as children were almost 4 times more likely than other men to have perpetrated domestic violence as adults.³

These statistics paint an ugly picture. In addition to the terrible cost domestic and sexual violence has on the lives of individual victims and their families, these crimes also come at a high cost for taxpayers and communities. The cost of intimate partner violence exceeds \$5.8 billion each year, \$4.1 billion of which is for direct

¹Bureau of Justice Statistics (2008). Homicide Trends in the U.S. from 1976–2005. U.S. Dept. of Justice.

²McDonald, R., et al. (2006). "Estimating the Number of American Children Living in Partner-Violence Families." *Journal of Family Psychology*, 30(1), 137–142.

³Whitfield, C.L., Anda, R.F., Dube, S.R., & Felitti, V.J. (2003). "Violent childhood experiences and the risk of intimate partner violence in adults." *Journal of Interpersonal Violence*, 18, 166–185.

healthcare services.⁴ Translating this into 2018 dollars, based on the Bureau of Labor Statistics Consumer Price Index, the annual cost to the Nation is over \$9 billion per year. Domestic violence costs U.S. employers an estimated \$3 to \$13 billion annually.⁵

Despite this grim reality, we know that when a coordinated response is developed and immediate, and essential services are available, victims can escape from violence and succeed at rebuilding their lives. FVPSA and VAWA programs are essential to their success. I urge you to increase their funding in the fiscal year 2019 Labor, Health and Human Services Appropriations bill.

Family Violence Prevention and Services Act (FVPSA) (Administration for Children and Families)—\$175 million request.

Since its passage in 1984, as the first national legislation to address domestic violence, FVPSA remains as the only Federal funding solely for shelter programs. FVPSA has made substantial progress toward ending domestic violence, yet an unconscionable need remains for FVPSA-funded victim services. FVPSA is the cornerstone of our Nation's efforts to address domestic violence. There are more than 2,000 community-based domestic violence programs for victims and their children (approximately 1,500 of which are FVPSA-funded through State formula grants). These programs offer services such as emergency shelter, counseling, legal assistance, and preventative education to millions of adults and children annually and are at the heart of our Nation's response to domestic violence.

A multi-State study, funded by the National Institute of Justice, shows conclusively that the Nation's domestic violence shelters address both the urgent safety needs and long-term security needs of victims and are helping victims protect themselves and their children. This same study found that, if shelters did not exist, the consequences for victims would be dire, including "homelessness, serious losses including [loss of] children [or] continued abuse or death."⁶ Additionally, non-residential domestic violence services are essential to addressing victims' needs. Such programs provide a wide variety of services to victims including counseling, child care, financial support, and safety planning. Without the counseling services she received from her local domestic violence program, one victim said, "I would not be alive, I'm 100 percent certain about that."⁷

The Increased Need for Funding: to Maintain Programs and Bridge the Gap.

Many programs across the country use their FVPSA funding to keep the lights on and their doors open. We cannot overstate how important this funding is: victims must have a place to flee to when they are escaping life-threatening violence. As increased training for law enforcement, prosecutors and court officials has greatly improved the criminal justice system's response to victims of domestic violence, there is a corresponding increase in demand for emergency shelter, hotlines and supportive services. Additionally, several high-profile cases, national focus on domestic and sexual violence, and the #MeToo movement have given survivors the courage to come forward and hold their abusers accountable. As a result, shelters overwhelmingly report that they cannot fulfill the growing need for these services.

Each year the National Network to End Domestic Violence releases a report entitled Domestic Violence Counts: A 24-hr National Census of Domestic Violence Services (Census). The report revealed that in just one day in 2017, while more than 72,245 victims of domestic violence received services, and 11,441 requests for services went unmet, due to lack of funding and resources. Of those unmet requests, 65 percent were for safe housing. In 2017, domestic violence programs reported that they had laid off 1,077 staff positions in addition to reducing or eliminating services in the past year, including prevention services, therapy, and child welfare advocacy. I strongly encourage you to read NNEDV's DV Counts Census (www.nnedv.org/census) to learn more about the desperate needs of victims State-by-State and nationally.

⁴National Center for Injury Prevention and Control. Costs of Intimate Partner Violence Against Women in the United States. Atlanta (GA): Centers for Disease Control and Prevention; 2003.

⁵Bureau of National Affairs Special Rep. No. 32, Violence and Stress: The Work/Family Connection 2 (1990); Joan Zorza, Women Battering: High Costs and the State of the Law, Clearinghouse Rev., Vol. 28, No. 4, 383, 385.

⁶Lyon, E. & Lane, S. (2009). Meeting survivors' needs: A multi-State study of domestic violence shelter experiences. Harrisburg, PA: National Resources Center on Domestic Violence.

⁷Lyon, Eleanor, Bradshaw, Jill, Menard, Anne. Meeting Survivors' Needs through Non-Residential Services & Supports: Results of a Multi-State Study. Harrisburg, PA: National Resource Center on Domestic Violence. November, 2011.

Domestic violence programs funded by FVPSA provided shelter and nonresidential services to more than 1.3 million victims over a year. Due to lack of capacity, however, an additional 196,467 requests for shelter went unmet. For those individuals who are not able to find safety, the consequences can be extremely dire, including continued exposure to life-threatening violence or homelessness. It is absolutely unconscionable that victims cannot find safety for themselves and their children due to a lack of adequate investment in these services. In order to help meet the immediate needs of victims in danger and to prevent and end domestic violence, I urge you to increase FVPSA funding to its authorized level of \$175 million.

ADDITIONAL REQUESTS

DELTA (CDC)—\$6 Million Funding Request

The Domestic Violence Prevention Enhancements and Leadership Through Alliances (DELTA) program at the Centers for Disease Control (CDC) is the only dedicated Federal funding source for the primary prevention of domestic violence. In approximately 50 communities across the Nation, the DELTA program works to identify effective strategies for preventing first-time perpetration and first-time victimization of domestic violence. Through the use of evidence-supported initiatives, including social change and public health strategies, DELTA states have piloted and evaluated a range of programs, designed to promote safety and respect across communities. The growing evidence base shows that such strategies have the potential to reduce multiple forms of violence. Over the history of the program, only 16 States have been able to participate as DELTA projects. Preliminary evaluation results show a growing body of evidence that supports this work, indicating that domestic violence and dating violence rates can be decreased over time with the implementation of DELTA programming. The work being done with multi-level strategies (individual, relationship, community and societal strategies) focuses on changing social norms and promoting behaviors that support healthy relationships. An increase in funding will enable the DELTA program to expand to additional States and communities, and will also provide the opportunities for communities to leverage additional funding. I urge you to fund DELTA at its \$6 million authorization level.

- Rape Prevention and Education (RPE) (Centers for Disease Control and Injury Prevention)—\$50 million;
- National Domestic Violence Hotline (Administration for Children and Families)—\$9.25 million;
- Preventative Health and Health Services Block Grant, Rape Set-Aside—\$7 million; and
- Violence against Women Health Initiative, (Office On Women’s Health)—\$10 million.

Thank you again, for your dedicated support of these programs and for considering our request.

[This statement was submitted by Kim Gandy, President and CEO, National Network to End Domestic Violence.]

PREPARED STATEMENT OF THE NATIONAL NURSE-LED CARE CONSORTIUM

On behalf of the National Nurse-Led Care Consortium (NNCC), I would like to thank the members of the Subcommittee for the opportunity to submit testimony regarding the importance of fully funding nursing workforce programs and how these programs impact nurses working in nurse-led models of care. Specifically, NNCC requests that \$266 million be appropriated for the Nursing Workforce Development Programs (authorized under Title VIII of the Public Health Service Act [42 U.S.C. 296 et seq.]), and \$170 million be appropriated for the National Institute of Nursing Research (NINR).

NNCC is a 501(c)(3) nonprofit public health organization that seeks to advance all forms of nurse-led care through policy development, technical assistance, and innovative programing. Because of their education and community connections, advanced practice nurses are able to deliver high quality and cost-effective services to our most vulnerable populations. The health centers and practices NNCC represents are primarily run by nurse practitioners. Nurse practitioners and other advanced practice nurses offer patient-centered care that is sensitive to patient needs and concerns. They work in all types of healthcare settings and specialties, such as retail health and acute care, but their services primarily revolve around primary care. NNCC assists these nurses by advocating for policy reforms that increase access to nurse-led care, designing community-based programs that address public health

needs and offering expert technical assistance that enhances the sustainability of innovative nurse-led practice models.

As part of its mission, NNCC represents nonprofit, nurse-managed health clinics (sometimes called nurse-managed health centers or NMHCs). Section 254c-1a of the Public Health Service Act defines the term ‘nurse-managed health clinic’ as a “nurse-practice arrangement, managed by advanced practice nurses, that provides primary care or wellness services to underserved or vulnerable populations and that is associated with a school, college, university or department of nursing, federally qualified health center (FQHC), or independent nonprofit health or social services agency.”¹ Recent estimates indicate that there are approximately 500 nurse-managed clinics nationwide, including birthing centers and school-based clinics. There are also approximately 2,500 nurse-led retail clinics based in pharmacies, grocery stores and other retail outlets around the country. Nurse-led models of care offer a full range of health services, including health promotion and disease prevention, to low-income, underinsured, and uninsured clients.

Because many nurse-led models of care are affiliated with schools of nursing, these clinics also help to build the capacity of the community-based healthcare workforce by acting as teaching and practice sites for nursing students and other health professionals. Each clinic associated with a nursing institution provides clinical placements for an average of 50 to 60 students a year.² These students include graduate and undergraduate nursing students, as well as medical, physician assistant, and social work students, among others.³ Students participating in post-clinical focus groups express a high level of satisfaction with NMHC-based clinical placements, commenting that their experience in NMHCs highlighted the need to reduce healthcare disparities and respect patient diversity. A large percentage of the Federal funding for academically-affiliated NMHCs comes from the Title VIII Nurse Education, Practice, Quality, and Retention (NEPQR) program. Granting the requested appropriation will help ensure NMHCs and others forms of nurse-led care can continue taking advantage of the NEPQR program. Nurse-led clinical placements are particularly important to nursing education, because they offer nursing students hands-on experience working in underserved communities. These clinical placement sites also provide students with the opportunity to form relationships with nurse mentors working in leadership roles that can help build important business development and practice management skills often underemphasized in traditional nursing school curriculums.

One good example of the benefit of Title VIII funding to nurse-led clinics comes from the Vanderbilt University School of Nursing, which received a \$999,101 grant from the NEPQR program in 2017. The 2-year grant gives the Clinic at Mercury Courts, a nurse-managed primary care clinic located in one of Nashville’s most economically depressed areas, the resources to add a psychiatric mental health nurse practitioner, social worker, and psychiatrist to its existing primary care team. The rate of substance abuse and mood disorders experienced by the community served by this clinic is more than four times the national average. The additional providers enable the clinic to comprehensively screen and treat both medical and behavioral health conditions, while addressing some of the problems associated with the deepening opioid crisis. In addition to its clinical services, the Mercury Courts clinic strengthens nursing education by offering clinical placements to nursing, medical, pharmacy, social work, and physician assistant students from a variety of disciplines and schools, including Lipscomb University, Tennessee State University, Trevecca Nazarene University, University of Tennessee, and Vanderbilt’s College of Arts and Science, Owen Graduate School of Management, Peabody College and Schools of Nursing, Divinity, Law and Medicine.

Title VIII funding is crucial to the success of the Mercury Court clinic, as well as hundreds of others like it across the nation. For this reason, NNCC again requests that the Subcommittee appropriate \$266 million to support Title VIII programs.

With regard to the National Institute of Nursing Research, NNCC believes that fully funding nursing research is vital to the recruitment and retention of qualified nursing faculty. According to the American Association of Colleges of Nursing’s report on 2016–2017 Enrollment and Graduations in Baccalaureate and Graduate Programs in Nursing, U.S. nursing schools turned away 64,067 qualified applicants from baccalaureate and graduate nursing programs in 2016 due to an insufficient number of faculty, clinical sites, classroom space, clinical preceptors, and budget

¹ Section 5208 of the Affordable Care Act.

² NNCC membership survey.

³ NNCC membership survey.

constraints.⁴ Appropriating \$170 million to the National Institute of Nursing Research will ensure that there are adequate research opportunities available to attract and retain experienced nursing faculty, while also improving nursing practice and patient outcomes. These enhanced research opportunities, in conjunction with the increase in clinical placement sites created by nurse-led practices funded through the requested Title VIII appropriation, constitute a two-pronged strategy for alleviating the nursing faculty shortage.

NNCC once again thanks the members of the Subcommittee for the opportunity to submit this testimony. If there any questions, please do hesitate to contact me at cfattibene@nncc.us.

Sincerely.

[This statement was submitted by Cheryl Fattibene, MSN, MPH, CRNP, Chief Nurse Practitioner, National Nurse-Led Care Consortium.]

PREPARED STATEMENT OF THE NATIONAL PSORIASIS FOUNDATION

On behalf of the more than 8 million Americans living with psoriasis and psoriatic arthritis, the National Psoriasis Foundation (NPF) requests that the committee include \$1 million in funding, along with corresponding report language, for the Centers for Disease Control and Prevention (CDC) in the fiscal year 2019 Labor, Health and Human Services, and Education, and Related Agencies Appropriations Act. Specifically, this funding would be used to establish a grant-based network of researchers to explore the connection between psoriasis, psoriatic arthritis, and other comorbid conditions, such as cardiovascular disease, obesity and mental health.

As the patient advocacy organization for the psoriatic disease community for over 50 years, the NPF understands the needs of individuals with psoriasis, a systemic, immune-mediated disease that affects approximately 3 percent of the adult U.S. population.¹ Individuals living with psoriasis experience periods of intense pain, fatigue, unbearable itching, whole-body inflammation, along with flaking and bleeding of large swaths of skin. While these symptoms can be managed with a range of treatments, there is no cure. Up to 30 percent of individuals with psoriasis will also develop psoriatic arthritis, an inflammatory form of arthritis that can lead to irreversible joint damage if left untreated.² A recent study estimates that psoriasis costs the Nation as much as \$135 billion per year in direct and indirect costs (in 2013 dollars).³

As chronic, immune-mediated, inflammatory diseases, psoriasis and psoriatic arthritis affect more than the skin and joints. Individuals living with psoriatic disease face a higher incidence of comorbid conditions, including cardiovascular disease,⁴ di-

⁴American Association of Colleges of Nursing, Nursing Faculty Shortage Information Sheet, Available here: <http://www.aacnnursing.org/News-Information/Fact-Sheets/Nursing-Faculty-Shortage>.

¹Helmick CG, Lee-Han H, Hirsch SC, Baird TL, Bartlett CL. Prevalence of Psoriasis Among Adults in the U.S: 2003–2006 and 2009–2010 National Health and Nutrition Examination Surveys. *American journal of preventive medicine*. 2014;47(1):37–45. doi:10.1016/j.ampere.2014.02.012.

²Goldman DD, Antoni C, Mease P, et al. Psoriatic arthritis: epidemiology, clinical features, course, and outcome. *Ann Rheum Dis*. 2005;64(suppl 2):ii14–ii17.—See more at: <http://www.rheumatologynetwork.com/psoriatic-arthritis/classification-criteria-psoriatic-arthritis-caspar#sthash.Or6zBLgM.dpuf>.

³Brezinski, E.A., Dhillon, J.S., and Armstrong, A.W. Economic burden of psoriasis in the United States: a systematic review. *JAMA Dermatol*. 2015; 151: 651–658.

⁴Neimann AL, Shin DB, Wang X, Margolis DJ, Troxel AB, Gelfand JM. Prevalence of cardiovascular risk factors in patients with psoriasis. *Journal of the American Academy of Dermatology*. 2006; 55(5):829–35. And: Prodanovich S, Kirsner RS, Kravetz JD, Ma F, Martinez L, Federman DG. Association of psoriasis with coronary artery, cerebrovascular, and peripheral vascular diseases and mortality. *Archives of Dermatology*. 2009 Jun; 145(6):700–3.

abetes,⁵ hypertension,⁶ and stroke.⁷ A recent study also found that the risk for cardiovascular disease may increase with the severity of psoriatic disease.⁸ Compared to the general population, the psoriasis community also has a higher prevalence of atherosclerosis,⁹ Crohn's disease,¹⁰ cancer,¹¹ metabolic syndrome,¹² obesity¹³ and liver disease.¹⁴ In addition, individuals with psoriatic disease are 39 percent and 31 percent more likely to be diagnosed with depression and anxiety, respectively.¹⁵ Of the estimated annual cost of psoriasis, \$36.4 billion is spent on healthcare costs of comorbid conditions, making their identification and treatment a high priority both to improve patient health and reduce the economic burden of disease.¹⁶ However, while the link between psoriatic disease and comorbid conditions has been observed, the underlying, biological connection is not fully understood.

The requested funding would allow the CDC to build on its previous work with psoriatic disease to better understand the connection between psoriasis, psoriatic arthritis, and other chronic conditions. As you are aware, \$1.5 million was appropriated in fiscal year 2010 for the CDC to develop a public health agenda on psoriatic disease. In developing the public health agenda, the CDC met with experts and reviewed existing peer-reviewed public health literature to summarize current knowledge and identify needs and gaps.¹⁷ The report identified the need for further research on the relationship between psoriatic disease and comorbid conditions along with a gap in knowledge about the relationship between the prevalence of comorbid conditions within mild, moderate, and severe psoriatic disease.

Following this report, the CDC authored a professional judgment document in 2015 that identified two high-priority research areas, including the need to research the relationship between psoriatic disease and other chronic conditions. In the professional judgment, the CDC stated that \$1 million is required to support the estab-

⁵Armstrong AW, Harskamp CT, Armstrong EJ. Psoriasis and the risk of diabetes mellitus: a systematic review and meta-analysis. *JAMA Dermatology*. 2013 Jan; 149(1): 84–91. And: Neimann AL, Shin DB, Wang X, Margolis DJ, Troxel AB, Gelfand JM. Prevalence of cardiovascular risk factors in patients with psoriasis. *Journal of the American Academy of Dermatology*. 2006; 55(5):829–35.

⁶Robinson D Jr., Hackett M, Wong J, Kimball AB, Cohen R, Bala M; the IMID Study Group. Co-occurrence and comorbidities in patients with immune-mediated inflammatory disorders: an exploration using US healthcare claims data, 2001–2002. *Current medical research and opinion*. 2006; 22(5):989–1000. And: Armstrong AW, Harskamp CT, Armstrong EJ. The association between psoriasis and hypertension: a systematic review and meta-analysis of observational studies. *Journal of Hypertension*. 2012 Dec 15. [Epub ahead of print].

⁷Gelfand JM, Dommasch ED, Shin DB, Azfar RS, Kurd SK, Wang X, Troxel AB. The Risk of Stroke in Patients with Psoriasis. *Journal of Investigative Dermatology*. 2009; 129, 2411–2418.

⁸Naik HB, Natarajan B, Stansky E, Ahlman MA, Teague H, Salahuddin T, Ng Q, Joshi AA, Krishnamoorthy P, Dave J, Rose SM, Doveikis J, Playford MP, Prussick RB, Ehrlich A, Kaplan MJ, Lockshin BN, Gelfand JM, Mehta NN. Severity of Psoriasis Associates With Aortic Vascular Inflammation Detected by FDG PET/CT and Neutrophil Activation in a Prospective Observational Study. *Arterioscler Thromb Vasc Biol*. 2015 Dec;35(12):2667–76. doi: 10.1161/ATVBAHA.115.306460. Epub 2015 Oct 8.

⁹Prodanovich S, Kirsner RS, Kravetz JD, Ma F, Martinez L, Federman DG. Association of psoriasis with coronary artery, cerebrovascular, and peripheral vascular diseases and mortality. *Archives of Dermatology*. 2009 Jun; 145(6):700–3.

¹⁰Najarian DJ, Gottlieb AB. Connections between psoriasis and Crohn's disease. *Journal of the American Academy of Dermatology* 2003; 48:805–21.

¹¹Gelfand JM, Shin DB, Neimann AL, Wang X, Margolis DJ, Troxel AB. The risk of lymphoma in patients with psoriasis. *Journal of Investigative Dermatology*. 2006 Oct; 126(10):2194–201.

¹²Azfar RS, Gelfand JM. Psoriasis and metabolic disease: epidemiology and pathophysiology. *Current Opinion in Rheumatology*. 2008; 20(4):416–22. And: Armstrong AW, Harskamp CT, Armstrong EJ. Psoriasis and metabolic syndrome: A systematic review and meta-analysis of observational studies. *Journal of the American Academy of Dermatology*. 2013 Apr; 68(4):654–62.

¹³Ogden CL, Fryar CD, Carroll MD, Flegal KM. Mean body weight, height and body mass index, United States 1960–2002. *Advance Data* 2004; 347:1–17.

¹⁴Robinson D Jr., Hackett M, Wong J, Kimball AB, Cohen R, Bala M; the IMID Study Group. Co-occurrence and comorbidities in patients with immune-mediated inflammatory disorders: an exploration using US healthcare claims data, 2001–2002. *Current medical research and opinion*. 2006; 22(5):989–1000.

¹⁵Kurd, S. K., Troxel, A. B., Crits-Christoph, P., & Gelfand, J. M. (2010). The risk of depression, anxiety and suicidality in patients with psoriasis: A population-based cohort study. *Archives of Dermatology*, 146(8), 891–895. <http://doi.org/10.1001/archdermatol.2010.186>.

¹⁶Brezinski, E.A., Dhillon, J.S., and Armstrong, A.W. Economic burden of psoriasis in the United States: a systematic review. *JAMA Dermatol*. 2015; 151: 651–658.

¹⁷Centers for Disease Control and Prevention: National Center for Chronic Disease Prevention and Health Promotion. Developing and Addressing the Public Health Agenda for Psoriasis and Psoriatic Arthritis. 2010. <https://www.cdc.gov/psoriasis/pdf/Public-Health-Agenda-for-Psoriasis.pdf>.

ishment of a grant-based research network that would explore the complex relationships between these conditions. With a research network in place, this gap in knowledge could be filled with a deeper understanding of psoriatic disease and other chronic conditions, ultimately leading to new prevention and treatment strategies, which could contribute to improved quality of life and lower healthcare costs for patients.

In fiscal year 2018, Congress included language in the reports accompanying the House and Senate Labor, Health and Human Services, and Education, and Related Agencies Appropriations bills directing the CDC to develop an action plan for how it could leverage funding from existing programs to carry out this research. Unfortunately, the CDC has confirmed, both in its fiscal year 2019 congressional budget justification and in discussions with the NPF, that it is unable to use funds for existing programs to carry out research on the comorbid conditions of psoriatic disease or any of the other research priorities identified in the public health agenda. As noted in the CDC's budget justification, "CDC has not received funding for Psoriasis and Psoriatic Arthritis since 2010, and does not currently have specific programming activities addressing these conditions."

The outcomes of this research would have far reaching benefits both for the psoriatic disease community and for patients and researchers in other disease spaces. For the psoriatic disease community, this research could lead to targeted public health interventions for better disease management and earlier identification of comorbid conditions. Importantly, the benefits of this research will extend beyond the psoriatic disease community. Scientists and clinicians conducting research on related conditions, such as cardiovascular disease, obesity, and mental health, would gain a better understanding of the underlying causes of these diseases, potentially leading to better treatments or cures. This network of researchers would also foster a collaborative environment that would bridge scientific disciplines and provide opportunities for partnership across research programs. Furthermore, the CDC would have an opportunity to leverage funding in other programs such as Arthritis, Cardiovascular Health, and Mental Illness for improved fiscal stewardship of appropriated funds and more collaborative research funded by the agency.

To guide the use of these funds, we request that you include the following report language under the Chronic Disease Prevention and Health Promotion subheading within the CDC section of the report.

Psoriasis and Psoriatic Arthritis.—The Committee recognizes the growing body of evidence linking psoriatic disease, which impacts more than eight million Americans, to other comorbidities such as cardiovascular disease, mental health and substance abuse challenges, kidney disease, and other conditions. The Committee commends the CDC for identifying opportunities for expanded research on psoriatic disease in its Public Health Agenda for Psoriasis and Psoriatic Arthritis and directs CDC to increase funding for intramural and grant-based research on the comorbidities of psoriatic disease, including research that can be done in collaboration with or funded by other disease programs such as Arthritis, Cardiovascular Health, or Mental Illness.

Thank you for your attention to our comments and consideration of our request. We look forward to working with you to fund research that expands our knowledge of psoriatic disease and comorbid conditions to ultimately improve the lives of the over 8 million Americans living with psoriasis and psoriatic arthritis, as well as the many more who live with other chronic conditions. If you or your colleagues have any questions, please feel free to contact the NPF by reaching out to Patrick Stone, Vice President of Government Relations and Advocacy at pstone@psoriasis.org.

[This statement was submitted by Patrick Stone, Vice President, Government Relations and Advocacy.]

PREPARED STATEMENT OF THE NATIONAL PTA AND PACER CENTER

National PTA and the PACER Center would like to thank the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies (L–HHS–ED) for soliciting the views and recommendations of public witnesses on fiscal year 2019 funding. National PTA and the PACER Center, two of the nation's leading family engagement organizations, respectfully request that the Senate L–HHS–ED Appropriations Subcommittee include \$10 million for the Statewide Family Engagement Centers (SFECs) grant program in fiscal year 2019 funding legislation. National PTA is the oldest and largest volunteer child advocacy association in the United States with 4 million PTA members working to make every child's potential a reality by engaging and empowering families and communities to advocate for all children. Since 1977, PACER Center, a nationwide parent engage-

ment center, has enhanced the quality of life and expanded opportunities for children, youth and young adults by ensuring that families have the tools to help their children succeed in school and life.

Our organizations request \$10 million in funding for the fiscal year 2019 U.S. Department of Education's SFECs grant program. This fiscal year 2019 investment comes after you and your Senate counterparts saw fit to provide \$10 million for this program in the L-HHS-ED portion of the fiscal year 2018 Omnibus Appropriations bill. We very much appreciate the Subcommittee's leadership in making this 2018 investment and urge continued funding for this program in fiscal year 2019.

Our organizations support high-quality public education that ensures families are engaged in their child's education. More than 40 years of research shows—regardless of a family's income or socioeconomic background—students with engaged families attend school more regularly, earn better grades, enroll in advanced-level programs and have higher graduation rates.¹ Additionally, teachers are more likely to remain in schools where families are involved and where they develop trusting relationships.² Both the inclusion of SFECs in the Every Student Succeeds Act (ESSA) and the \$10 million appropriation in fiscal year 2018 funding is evidence of Congress' recognition of the importance of parent and family engagement.

An fiscal year 2019 \$10 million investment in the SFECs grant program will further build capacity for States and school districts to systematically embed family engagement policies and practices in their education plans. The program will provide much needed professional development for educators and school leaders to strengthen school-family partnerships and parent-teacher relationships. This additional investment will also provide direct services to families to give them the tools to effectively work with their child's school to improve their child's academic outcomes and overall well-being.

With ESSA implementation well underway, especially at the school district and school level, school leaders and parents need the resources that SFECs can provide to engage parents as stakeholders and effectively implement ESSA as Congress intended. Therefore, National PTA and PACER Center urge the L-HHS-ED Subcommittee to include \$10 million for the Statewide Family Engagement Centers program in the fiscal year 2019 L-HHS-ED appropriations bill.

We appreciate your consideration of this request and are happy to follow up on any questions you may have.

[This statement was submitted by Nathan R. Monell, CAE, Executive Director, National PTA and Paula F. Goldberg, Executive Director, PACER Center.]

PREPARED STATEMENT OF THE NATIONAL RESPITE COALITION

Mr. Chairman, I am Jill Kagan, Chair, National Respite Coalition (NRC), which is a network of State respite coalitions, respite providers, family caregivers, and national, State and local organizations that support respite. We are requesting that the Subcommittee include \$5.0 million for the Lifespan Respite Care Program administered by the Administration for Community Living, Department of Health and Human Services, in the fiscal year 2019 Labor, HHS, and Education Appropriations bill. This modest increase will enable:

- State replication of Lifespan Respite best practices to allow family caregivers, regardless of the care recipient's age or disability, to have access to affordable respite.
- Improvement in respite quality and expansion of respite capacity; and
- Greater consumer direction by providing family caregivers with training and information on how to find, use and pay for both formal and informal respite services.

Respite Care Saves Money and is it Helpful to the People it Serves

Compelling budgetary benefits accrue because of respite. Delaying a nursing home placement for individuals with Alzheimer's or avoiding hospitalization for children with autism can save Medicaid billions of dollars. Researchers at the University of Pennsylvania studied the records of 28,000 children with autism enrolled in Med-

¹Henderson, A. T., & Mapp, K. L. (2002). A New Wave of Evidence: The Impact of School, Family, and Community Connections on Student Achievement. Annual Synthesis 2002. National Center for Family and Community Connections with Schools. Retrieved from <https://www.sedl.org/connections/resources/evidence.pdf>.

²Allensworth, E, S. Ponisciak, and C. Mazzeo. (2009). The Schools Teachers Leave: Teacher Mobility in Chicago Public Schools. Chicago, IL: Consortium on Chicago School Research at the University of Chicago Urban Education Institute. Retrieved from https://consortium.uchicago.edu/sites/default/files/publications/CCSR_Teacher_Mobility.pdf.

icaid in 2004. They concluded that for every \$1,000 States spent on respite, there was an 8 percent drop in the odds of hospitalization (Mandell, et al., 2012). A US Department of Health and Human Services report found that reducing key stresses on caregivers through services such as respite would reduce nursing home entry (Spillman and Long, USDHHS, 2007). Respite may reduce administrative burdens, help delay or avoid facility-based placements, improve maternal employment (Caldwell, 2007), strengthen marriages (Harper, 2013), and significantly reduce caregiver stress levels linked to improved caregiver health (Zarit, et al., 2014). In a survey of caregivers of individuals with Multiple Sclerosis, two-thirds said that respite would help keep their loved one at home. When the care recipient with MS also has cognitive impairment, the percentage of those saying respite would be helpful to avoid or delay nursing home placement jumps to 75 percent (NAC, 2012).

With at least two-thirds (66 percent) of family caregivers in the workforce (Matos, 2015), U.S. businesses lose from \$17.1 to \$33.6 billion per year in lost productivity of family caregivers who are often overwhelmed by caregiving responsibilities (MetLife Mature Market Institute, 2006). Higher absenteeism among working caregivers costs the U.S. economy an estimated \$25.2 billion annually (Witters, 2011). Respite for working family caregivers could improve job performance, saving employers billions.

Who Needs Respite?

More than 43 million adults in the U.S. are family caregivers of an adult or a child with a disability or chronic condition (National Alliance for Caregiving (NAC) and AARP Public Policy Institute, 2015). The estimated economic value of family caregiving of adults alone is approximately \$470 billion annually (Reinhard, et al., 2015). Eighty percent of those needing long-term services and supports (LTSS) are living at home. Two out of three (66 percent) older people with disabilities who receive LTSS at home get all their care exclusively from family caregivers (Congressional Budget Office, 2013).

Immediate concerns about how to provide care for a growing aging population are paramount. However, caregiving is a lifespan issue with the majority of family caregivers caring for someone between the ages of 18 and 75 (53 percent) (NAC and AARP Public Policy Institute, 2015). The most recent National Survey of Children's Health found that 14.6 million children under age 18 have special healthcare needs (National Survey of Children's Health, 2016).

National, State and local surveys have shown respite to be the most frequently requested service by family caregivers (Maryland Caregivers Support Coordinating Council, 2015; The Arc, 2011; National Family Caregivers Association, 2011). Yet, 85 percent of family caregivers of adults are not receiving respite services at all (NAC and AARP Public Policy Institute, 2015). Nearly half of family caregivers of adults (44 percent) identified in the National Study of Caregiving were providing substantial help with healthcare tasks. Of this group, despite their high level of care, fewer than 17 percent used respite (Wolff, et al., 2016). A 2014 Rand Corporation report prepared for the Elizabeth Dole Foundation, *Hidden Heroes: America's Military Caregivers*, recommended that respite care should be more widely available to military caregivers (Ramchand, et al., 2014). The Dole Foundation's Respite Impact Council found that traditional respite services do not address the needs of military caregivers and the Lifespan Respite Care program should be fully funded to help meet those needs.

Respite Barriers and the Effect on Family Caregivers

While most families want to care for family members at home, and many family caregivers rate their caregiving experiences as positive, research shows that family caregivers are at risk for emotional, mental, and physical health problems (Population Reference Bureau, 2016; American Psychological Association, 2012; Spillman, J., et al., 2014). When caregivers lack effective coping styles or are depressed, care recipients may be at risk for falling, developing preventable secondary health conditions or limitations in functional abilities. The risk of care recipient abuse increases when caregivers are depressed or in poor health (American Psychological Association, nd). Parents of children with special healthcare needs report poorer general health, more physical health problems, worse sleep, and increased depressive symptoms compared to parents of typically developing children (McBean, A, et al., 2013).

Respite, that has been shown to ease family caregiver stress, is too often out of reach or completely unavailable. A survey of nearly 5000 caregivers of individuals with intellectual and developmental disabilities (I/DD) found that caregivers report physical fatigue (88 percent), emotional stress (81 percent) and upset or guilt (81 percent), yet more than 75 percent could not find respite (The Arc, 2011). Despite their higher burden of care, caregivers of persons with dementia are more prone to

underutilizing and/or delaying respite. The 2013 Johns Hopkins Maximizing Independence at Home Study, in which researchers surveyed persons with dementia residing at home with their informal caregivers, found that nearly half of the caregivers had unmet needs for mental healthcare and most of these, according to the researchers, needed emotional support or respite care (Black, B, et al., 2013). Respite may not exist at all for children with autism, adults with ALS, MS, spinal cord or traumatic brain injuries, or individuals 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. A critically short supply of well-trained respite providers may prohibit a family from making use of a service they so desperately need.

Lifespan Respite Care Program

The Lifespan Respite Care Program, designed to address these barriers to respite quality, affordability and accessibility, is a competitive grant program administered by the Administration for Community Living (ACL) in its Center for Integrated Programs. The premise behind the program is both care relief and cost effectiveness. Lifespan Respite provides funding to States to expand and enhance local respite services across the country, coordinate community-based respite services to reduce duplication and fragmentation, improve coordination with other community resources, and to improve respite access and quality. Under the program, States are required to establish State and local coordinated Lifespan Respite care systems to serve families regardless of age or special need, provide new planned and emergency respite services, train and recruit respite workers and volunteers, and assist caregivers in gaining access. Those eligible include family members, foster parents or other adults providing unpaid care to adults who require care to meet basic needs or prevent injury and to children who require care beyond basic needs.

To date, 37 States and the District of Columbia have received basic grants to build coordinated systems of community-based respite services. Many of these States have also received follow on grants to provide or expand direct services, to help integrate services and grant activities into statewide long-term services and support systems, and to develop long-term sustainability plans.

How is Lifespan Respite Program Making a Difference?

In describing the Lifespan Respite Care Program, a distinguished panel from the National Academies of Sciences, Engineering, and Medicine recently concluded in the report *Families Caring for an Aging America*, “Although the program is relatively small, respite is one of the most important caregiver supports.” With limited funds, Lifespan Respite grantees are engaged in innovative activities:

- AL, AZ, DE, MT, NE, NV, NC, OK, RI, SC, TN, VA, and WA, have successfully used consumer-directed respite vouchers for serving underserved populations, such as individuals with MS or ALS, adults with intellectual or developmental disabilities (I/DD), children with autism, or those on waiting lists for services.
- ID, IL, IA, and NE offer emergency respite support.
- AL, AR, CO, NE, NY, OH, PA, SC and TN are providing new volunteer or faith-based respite services.
- Innovative and sustainable respite services, funded in CO, MA, NC, NY, OH, PA, and SC through mini-grants to community-based agencies, have documented benefits to family caregivers.
- Respite provider recruitment and training are priorities in AR, NE, NH, VA, and WI.

Additional partnerships between State agencies are changing the landscape. The AZ Lifespan Respite program housed in Aging and Adult Services partnered with AZ’s Children with Special Health Care Needs Program to provide respite vouchers to families across the age and disability spectrum. The OK Lifespan Respite program partnered with the State’s Transit Administration to develop mobile respite to serve isolated rural areas of the State. The WA State Lifespan Respite grantee partnered with Tribal entities to provide respite to kinship caregivers. States are building respite registries and “no wrong door systems” in partnership with Aging and Disability Resource Centers/No Wrong Door Systems to help family caregivers access respite and funding sources. Funding must be increased to help sustain these innovative State efforts and expand grants to new States. States are developing long-term sustainability plans, but without Federal support, many of the grantees will lose funding.

Funding Levels

Congress initially passed the Lifespan Respite Care Program in a bipartisan manner and the program maintains strong, bipartisan support in Congress. The program was authorized at \$50 million/year based on the magnitude of our Nation’s

family caregivers' needs, but Congress first appropriated funds for the program in fiscal year 2009 at \$2.5 million, and continued to fund the program at this level through fiscal year 2012. The program received slightly less funding in fiscal year 2013–fiscal year 2015 due to sequestration. In fiscal year 2016, given the strong bipartisan support for the program, Congress increased appropriations by \$1 million to \$3.36 million. This allowed six of the current grantees to receive 1 year expansion grants to provide direct services to unserved groups, and allowed Maryland and Mississippi to receive first-time awards. For fiscal year 2017, the program was once again funded at \$3.36. This permitted funding of two new States (ND and SD) and enabled 12 grantees to continue their ground-breaking work to serve more families. The increase in funding to \$4.1 million in the fiscal year 2018 Omnibus spending bill, will again allow ACL to fund several new States or enable additional grantees to continue their important initiatives.

No other Federal program has respite as its sole focus. The Lifespan Respite Care Program is the only Federal program that helps ensure respite quality and choice, allows funds for respite start-up, training and coordination, and addresses basic accessibility and affordability issues for families regardless of age or disability issues. We urge you to include \$5 million in the fiscal year 2019 Labor, HHS, and Education appropriations bill. Families will be able to keep loved ones at home, saving Medicaid and other Federal programs billions of dollars.

For more information or a list of complete references, please contact Jill Kagan, National Respite Coalition at jkagan@archrespite.org.

[This statement was submitted by Jill Kagan, Chair, National Respite Coalition.]

PREPARED STATEMENT OF THE NATIONAL RURAL HEALTH ASSOCIATION

SUPPORT STRONG FUNDING FOR THE RURAL HEALTH SAFETY NET

On behalf of the National Rural Health Association (NRHA) we ask that you continue to support several critically important rural health programs as you move forward with the fiscal year 2019 funding measures. We thank you for your leadership and support for rural health programs and hope you will continue these important efforts.

NRHA is a national nonprofit membership organization with more than 21,000 members with a mission to provide leadership on rural health issues. NRHA membership consists of a diverse collection of individuals and organizations that share a common interest in ensuring all rural communities have access to quality, affordable healthcare.

We greatly appreciate the efforts of the Subcommittee on Labor, Health and Human Services, Education, and Related Agencies and applaud your leadership in supporting rural health programs. This letter outlines recommendations that we believe will strengthen the rural healthcare safety net while ensuring that rural Americans maintain their access to critical services.

While we understand the current Federal budget situation, rural health discretionary spending is relatively small but is vitally important for maintaining access to care for individuals living in rural America. The rural healthy safety net programs outlined below are effective and crucial for the physical and economic health of many rural communities. Please continue to support these important programs that help in solidifying the fragile rural healthcare infrastructure in the United States.

Many vital discretionary programs help ensure the efficient and equitable delivery of healthcare services in rural areas. To better meet these needs, while simultaneously understanding the fiscal constraints demanded by Congress, the NRHA requests a modest, across-the-board funding increase of 10 percent (unless another amount has specifically been authorized by law).

NRHA appreciates the support that Congress has for opioid funding, but we ask that Congress ensure that this funding is targeted to the communities that need it most. Rural areas have been disproportionately impacted by the opioid epidemic, and we ask that additional funding for programs critical to combatting this crisis be target to ensure a robust rural response.

These programs include:

The Outreach Grant Program funds community-based project for 3 years to increase access to care. Typical projects include efforts to address diabetes, obesity, health promotion, screening, wellness, adolescent health, oral health, and mental health. More than 2 million people have benefited and more than 85 percent of grant programs continue to deliver services 5 years after Federal funding has ended. Rural Access to Emergency Devices Grants assist rural communities with the pur-

chase of automated external defibrillators (AEDs) and provide training in their use and maintenance.

Network Development Grants address the business and management challenges of working with underserved rural communities. These three-year projects help to overcome the fragmentation of healthcare services in rural areas and help to achieve economies of scale. A Network Development Planning Grant Program provides 1 year of funding to rural communities that are beginning to examine the benefits of building networks so they can initiate the process.

Rural Health Research/Policy funds the Federal Office of Rural Health Policy (FORHP). FORHP administers rural health programs, coordinates activities related to rural healthcare, and analyzes the possible effects of policy on the 60 million rural Americans and advises the Secretary on access to care, the viability of rural hospitals, and the availability of physicians and other health professionals.

State Offices of Rural Health, located in all 50 states, help their individual rural communities build healthcare delivery systems. They accomplish this mission by collecting and disseminating information, providing technical assistance, helping to coordinate rural health interests state-wide, and by supporting efforts to improve recruitment and retention of health professionals.

Rural Hospital Flexibility Grants are used by each state to implement new technologies, strategies and plans in Critical Access Hospitals (CAH). CAHs provide essential services to a community. Their continued viability is critical for access to care and the health of the rural economy.

EMS Sustainability Grants are included in this program. These grants build an evidence base for sustainable rural EMS model, and they are essential in the changing landscape of rural EMS (decreased volunteer ambulance staff, declining financial support, loss of local rural Emergency Departments following rural hospital closures, and increased educational requirements for EMTs and paramedics.) These grant programs offer the opportunity to develop and implement projects to ensure continued access to EMS in rural America.

Additional funding for the Rural Hospital Flexibility Grants in the 2018 Omnibus allowed for the Vulnerable Rural Hospitals Assistance Program. Through this program, HRSA will fund one entity up to \$800,000 to provide targeted, in-depth assistance to vulnerable rural hospitals struggling to maintain healthcare services with the goal for residents in those rural communities to continue to have access to essential healthcare. The awardee will work with individual hospitals and their communities on ways to understand community health needs and find ways to ensure hospitals and communities can keep needed care locally.

Telehealth funding is for the Office for the Advancement of Telehealth, including the Telehealth Network Grant Program, which promotes the effective use of technologies to improve access to health services and to provide distance education for health professionals.

National Health Service Corps supports qualified healthcare providers that are dedicated to working in underserved areas by providing scholarship and loan-repayment programs for those serving medically underserved communities and populations with health professional shortages and/or high unmet needs for health services.

Title VII and VIII programs, including Rural Physician Training Grants, Area Health Education Centers, and Geriatric programs, provide policy leadership and grant support for health professions workforce development for shortage areas.

National Health Care Workforce Commission, a multi-stakeholder workforce advisory committee charged with developing a national healthcare workforce strategy, was created under the Affordable Care Act but no appropriation has been made for the Commission and consequently it has not met since it was created.

NRHA is grateful for your support in recognizing the need for providing a sound future for the delivery of rural healthcare. We hope you will continue to support the millions of Americans in rural and underserved areas by acknowledging and considering these funding priorities.

FUNDING FOR THE RURAL HEALTH SAFETY NET

[Dollars in millions]

| | Fiscal Year | | | | | 2019 NRHA Request |
|--|-----------------|-----------------|---------------|----------------|-----------------|----------------------|
| | 2015 Enacted | 2016 Omnibus | 2017 House | 2017 Senate | 2018 Omnibus | |
| Rural Outreach & Network Grants ¹ | 59 | 63.5 | 65.5 | 65.5 | 65.5 | 72.4 |
| Rural Health Research/Policy | 9.3 | 9.4 | 9.4 | 9.4 | 9.4 | 10.4 |

FUNDING FOR THE RURAL HEALTH SAFETY NET—Continued

[Dollars in millions]

| | Fiscal Year | | | | | |
|--|-----------------|-----------------|----------------|----------------|-----------------|----------------------|
| | 2015 Enacted | 2016 Omnibus | 2017 House | 2017 Senate | 2018 Omnibus | 2019 NRHA Request |
| State Offices of Rural Health | 9.5 | 9.5 | 10.5 | 9.5 | 10 | 10 |
| Rural Opioid Reversal Grant | | | 10 | 0 ² | 0 ² | 11.1 |
| Rural Hospital Flexibility Grants | 41.6 | 41.6 | 45.6 | 41.6 | 49.6 | 50.4 |
| Telehealth ³ | 14.9 | 17 | 19 | 18 | 18.5 | 21 |
| National Health Service Corps | 0 | 0 | 0 | 0 | 0 | 337 |
| National Health Care Workforce Commission | 0 ⁴ | 0 ⁴ | 0 ⁴ | 0 ⁴ | 0 ⁴ | 3 |
| Title VII and VIII Programs of Particular Interest to Fund | | | | | | |
| Rural Physician Training Grants | 0 ⁵ | 0 ⁵ | 0 ⁵ | 0 ⁵ | 0 ⁵ | 5.3 |
| Area Health Education Centers | 30.3 | 30.3 | 30.3 | 30.3 | 30.3 | 33.5 |
| Geriatric Programs | 34.2 | 38.7 | 38.7 | 38.7 | 38.7 | 42.8 |

Source: National Rural Health Association.

¹ Rural & Community Access to Emergency Devices is funded through this program.² Program was not funded under HRSA, but funds were provided to combat the opioid epidemic in rural communities through the Centers for Substance Abuse within SAMHSA.³ Reflects only telehealth funding for the Office for the Advancement of Telehealth, including the telehealth Network Grant Program.⁴ No appropriation has been made for the Commission and consequently it has not met since it was created.⁵ Funding was authorized but not appropriated.PREPARED STATEMENT OF THE NATIONAL TECHNICAL INSTITUTE FOR THE DEAF AND
ROCHESTER INSTITUTE OF TECHNOLOGY

Mr. Chairman and Members of the Committee:

I am pleased to present the fiscal year 2019 budget request for NTID, one of nine colleges of RIT, in Rochester, N.Y. Created by Congress by Public Law 89-36 in 1965, NTID provides a university-level technical and professional education for students who are deaf and hard of hearing, leading to successful careers in high-demand fields for a sub-population of individuals historically facing high rates of unemployment and under-employment. NTID students study at the associate, baccalaureate, master's and doctoral levels as part of a university (RIT) that includes more than 17,000 hearing students. NTID also provides baccalaureate and graduate-level education for hearing students in professions serving deaf and hard-of-hearing individuals.

BUDGET REQUEST

On behalf of NTID, for fiscal year 2019 I would like to request \$76,000,000 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 29 percent of NTID's Operations budget coming from non-Federal funds, up from 9 percent in 1970. Since fiscal year 2006, NTID raised \$23.7 million in support from individuals and organizations. NTID has also recognized that construction funding is limited and planned for critical and long overdue renovations using existing Federal and non-Federal funds.

NTID's fiscal year 2019 request of \$76,000,000 in Operations would allow NTID to build on the success of the NSF grant-funded DeafTEC partnerships and new NTID Regional STEM Center (NRSC)-Southeast by establishing three additional regional partnerships to serve deaf and hard-of-hearing students in Western, Midwestern, and Northeastern 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 NRSCs, deaf and hard-of-hearing middle school students across the country would be introduced to STEM programs and careers that will help inform their academic and career decisions. Deaf and hard-of-hearing high school students could take NTID STEM dual credit courses and participate in career exploration and preparation programs that will help them transition from high school to college. This funding would also allow NTID to admit all qualified students for Fall 2019 enrollment, keep the fiscal year 2019 tuition increase relatively low, and continue to offer Grants in Aid to more students. With this funding, NTID can maintain newly added staff (sign language interpreters and captionists) in student access

services to meet unprecedented demand, complete much needed capital and renovation projects, and manage inflationary costs.

ENROLLMENT

Truly a national program, NTID has enrolled students from all 50 States. In Fall 2017 (fiscal year 2018), NTID's enrollment was 1,262 students. NTID's enrollment history over the last 10 years is shown below:

NTID ENROLLMENTS: FISCAL YEAR 2009—FISCAL YEAR 2018

| Fiscal Year | Deaf/Hard-of-Hearing Students | | | | Hearing Students | | | | Grand Total |
|-------------|-------------------------------|----------|------|-----------|----------------------|-------|------|-----------|-------------|
| | Undergrad | Grad RIT | MSSE | Sub-Total | Interpreting Program | MSHCI | MSSE | Sub-Total | |
| 2018 | 1,025 | 56 | 9 | 1,090 | 147 | 15 | 10 | 172 | 1,262 |
| 2017 | 1,078 | 44 | 14 | 1,136 | 140 | 8 | 16 | 164 | 1,300 |
| 2016 | 1,167 | 53 | 15 | 1,235 | 151 | N/A | 27 | 178 | 1,413 |
| 2015 | 1,153 | 44 | 16 | 1,213 | 146 | N/A | 28 | 174 | 1,387 |
| 2014 | 1,195 | 42 | 18 | 1,255 | 147 | N/A | 30 | 177 | 1,432 |
| 2013 | 1,269 | 37 | 25 | 1,331 | 167 | N/A | 31 | 198 | 1,529 |
| 2012 | 1,281 | 42 | 31 | 1,354 | 160 | N/A | 33 | 193 | 1,547 |
| 2011 | 1,263 | 40 | 29 | 1,332 | 147 | N/A | 42 | 189 | 1,521 |
| 2010 | 1,237 | 38 | 32 | 1,307 | 138 | N/A | 29 | 167 | 1,474 |
| 2009 | 1,212 | 48 | 24 | 1,284 | 135 | N/A | 31 | 166 | 1,450 |

(In the chart above,

Grad RIT: other graduate programs at RIT;

MSSE: Master of Science in Secondary Education of Students who are Deaf or Hard of Hearing;

MSHCI: Master of Science in Health Care Interpretation.)

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, 313 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 higher rates than the national persistence and graduation rates for all students at 2-year and 4-year colleges. For NTID deaf and hard-of-hearing graduates, over the past 5 years, an average of 94 percent have found jobs commensurate with their education level. Of our fiscal year 2016 graduates (the most recent class for which numbers are available), 94 percent were employed 1 year later, with 70 percent employed in business and industry, 20 percent in education and non-profits, and 10 percent in government.

Graduation from NTID has a demonstrably positive effect on students' earnings over a lifetime, and results in a notable reduction in dependence on Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). In fiscal year 2012, NTID, the Social Security Administration (SSA), and Cornell University examined earnings and Federal program participation data for more than 16,000 deaf and hard-of-hearing individuals who applied to NTID over our entire history. The study showed that NTID graduates, over their lifetimes, are employed at a higher rate and earn more (therefore paying more in taxes) than students who withdraw from NTID or attend other universities. NTID graduates also participate at a lower rate in SSI programs than students who withdrew from NTID.

Using SSA data, at age 50, 78 percent of NTID deaf and hard-of-hearing graduates with bachelor degrees and 73 percent with associate degrees report earnings, compared to 58 percent of NTID deaf and hard-of-hearing students who withdrew from NTID and 69 percent of deaf and hard-of-hearing graduates from other universities. Equally important is the demonstrated impact of an NTID education on grad-

uates' earnings. At age 50, \$58,000 is the median salary for NTID deaf and hard-of-hearing graduates with bachelor degrees and \$41,000 for those with associate degrees, compared to \$34,000 for deaf and hard-of-hearing students who withdrew from NTID and \$21,000 for deaf and hard-of-hearing graduates from other universities.

An NTID education also translates into reduced dependency on Federal transfer programs, such as SSI and SSDI. At age 40, less than 2 percent of NTID deaf and hard-of-hearing associate and bachelor degree graduates participated in the SSI program compared to 8 percent of deaf and hard-of-hearing students who withdrew from NTID. Similarly, at age 50, only 18 percent of NTID deaf and hard-of-hearing bachelor degree graduates and 28 percent of associate degree graduates participated in the SSDI program, compared to 35 percent of deaf and hard-of-hearing students who withdrew from NTID.

ACCESS SERVICES

Access services include sign language interpreting, real-time captioning, classroom notetaking services, captioned classroom video materials, and assistive listening services. NTID provides an access services system to meet the needs of a large number of deaf and hard-of-hearing students enrolled in baccalaureate and graduate degree programs in RIT's other colleges as well as students enrolled in NTID programs who take courses in the other colleges of RIT. Access services also are provided for events and activities throughout the RIT community. Historically, NTID has followed a direct instruction model for its associate-level classes, with limited need for sign language interpreters, captionists, or other access services. However, the demand for access services has grown recently as associate-level students request communication based on their preferences.

During fiscal year 2017, 152,630 hours of interpreting were provided—an increase of 31 percent compared to fiscal year 2010. During fiscal year 2017, 25,952 hours of real-time captioning were provided to students—a 33 percent increase over fiscal year 2010. The increase in demand is partly a result of the increase in the number of students enrolled in programs at RIT and the number of students with cochlear implants. In fiscal year 2018, there were 576 deaf and hard-of-hearing students enrolled in baccalaureate or graduate programs at RIT, a 12 percent increase compared to fiscal year 2010, and 416 students with cochlear implants, a 52 percent increase over fiscal year 2010.

As a result, NTID's fiscal year 2019 funding request recognizes the need to support additional access services staff and research on technologies that might serve as an alternative to traditional access services.

SUMMARY

NTID's fiscal year 2019 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 higher rates than 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 94 percent over the past 5 years. Therefore, I ask that you please consider funding our fiscal year 2019 request of \$76,000,000 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 VIOLENCE PREVENTION NETWORK

Thank you for this opportunity to submit testimony in support of funding for the National Violent Death Reporting System (NVDRS), which is administered by the National Center for Injury Prevention and Control at the Centers for Disease Control and Prevention (CDC). The National Violence Prevention Network, a broad and diverse alliance of health and welfare, suicide and violence prevention, and law en-

forcement advocates supports continuing the funding level for fiscal year 2019 at \$23.5 million to allow for the nationwide expansion of the NVDRS program including all 50 States, District of Columbia and U.S territories. Fiscal year 2018 NVDRS funding is \$23.5 million.

BACKGROUND

Each year, more than 61,000 Americans die violent deaths.¹ In addition, an average of 123 people² (20 of which are military veterans)³ take their own lives each day. Violence-related death and injuries cost the United States \$107 billion in medical care and loss in productivity.⁴

The NVDRS program makes better use of data that are already being collected by health, law enforcement, and social service agencies. The NVDRS program, in fact, does not require collection of any new data. Instead it links together information that, when kept in separate compartments, is much less valuable as a tool to characterize and monitor violent deaths. With a clearer picture of why violent deaths occurs, law enforcement, public health officials and others can work together to identify those at risk and target effective preventive services.

Currently, NVDRS is only operating in 42 States.⁵ The just-passed fiscal year 2018 funding level of \$23.5 million will allow NVDRS to begin operating in all 50 States, although that funding level will not reach the totality of every State.

NVDRS IN ACTION

Opioid deaths are a serious public health issue. Drug overdose deaths are the leading cause of injury deaths in America.⁶ It is important to invest in surveillance of opioid addiction to determine the extent of the problem and implement treatment options and community-based prevention strategies. NVDRS has already proven to be an invaluable tool in many States like Alaska, Indiana and Utah that collect information, through toxicology reports, about prescription-opioid overdose associated with violent deaths. Combined 2010 NVDRS data showed that 24 percent of violent deaths tested were positive for opiates.^{7,8}

Children are often the most vulnerable as they are dependent on their caregivers during infancy and early childhood. Sadly, NVDRS data has shown that young children are at the greatest risk of homicide in their own homes. Combined NVDRS data from 18 of the 42 States that currently participate in NVDRS, showed that African American children aged 4 years and under are more than three times as likely to be victims of homicide than Caucasian children,⁹ and that homicides of children aged four and under are most often committed by a parent or caregiver in the home. The data further notes that household items, or “weapons of opportunity,” were most commonly used, suggesting that poor stress responses may be factors in these deaths. Knowing the demographics and methods of child homicides can lead to more effective, targeted prevention programs.

Intimate partner violence (IPV) is another issue where NVDRS is proving its value. While IPV has declined along with other trends in crime over the past decade, thousands of Americans still fall victim to it every year. An analysis of intimate partner homicide based on NVDRS data from 18 States shows that intimate partners represented 87 percent of intimate partner violence-related homicides victims and corollary victims (family members, police officers, friends etc.) represented the remaining 13 percent of victims.¹⁰

Despite being in its early stages in several States, NVDRS is already providing critical information that is helping law enforcement and public health officials target their resources to those most at risk of intimate partner violence. For example, NVDRS data shows that while occurrences are rare, most murder-suicide victims are current or former intimate partners of the suspect or members of the suspect's family. In addition, NVDRS data indicate that women are about seven times more likely than men to be killed by a spouse, ex-spouse, lover, or former lover, and most of these incidents occurred in the women's homes.⁷

NVDRS & VA SUICIDES

Although it is preventable, every year more than 44,193 Americans die by suicide and another one million Americans attempt it, costing more than \$44 billion in lost wages and work productivity.² In the United States today, there is no comprehensive national system to track suicides. However, because NVDRS includes information on all violent deaths—including deaths by suicide—the program can be used to develop effective suicide prevention plans at the community, State, and national levels.

A 2015 study showed that 19.9 percent of all veteran deaths between 2001 and 2007 were suicide, with male veterans three times as likely as female veterans to

commit suicide.¹¹ The central collection of such data can be of tremendous value for organizations such as the Department of Veterans Affairs that are working to improve their surveillance of suicides. The types of data collected by NVDRS including gender, blood alcohol content, mental health issues and physical health issues can help prevention programs better identify and treat at-risk individuals.

In addition to veteran suicides, NVDRS data has been crucial in many States like Oregon, Utah, New Jersey and North Carolina in understanding the circumstances surrounding elder suicide. This has allowed the States to collaborate locally and implement programs that target those populations at greatest risk.

FEDERAL ROLE NEEDED

NVDRS is a relatively low-cost program that yields high-quality results. While State-specific information provides enormous value to local public health and law enforcement officials, data from all 50 States, the U.S. territories and the District of Columbia must be obtained to complete the national picture. Aggregating this additional data will allow us to analyze national trends and also more quickly and accurately determine what factors can lead to violent death so that we can devise and disseminate strategies to address those factors.

STRENGTHENING AND EXPANDING NVDRS IN FISCAL YEAR 2019

We cannot reduce funding for a program that just reached its capacity to start operations in all 50 States. Congress needs to continue funding for NVDRS at the level of \$23.5 million.

We thank you for the opportunity to submit this statement for the record. The investment in NVDRS has already begun to pay off, as NVDRS-funded States are adopting effective violence prevention programs. We believe that national implementation of NVDRS is a wise public health investment that will assist State and national efforts to prevent deaths from domestic violence, veteran suicide, teen suicide, gang violence and other violence that affect communities around the country. We look forward to working with you to complete the nationwide expansion of NVDRS by securing an fiscal year 2019 appropriation of \$23.5 million.

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[This statement was submitted by Kate McFadyen, Chair, National Violence Prevention Network.]

PREPARED STATEMENT OF NEPHCURE KIDNEY INTERNATIONAL

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2019

- Provide \$39.3 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.
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Chairman Blunt and Ranking Member Murray, thank you for the opportunity to present the views of NephCure Kidney International regarding research on idiopathic focal segmental glomerulosclerosis (FSGS) and primary nephrotic syndrome (NS). NephCure is the only non-profit organization exclusively devoted to fighting FSGS and the NS disease group. Driven by a panel of respected medical experts and a dedicated band of patients and families, NephCure works tirelessly to support kidney disease research and awareness.

NS is a collection of signs and symptoms caused by diseases that attack the kidney's filtering system. These diseases include FSGS, Minimal Change Disease and Membranous Nephropathy. When affected, the kidney filters leak protein from the blood into the urine and often cause kidney failure, which requires dialysis or kidney transplantation. According to a Harvard University report, 73,000 people in the United States have lost their kidneys as a result of FSGS. Unfortunately, the causes of FSGS and other filter diseases are poorly understood.

FSGS is the second leading cause of NS and is especially difficult to treat. There is no known cure for FSGS and current treatments are difficult for patients to endure. These treatments include the use of steroids and other dangerous substances which lower the immune system and contribute to severe bacterial infections, high blood pressure and other problems in patients, particularly child patients. In addition, children with NS often experience growth retardation and heart disease. Finally, NS that is caused by FSGS, MCD or MN is idiopathic and can often reoccur, even after a kidney transplant.

FSGS disproportionately affects minority populations and is five times more prevalent in the African American community. In a groundbreaking study funded by NIH, researchers found that FSGS is associated with two APOL1 gene variants. These variants developed as an evolutionary response to African sleeping sickness and are common in the African American patient population with FSGS/NS. Researchers continue to study the pathogenesis of these variants.

FSGS has a large social impact in the United States. FSGS leads to end-stage renal disease (ESRD) which is one of the most costly chronic diseases to manage. In 2008, the Medicare program alone spent \$26.8 billion, 7.9 percent of its entire budget, on ESRD. In 2005, FSGS accounted for 12 percent of ESRD cases in the U.S., at an annual cost of \$3 billion. It is estimated that there are currently approximately 20,000 Americans living with ESRD due to FSGS.

Research on FSGS could achieve tremendous savings in Federal healthcare costs and reduce health status disparities.

ENCOURAGE FSGS/NS RESEARCH AT NIH

There is no known cause or cure for FSGS and scientists tell us that much more research needs to be done on the basic science behind FSGS/NS. More research could lead to fewer patients undergoing ESRD and tremendous savings in healthcare costs in the United States. NephCure works closely with NIH and has partnered with NIH on two large studies that will advance the pace of clinical research and support precision medicine. These studies are the Nephrotic Syndrome Study Network and the Cure Glomerulonephropathy Network.

With collaboration from other Institutes and Centers, ORDR established the Rare Disease Clinical Research Network. This network provided an opportunity for NephCure Kidney International, the University of Michigan, and other university research health centers to come together to form the Nephrotic Syndrome Study Network (NEPTUNE). Now in its second 5-year funding cycle, NEPTUNE has recruited over 450 NS research participants, and has supported pilot and ancillary studies utilizing the NEPTUNE data resources. NephCure urges the subcommittee to continue its support for RDCRN and NEPTUNE, which has tremendous potential to facilitate advancements in NS and FSGS research.

NIDDK houses the Cure Glomerulonephropathy Network (Cure GN), a multi-center 5-year cohort study of glomerular disease patients. Participants will be followed longitudinally to better understand the causes of disease, response to therapy, and disease progression, with the ultimate objective to cure glomerulonephropathy. NephCure recommends that the subcommittee continues to support the work that the Cure Glomeruloneuropathy [CureGN] initiative has accomplished towards further understanding rare forms of kidney diseases. It is estimated that annually there are 20 new cases of ESRD per million African Americans due to FSGS, and 5 new cases per million Caucasians. This disparity is largely due to variants of the APOL1 gene. Unfortunately, the incidence of FSGS is rising and there are no known strategies to prevent or treat kidney disease in individuals with the APOL1 genotype. NIMHD began supporting research on the APOL1 gene in fiscal year 2013. Due to the disproportionate burden of FSGS on minority populations, it remains appropriate for NIMHD to continue to advance this research. NephCure asks the subcommittee to recognize the work that NIMHD and NIDDK are doing to address the connection between the APOL1 gene and the onset of FSGS and encourage NIMHD to work with community stakeholders to identify areas of collaboration.

Patient Perspectives

My name is Kimberly Queen and I was diagnosed with Focal Segmental Glomerulosclerosis (FSGS) in 2012 at the age of 25. At that time, I was fulfilling my passion teaching Georgia State Pre-k when I received the news; it was only my third-year teaching. After only 2 months of being diagnosed and being prescribed 60mg of Prednisone, I went into septic shock. Thankfully I was surrounded by amazing doctors who saved my life. It was then that I realized it was time to fight this disease. However, just as I was starting my fight, my kidneys failed in the first 9 months. I am forever grateful to my brother who donated his kidney to me on November 7, 2014, but with FSGS there is always a chance of reoccurrence, which I saw firsthand shortly after when I began spilling protein. During the two weeks I spent in the hospital, we started putting together a game plan for how to put this awful disease into remission.

I began daily plasmapheresis along with taking a blood pressure medication. We saw a little change but not enough. It's now been 3 years since my reoccurrence. In that time, I have done over three hundred plasmapheresis treatments, experimented with different dosages of Prednisone, tried different blood pressure medications, started using Acthar Gel and started Rituximab. I have attained partial remission using the Acthar Gel, and we are hoping to reach full remission with the Rituximab. More research is needed with this disease so that myself, and others do not feel like "test subjects" trying different medications and so there can be a higher success rate. I would love to be able to live my life not focused around doctor appointments, treatments and long infusions. Luckily, I am surrounded by a family who understands how FSGS has impacted my life, as well as friends who support me and encourage me to stay strong daily fighting a disease with no cure.

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I was diagnosed when I was 7 years old with Nephrotic Syndrome. I am almost 9 years old now. When I get very sick it is called a relapse and then I have to start taking higher doses of steroids (prednisolone). Taking steroids doesn't seem like a big deal but it makes me really hungry all the time. I started a new medicine (tacrolimus) on August 10th that is working, so January 6th, 2018 was my last day of taking steroids, hopefully forever. I didn't like being on steroids. Besides being hungry all the time, it made my face really big and I gained a lot of weight, and I stopped growing taller, so my twin brother is now way taller than me. They say I could still catch up, but I have to wait and see. I'm 2 minutes older and was always bigger but I'm being patient. I still have to take a blood pressure medicine. I take the same pills as my 90 year old great grandfather! This is from both the steroids and the disease. I check my urine and blood pressure every day and have to take the tacro at 8am and 8pm. We have alarms to remind us all. My Mom was worried when school started because steroids can make you act crazy she says. I

love school so I never let it get me in trouble. I was even invited into the ALPS program which is Advanced Learning Program for Students because I did so well! I play baseball and basketball because my parents won't let my disease define me, so as long as the doctors say it is okay and I want to do it, they let me do it. I wish a cure could be found for Nephrotic Syndrome. I don't like having to explain it to my friends, and I don't like how worried my parents always are.

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Paige was diagnosed at the age of three, over 8 years ago. Her body responds to steroids so we rely solely on that drug to maintain her health. Paige's current treatment plan is identical to someone who was diagnosed with this condition in the 1970's. Can you imagine being diagnosed with a chronic condition and the Dr. using case studies from over 40 years ago to develop your initial treatment plan? It is a devastating feeling to know there remains no known cause or cure to the condition that affects your child daily.

The side effects of steroid use are numerous, the list is very long. Research is needed to find alternative and better treatment methods. Paige relapses when her immune system is tested and yet the treatment method we have to rely on causes her immune system to weaken. Nephrotic Syndrome and steroids have changed the way we live our lives, we have worry and stress over her health instead of joy.

Nephrotic Syndrome changed Paige's life, but she does not allow Nephrotic Syndrome to ruin it. She is a smart, determined, kind young person who is a scholar and a competitive swimmer and has the best giggle around. She makes a positive difference in this world. Our family supports the need for additional research organizing annual running teams to raise vital funds to support research. Paige may not remember how life was like without Nephrotic Syndrome but we certainly do. We ask for your support in funding additional, vital research to help find a cure for these devastating kidney conditions. Thank you.

Thank you for the opportunity to present the views of the FSGS/NS community.

[This statement was submitted by Irving Smokler, Ph.D., President and Founder, NephCure Kidney International.]

PREPARED STATEMENT OF THE NEUROFIBROMATOSIS NETWORK

Thank you for the opportunity to submit testimony to the Subcommittee on the importance of funding for the National Institutes of Health (NIH), and specifically for continued research on Neurofibromatosis (NF), a genetic disorder closely linked to many common diseases widespread among the American population. My name is Kim Bischoff and I am the Executive Director of the Neurofibromatosis (NF) Network, a national organization of NF advocacy groups. We respectfully request that you include the following report language on NF research at the National Institutes of Health within your fiscal year 2019 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 NIH Institutes, including NCI, NINDS, NIDCD, NHLBI, NICHD, NIMH, NCATS, and NEI. Children and adults with NF are at significant risk for the development of many forms of cancer; the Committee encourages NCI to increase its NF research portfolio in fundamental basic science, translational research and clinical trials focused on NF. The Committee also encourages the NCI to support NF centers, NF clinical trials consortia, NF preclinical mouse models consortia and NF-associated tumor sequencing efforts. Because NF causes brain and nerve tumors and is associated with cognitive and behavioral problems, the Committee urges NINDS to continue to aggressively fund fundamental basic science research on NF relevant to nerve damage and repair. 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 expand their investments in laboratory-based and clinical 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 basic and clinical research. NF1 can cause vision loss due to optic gliomas, the Committee encourages NEI to expand its investment in NF1 basic and clinical research.

On behalf of the Neurofibromatosis (NF) Network, I speak on behalf of the over 100,000 Americans who suffer from NF as well as approximately 175 million 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.

Wound Healing, Inflammation and Blood Vessel Growth

Wound healing requires new blood vessel growth and tissue inflammation. Mast cells, important players in NF1 tumor growth, are critical mediators of inflammation, and they must be quelled and regulated in order to facilitate healing. Researchers have gained deep knowledge on how mast cells promote tumor growth, and this research has led to ongoing clinical trials to block this signaling, resulting in slower tumor growth. As researchers learn more about blocking mast cell signals in NF, this research can be translated to the management of mast cells in wound healing.

Cancer

NF can cause a variety of tumors to grow, which includes tumors in the brain, spinal cord and nerves. NF affects the RAS pathway which is implicated in 70 percent of all human cancers. Some of these tumor types are benign and some are malignant, hard to treat and often fatal. Previous studies have found a high incidence

of intracranial glioblastomas and malignant peripheral nerve sheath tumors (MPNSTs), as well as a six fold incidents of breast cancer compared to the general population. One of these tumor types, malignant peripheral nerve sheath tumor (MPNST), is a very aggressive, hard to treat and often fatal cancer. MPNSTs are fast growing, and because the cells change as the tumor grows, they often become resistant to individual drugs. Clinical trials are underway to identify a drug treatment that can be widely used in MPNSTs and other hard-to-treat tumors.

The enormous promise of NF research, and its potential to benefit over 175 million Americans who suffer from diseases and conditions linked to NF, has gained increased recognition from Congress and the NIH. This is evidenced by the fact that numerous institutes are currently supporting NF research, and NIH's total NF research portfolio has increased from \$3 million in fiscal year 1990 to an estimated \$31 million in fiscal year 2017. 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.

PREPARED STATEMENT OF NEW LEADERS

Thank you for the opportunity to provide testimony regarding the fiscal year 2019 Labor, Health and Human Services, Education, and Related Agencies Appropriations bill.

New Leaders is a national nonprofit organization dedicated to ensuring high academic achievement for all children, especially students in poverty and students of color, by developing transformational school leaders and advancing the policies and practices that allow great leaders to succeed. Since 2000, we have trained 3,200 outstanding school leaders who annually reach approximately 500,000 students in partnership with more than 30 districts and 150 charter schools. Moreover, our leaders overwhelmingly work on behalf of historically underserved students: 78 percent of students served are low-income and 87 percent are children of color. In addition, our programs are evidence-based. An independent study by the RAND Corporation found that students who attend New Leader schools outperform their peers by statistically significant margins specifically because of the strong leadership of their New Leader principal.¹ And a recent review of school leadership interventions cited New Leaders as the principal preparation program with the strongest evidence of positive impact on student achievement.²

New Leaders is committed to getting a well-prepared, well-supported principal in every school so that our Nation's teachers and students can thrive. We can reach this goal by paying more attention to how our schools—not just individual classrooms, but all classrooms within a school—are organized and led. More than a decade of research shows that well-prepared, well-supported principals have a huge influence on teacher practice and student success. School leaders account for 25 percent of a school's impact on student learning,³ and an above-average principal can improve student achievement by 20 percentage points.⁴ Moreover, outstanding school leaders attract and retain great educators: fully 97 percent of teachers list principal quality as critical to their retention and career decisions—more than any other factor.⁵ And school leaders transform the lowest-performing schools, where the

¹Gates, S., Hamilton, L., Martorell, P., et. al. (2014). Preparing Principals to Raise Student Achievement: Implementation and Effects of the New Leaders Program in Ten Districts. The RAND Corporation. Retrieved from http://www.rand.org/pubs/research_reports/RR507.html.

²Herman, R., Gates, S. M., Chavez-Herrerias, E. R., and Harris, M. (2016). School Leadership Interventions Under the Every Student Succeeds Act (Volume I). The RAND Corporation. Retrieved from http://www.rand.org/content/dam/rand/pubs/research_reports/RR1500/RR1550/RAND_RR1550.pdf.

³Leithwood, K., Seashore Louis, K., Anderson, S., & Wahlstrom, K. (2004). How leadership influences student learning: A review of research for the Learning from Leadership Project. New York, NY: The Wallace Foundation. Retrieved from <http://www.wallacefoundation.org/knowledge-center/Pages/How-Leadership-Influences-Student-Learning.aspx>.

⁴Marzano, R. J., Waters, T., & McNulty, B. A. (2005). School leadership that works: From research to results. Alexandria, VA: Association for Supervision and Curriculum Development.

⁵Scholastic Inc. (2012). Primary Sources: America's Teachers on the Teaching Profession. New York, NY: Scholastic and the Bill and Melinda Gates Foundation. Retrieved from http://www.scholastic.com/primarysources/pdfs/Gates2012_full.pdf.

positive effects of strong leadership on student achievement are most pronounced.⁶ In fact, a landmark study found “virtually no documented instances of troubled schools being turned around without intervention by a powerful leader.”⁷

We were pleased that the Every Student Succeeds Act (ESSA) maintained and strengthened the School Leader Recruitment and Support Program (SLRSP). However, we were deeply dismayed to see funding for SLRSP zeroed out in the fiscal year 2018 spending deal.

The School Leader Recruitment and Support Program (SLRSP) was authorized under ESSA with bipartisan support and is the only Federal program with an exclusive focus on evidence-based school leadership interventions for high-need schools. SLRSP updates the School Leadership Program (SLP, the program included in the previous version of the Elementary and Secondary Education Act (ESEA)) and provides districts with resources to develop and support dynamic leaders who have a measurable, positive impact on student achievement. The program empowers eligible entities—including State or local educational agencies—to pursue a range of activities in support of school leadership for high-need schools, such as the development and implementation of leadership training programs, the provision of ongoing professional development for school leaders, and the dissemination of best practices regarding the recruitment and retention of highly effective school leaders. In addition, eligible entities may carry out projects in partnership with nonprofit organizations and institutions of higher education. Finally, under priorities set forth in the reauthorized statute, SLRSP incentivizes eligible entities to focus on principal preparation and professional development practices for which there is evidence of effectiveness, as demonstrated through rigorous research.

As implementation of ESSA moves to the State, local, and school levels, it is more important than ever that we ensure every school is led by an outstanding principal—a focus that can lead to incredible results for kids while representing a cost-effective use of Federal resources. According to a national analysis, the average cost to recruit, prepare, and hire a new principal is \$75,000.⁸ Because 12 percent of principals leave the profession every year, replacing each requires significant resources—upwards of \$200 million for the Nation’s high-need schools. That same analysis found that the average cost of principal support is \$16,500—requiring more than \$350 million annually to mentor and support the leaders of high-need schools. Though the need is great, investments in leadership are extremely cost-effective: supporting one principal is actually an investment in the 25 teachers and 500 or more students he or she, on average, supports. In fact, a National Governors Association report describes how slightly shifting the balance of educator investments toward principals is a smart way to improve school working conditions to foster stronger teaching and better outcomes for kids.⁹ Further, strategies to address principal burnout, which disproportionately affects high-need schools,¹⁰ can yield huge cost savings.¹¹

The Federal Government has a crucial role to play in advancing innovation and sharing best practices with the field so that State and local leadership strategies, especially for high-need schools, can be strengthened, now and in the future, by a strong and growing evidence base. The SLP helped launch and expand some of the country’s most innovative and effective leadership development programs, including New Leaders, New Teacher Center, NYC Leadership Academy, and TNTP. Since receiving SLP grants, these organizations have grown exponentially to reach many more schools, teachers, and students in high-need communities—greatly expanding the impact of the Federal Government’s initial investment. Further, SLP grantees, including those affiliated with the University Council of Educational Administrators (UCEA), have demonstrated a remarkable commitment to programmatic evaluation,

⁶Seashore Louis, K., Leithwood, K., Wahlstrom, K., & Anderson, S. (2010). Investigating the links to improved student learning. Washington, DC: Wallace Foundation. Retrieved from <http://www.wallacefoundation.org/knowledge-center/Pages/Investigating-the-Links-to-Improved-Student-Learning.aspx>.

⁷Leithwood, K., Seashore Louis, K., Anderson, S., & Wahlstrom, K. (2004).

⁸School Leaders Network. (2014). Churn: The High Cost of Principal Turnover. Retrieved from http://connectleadsucceed.org/sites/default/files/principal_turnover_cost.pdf#page=1&zoom=auto,-15,792.

⁹National Governors Association. (2015). Improving Educational Outcomes: How State Policy Can Support School Principals as Instructional Leaders. Washington, DC: National Governors Association. Retrieved from https://www.nga.org/files/live/sites/NGA/files/pdf/2015/1506_SupportingPrincipals.pdf.

¹⁰According to 2014 data from the National Center for Education Statistics, high-need schools must also grapple with an overall principal turnover rate of 28 percent, significantly higher than schools in more affluent communities.

¹¹According to School Leaders Network (2014), up to \$330,000 annually for a typical urban district.

continuous improvement, and transparency. By proactively sharing their lessons and resources open-source with the field, these organizations have helped to galvanize dramatic changes to the principal preparation sector as a whole¹²—inspiring necessary changes to the way principals are trained to lead our Nation’s schools in States and districts across the country.

It is worth noting that while there are other programs that can support effective school leadership programs and strategies, the reality is that leadership has historically been overlooked and consistently underfunded,¹³ so it is absolutely crucial that we reinstate this dedicated funding source. Without SLRSP, we lose a key Federal lever for seeding the next generation of effective principal development programs, promoting equity, advancing ongoing innovation, and sharing cutting-edge school leadership lessons with the broader field.

We urge Congress to restore funding for SLRSP at \$14.5 million to seed innovative, evidence-based school leadership programs and partnerships that promise a return for students, schools, and communities that far exceeds this targeted investment.

Thank you for the opportunity to provide the views of New Leaders on the fiscal year 2019 appropriations. If you would like to discuss our recommendations, please do not hesitate to contact policyteam@newleaders.org.

[This statement was submitted by Jean Desravines, CEO, New Leaders.]

PREPARED STATEMENT OF THE NEZ PERCE TRIBE

Honorable Chairman and members of the Committee, the Nez Perce Tribe (Tribe) would like to thank you for the opportunity to provide recommendations to the Committee as it evaluates and prioritizes fiscal year 2019 appropriations for programs within the Department of Labor, Department of Health and Human Services, and the Department of Education.

As with any government, the Tribe performs a wide array of work and provides a multitude of services to its tribal membership as well as the community at large. The Tribe has been a leader in education, workforce development, and social services in this area and places a high priority on these programs and the services they provide to residents on the Nez Perce Reservation (Reservation). The Tribe relies on specific Federal programs and grants to fund this important work and, therefore, provides the following fiscal year 2019 appropriations recommendations for these agencies.

The Tribe recommends \$20 billion be provided for Title I, Part A of the Every Student Succeeds Act Local Education Agency Grants. Rural public schools on the Reservation use this funding to address the obstacles low-income students face meeting academic standards.

The Tribe recommends \$5 million be allocated for the State-Tribal Education Partnership Program (STEP) authorized in Title VI, Part A, Subpart 3 of the Every Student Succeeds Act. The Tribe is one of the participants in the STEP which provides an avenue for States and tribes to work together to improve and enhance education delivery and parent involvement in areas with high populations of tribal students. The STEP has been a success for the Tribe and continued funding is needed to keep the program active.

The Tribe recommends the same amount be allocated in fiscal year 2019 as was allocated in fiscal year 2018 for Impact Aid, \$1.414 billion. Impact Aid compensates school districts for Federal ownership of lands within a district’s tax base. Idaho Public Schools on the Reservation rely heavily on Impact Aid dollars to provide education services. For example, Impact Aid accounts for 30 percent of the budget for the Lapwai School District. Without Impact Aid dollars, the school will be forced to make significant reductions in staffing and resources for students.

The Tribe recommends \$5 million for Tribal Education Departments which would complement the funding allocated to the Bureau of Indian Affairs for these programs. This funding provides for the development and implementation of education

¹²University Council for Educational Administration and New Leaders. (2016). State Evaluation of Principal Preparation Programs Toolkit. Retrieved from www.sepkit.org.

¹³For the past several years, more than two-thirds of districts have invested zero Federal professional development funds on school leaders. Sources: U.S. Department of Education (2015). Findings from the 2014–15 Survey on the Use of Funds Under Title II, Part A. U.S. Department of Education (2014). Findings from the 2013–14 Survey on the Use of Funds Under Title II, Part A. U.S. Department of Education (2013). Findings from the 2012–13 Survey on the Use of Funds Under Title II, Part A. All retrieved from <http://www2.ed.gov/programs/teacherqual/resources.html>.

programs operated by tribes to assist in the delivery of education services within a reservation.

The Tribe recommends the \$9.863 billion provided for Head Start in fiscal year 2018 be maintained for fiscal year 2019. Indian Head Start needs to be fully funded as these programs play a vital role in school readiness, child development, and early education for over 24,000 Native children. The Indian Head Start programs address the whole child from a health, cultural, and education perspective. These programs operate on slim budgets but provide extraordinary returns in ensuring children are as prepared as possible to begin their education journey.

The Tribe recommends the fiscal year 2018 funding levels be maintained for fiscal year 2019 for all Tribal Behavioral Health Grants under the Substance Abuse and Mental Health Services Administration. The grants address a wide range of mental health and substance abuse issues such as youth suicide, opioid addiction, and methamphetamine addiction that are prevalent on the Reservation and threaten to overwhelm the Tribe's Social Services Department and health clinic. In addition, the competitive grants and tribal set-asides provided for promoting safe and stable families, child welfare services, and child abuse prevention should be maintained at fiscal year 2018 levels as well.

The Tribe appreciates the \$50 million in funding for fiscal year 2018 to address the opioid crisis in Indian Country. However, this funding pales in comparison to the \$1.5 billion that has been provided to States on this issue through the 21st Century Cures Act and fiscal year 2018 funding. The Tribe recommends funding to address opioid use and its effects on communities be increased and also made available in forms other than grants. Indian Country suffers from opioid addiction at a higher rate than most communities and all communities need access to monies to help address this problem.

The Tribe recommends \$60.5 million be allocated to the Department of Labor's Division of Indian and Native American Programs, an increase of \$6.5 million over fiscal year 2018 funding. The Workforce Innovation and Opportunity Act, Section 166 Indian and Native American Programs serve the training and employment needs of tribes through programs such as the Indian Employment, Training, and Related Services Demonstration Act of 1992. The Tribe has used this funding to provide important programs that have helped develop the workforce and economy on the Reservation. This program has been very successful but will not continue without funding.

The Tribe also recommends continuing the Public Service Loan Forgiveness program (PSLF). The PSLF was established with the passage of the College Cost Reduction and Access Act of 2007, and was created to encourage individuals to enter lower-paying but vitally important public sector jobs such as military service, law enforcement, public education, and public health professions. The PSLF allows eligible borrowers to qualify for forgiveness of the remaining balance of their William D. Ford Federal Direct Loan Program loans after they have served full time at a public service organization for at least 10 years, while making 120 qualifying payments. Although there have been proposals to eliminate the program, the PSLF has shown to be a valuable tool for tribal governments in the recruitment of employees and an important resource for students to address educational debt while serving in jobs that may not be as financially lucrative as positions in the private sector. Most tribes are located in rural areas and face challenges in recruiting and retaining employees. This program has been useful in that regard and the Tribe recommends the program not be eliminated.

Thank you for your consideration of the Tribe's requests with respect to these fiscal year 2019 appropriations.

PREPARED STATEMENT OF THE NORTHWEST PORTLAND AREA INDIAN HEALTH BOARD

My name is Andy Joseph, Jr., and I serve on the Colville Business Council, as Co-Chair of the IHS National Tribal Budget Formulation Workgroup, and as Chairman of the Northwest Portland Area Indian Health Board. Established in 1972, NPAIHB is a Public Law 93-638 tribal organization that represents 43 federally recognized Tribes in the States of Idaho, Oregon, and Washington (Tribes) on healthcare issues. Over 353,000 American Indian and Alaska Native (AI/AN) people reside in these three States, representing 6.8 percent of the Nation's AI/AN population. On behalf of our 43 Tribes, I thank you for this opportunity to provide testimony on the President's proposed budget for fiscal year 2019 for the Department of Health and Human Services (HHS) to the Senate Subcommittee on Labor, Health and Human Services, Education, and Related Agencies.

Secretary's Minority AIDS Initiative Fund (SMAIF)

SMAIF has been funded at \$54 million for the past several years with \$3.6 million to the Indian Health Service (IHS) for HIV/HCV prevention, treatment, outreach and education. Every year these funds are in jeopardy of being eliminated. SMAIF funding and Minority AIDS Initiative (MAI) funding go directly to Federal agencies for dispersal in the form of grants, capacity building, infrastructure, etc. Agencies open to MAI funds include the CDC, HRSA, OMH and SAMHSA (among others). In fiscal year 2017, \$3.6 million of SMAIF dollars were allocated to IHS for HIV/AIDS and HCV prevention, treatment, outreach and education. There is no other direct and strategic funding for IHS through the MAI, only SMAIF funds are available to IHS.

Rates of HIV diagnoses increased for American Indians/Alaska Natives (AI/ANs) in the period from 2010 to 2014.¹ A total of 2,273 AI/ANs met the definition of newly diagnosed with HIV from 2005 through 2014, an average annual rate of 15.1 per 100,000 AI/ANs. Most (356/391) IHS health facilities recorded at least 1 new HIV diagnosis. The rate of new HIV diagnoses among males (21.3 per 100,000 AI/ANs) was twice as high as that among females (9.5 per 100,000 AI/ANs; rate ratio = 2.2; 95 percent confidence interval, 2.1–2.4); by age, rates were highest among those aged 20–54 for males and females. By region, the Southwest region had the highest number (n = 1016) and rate (19.9 per 100,000 AI/ANs) of new HIV diagnoses. Overall annual rates of new HIV diagnoses were stable from 2010 through 2014, although diagnosis rates increased among males (P < .001) and those aged 15–19 (P < .001), 45–59 (P < .001), and 50–54 (P = .01).² Moreover, AI/ANs are disproportionately affected by the Hepatitis C virus and have both the highest rate of acute HCV (Hepatitis C) infection and the highest HCV-related mortality rate of any US racial/ethnic group. AI/AN HCV-related mortality rates in Idaho, Oregon and Washington is over three times that of non-Hispanic whites.

Given this data, any proposed cuts to HCV/HIV funding will have far reaching and harmful impacts on Indian Country's ability to maintain ongoing HIV/HCV prevention, treatment, and outreach efforts. It will also have a devastating impact on the Tribes and Tribal Epidemiology Centers that carry out this important work. NPAIHB receives SMAIF funding from IHS and has had great outcomes with its SMAIF projects. We provide summaries of three projects at the NPAIHB:

National HIV Prevention Capacity Building and Technical Assistance: The capacity-building program has: increased routine HIV, STI and HCV screening in settings where widespread screening has not been previously performed; increased the availability of treatment for people living with HIV/AIDS (PLWHA); increased the availability of treatment for Hepatitis C positive people; carried out outreach activities to engage PLWHA and Hepatitis C people in diagnosis and treatment, especially reaching populations at disproportionate risk; advanced IHS customer service improvements with LGBT individuals, with special emphasis on appropriate services for MSM and transgender; and advanced IHS policy and procedures to address HCV needs of the service population, with special emphasis on services for people co-infected with HIV and HCV. Most notably, the capacity building made available to IHS via SMAIF dollars has provided technical assistance for IHS to achieve the following in the most recent data: Coverage of unique persons who had ever had an HIV test between the ages of 13–64 years old increased to 52.3 percent (222,690/425,915), an improvement over 49 percent in 2017; and 56,337/103,734 unique patients born between 1945 and 1965, or 54.3 percent percent of total, have ever received an HCV test. This is an improvement over the previous year's rate of 45 percent.

Hepatitis C ECHO Project: The project works closely with IHS, Tribal and urban Indian health providers (I/T/U) to screen, manage and treat patients infected with HIV/AIDS and hepatitis C virus (HCV) within existing systems I/T/U clinics nationwide. Project ECHO is a collaborative model of medical education and care management that empowers clinicians to provide better care to more people, right where they live. The ECHO model does not actually "provide" care to patients. Instead, it dramatically increases access to specialty treatment in rural and underserved areas by providing front-line clinicians with the knowledge and support they need to manage patients with complex conditions. It does this by engaging clinicians in a contin-

¹Health Equity Report 2017, available at <https://www.hrsa.gov/sites/default/files/hrsa/health-equity/2017-HRSA-health-equity-report.pdf>.

²Assessing New Diagnoses of HIV Among American Indian/Alaska Natives Served by the Indian Health Service, 2005–2014, available at <http://journals.sagepub.com/eprint/BKUmmb39hZemwFNxx/full>.

uous learning system and partnering them with specialist mentors at an academic medical center or hub. As the ECHO model expands, it is helping to address some of the healthcare system's most intractable problems, including inadequate or disparities in access to care, rising costs, systemic inefficiencies, and unequal or slow diffusion of best practices. The HCV ECHO collaborative, started in February of 2017, has provided recommendations to 250 HIV/HCV patients and connected over 130 providers into the ECHO knowledge-sharing network.

We R Native Project: We R Native is a comprehensive, multimedia health resource for Native youth, by Native youth. The service includes an interactive website (www.weRnative.org), a text messaging service (Text NATIVE to 97779), a Facebook page, a YouTube channel, Instagram, Twitter, and print marketing materials. Special features include 100+ Youth Ambassadors and an "Ask Auntie" Q&A service. The website launched on September 28, 2012, with over 360 health and wellness pages. Since then, the site has received 549,481 page views with highest number of 235,778 sessions by 18–24 year olds and 189,115 users. We R Native also disseminates culturally-relevant, evidence-based HIV/STI behavioral interventions to AI/AN youth across the U.S.

Recommendation: Fund SMAIF for fiscal year 2019 at \$54 million for fiscal year 2019 with \$3.6 targeted for the IHS.

CENTERS FOR MEDICARE AND MEDICAID SERVICES

Medicaid Expansion, 100 percent FMAP and Affordable Care Act Subsidies (ACA)

The Medicaid program provides critical health coverage for AI/AN people and has also become a very important source of financing for healthcare for Indian health programs. Because the IHS budget has not received adequate increases to maintain current services, Medicaid provides crucial revenue for Indian health providers. Medicaid resources make up over 50 percent of many tribal health programs total funding. Most of the IHS budget increases are directed toward staffing new facilities and minimally finance inflation and population growth for the Indian health programs. The increased coverage and revenue associated with Medicaid expansion has had a very positive effect on Northwest Tribal health programs. It is essential that the Federal trust responsibility for Indian healthcare be honored, and 100 percent Federal Medical Assistance Percentage (FMAP) for services received through an IHS and Tribal facility is preserved. Portland Area Tribes are opposed to any reform proposals (e.g., block grants) designed to stop or reduce Federal spending on these programs or that eliminate ACA subsidies. ACA subsidies make insurance affordable for some AI/ANs and many tribes have premium sponsorship programs that provide critical services to AI/ANs and bring in critical revenue to tribal clinics.

Recommendation: Continue to fully fund Medicaid expansion, 100 percent FMAP for services through an IHS or Tribal facility, and ACA subsidies.

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

Opioid Crisis and Funding

Prescription overdoses impact every family member in tribal communities throughout the Portland Area (Idaho, Oregon, and Washington). In the Portland Area a race-corrected analysis found the age-adjusted drug overdose death rate for AI/ANs for opioid, prescription drug, and all drug overdoses to be twice that of non-Hispanic whites. From 2006 to 2012, a total of 10,565 deaths occurred among AI/AN residents in the States of Idaho, Oregon, and Washington. There were 584,070 deaths among non-Hispanic White (NHW) in the three-State region. Drug overdoses accounted for 4.3 percent (450) of all deaths among Northwest AI/ANs and 1.7 percent (9,868) of all deaths among NHWs. Of the drug overdose deaths, 65.3 percent (294) of AI/AN deaths and 69.3 percent (6,837) of NHW deaths were from prescription drugs. Of the prescription drug overdose deaths, 77.2 percent (227) of AI/AN deaths and 75.4 percent (5,157) of NHW deaths were from opioid overdoses.³ Nationally, in 2015, the Centers for Disease Control and Prevention (CDC) reported that AI/ANs had the highest national drug overdose death rates of any race in 2015, and a 519 percent increase in the number of non-metropolitan overdose deaths from 1999–2015.⁴

Misuse of prescription opioids commonly leads to the use of other drugs, such as heroin in tribal communities. The National Institute of Drug Abuse noted that 21 to 29 percent of patients prescribed opioids for chronic pain misuse them, and 4 to

³Northwest Portland Area Indian Health Board IDEA-NW Project. 2016. Unpublished death certificate data from Idaho, Oregon, and Washington.

⁴CDC Morbidity and Mortality Weekly Report (MMWR), available at https://www.cdc.gov/mmwr/volumes/66/ss/ss6619a1.htm?_cid=ss6619a1_w (last accessed March 8, 2018).

6 percent who misuse prescription opioids transition to heroin. Furthermore, the death rate for heroin overdoses among AI/ANs have dramatically increased, rising 236 percent from 2010 to 2014.⁵

NPAIHB appreciates the inclusion of \$4 billion to fight the opioid crisis in fiscal year 2018, particularly the \$50 million set-aside for tribes and tribal organizations in the recently passed Consolidated Appropriations Act of 2018 (H.R.1625) and would like to see this tripled for fiscal year 2019. The \$5 million in fiscal year 2018 appropriations specifically for tribes under the Medication-Assisted Treatment (MAT) for Prescription Drug and Opioid Addiction program is also crucial for tribal clinics to implement the MAT program and administer the life-saving treatment and this should also be tripled in fiscal year 2019.

Portland Area Tribes need direct funding and programs to address the opioid epidemic in their communities such as State Targeted Response to Opioid Epidemic grants (STR). Tribes should not have to compete for funding through States, which is an issue for many of our smaller tribes. NPAIHB also requests funding for both medicated-assisted treatment (MAT) and prevention; and funding for outreach, education and training on opioid use disorder (OUD), especially pharmacy education. In our area, the Swinomish Tribe has established an opioid addiction treatment center that includes wrap around services and a full continuum of care for patients—MAT, counseling, primary care and oral health services. Other tribes in the Portland Area are interested in establishing similar comprehensive and integrated care programs, but need funding to do this.

Recommendations: Provide a tribal set aside of direct funding, not competitive grants, to tribes and tribal organizations, including Tribal Epidemiology Centers, to address the opioid epidemic and other substance abuse issues in the amount of \$150 million and \$15 million for MAT in fiscal year 2019. Relatedly, support legislation that would make tribes eligible for direct funding under the 21st Century Cures Act and that would allow use of funding not only for prevention and response to Opioids but also other substances such as alcohol, heroin and methamphetamine, and include the provision of mental health services.

RECOMMENDATIONS FOR OTHER AGENCIES

—*Administration for Children and Families (ACF):* Continue to fully fund the Low Income Home Energy Assistance Program (LIHEAP) in fiscal year 2019, which assists many low income AI/ANs in the Northwest.

—*Centers for Disease Control and Prevention (CDC):* Support public health infrastructure funding in fiscal year 2019; and funding for the National Center for Chronic Disease Prevention and Health Promotion for fiscal year 2019 (not “America’s Health Block Grant” proposal).

—*Health Resources & Services Administration (HRSA):* Support level funding for Centers of Excellence for fiscal year 2019, which funds the Native American Center of Excellence at Oregon Health Sciences University.

Thank you for this opportunity to provide our recommendations on the fiscal year 2019 HHS budget. I invite you to visit our Portland Area Tribes to learn more about the utilization of HHS funding and healthcare and social service needs in our Area.⁶

[This statement was submitted by Andrew Joseph, Jr., Chairman, Northwest Portland Area Indian Health Board.]

PREPARED STATEMENT OF THE NORTHWEST RESOURCE ASSOCIATES

Northwest Resource Associates (NWRA) offers the following testimony requesting increased funds for the following five programs under the supervision of the Administration for Children and Families (ACF): Child Welfare Services (CWS), Promoting Safe and Stable Families, the Adoption and Kinship Incentives Fund, and the Adoption Opportunities Act.

In February, Congress passed the Family First Prevention Services Act (Public Law 115–123). The legislation has potential to expand services that can prevent the placement of children into foster care. It challenges States to reduce the number of children and youth in congregate placements. It will be a challenge to States to build the capacity and access to services (mental health, substance use, and in-home services) and to build the infrastructure of services and providers.

⁵Dan Nolan and Chris Amico, How Bad is the Opioid Epidemic?, PBS.org (Feb. 23, 2016), available at <https://www.pbs.org/wgbh/frontline/article/how-bad-is-the-opioid-epidemic/>.

⁶For more information, please contact Laura Platero, NPAIHB, at lplatero@npaihb.org.

The challenge is against a backdrop of ever increasing foster care numbers driven by the opioid epidemic in parts of the country. Since 2012 the number of children in foster care has increased by 10 percent to 437,000 in 2016. NWRRA believes it is critical for Congress to fully fund six programs to both build capacity to effectively implement the Family First Act and help address the crisis many communities are facing as foster care placement demands explode.

The Family First Act provides funding for services to prevent the placement of children in foster care but does not fund services to prevent child abuse and neglect. Child welfare strategy must significantly increase funding for child abuse prevention.

NWRRA calls on Congress to fully fund Child Welfare Services from \$269 million to \$325 million and Promoting Safe and Stable Families from \$99 million in discretionary funding to \$200 million; increase funding to the Adoption Opportunities Act to \$60 million; fully fund the Adoption and Kinship Incentives Fund at \$75 million.

Impact of Opioids on Child Abuse and Neglect and Foster Care

Earlier this year HHS through the Secretary of Planning and Evaluation conducted an analysis of child welfare data and supplemented that work with field level research. Some of the key findings included:

- A 10 percent increase in overdose death rates correspond to a 4.4 percent increase in the foster care entry rate and a 10 percent increase in the hospitalization rate due to drug use corresponds to a 3.3 percent increase in the foster care entry rate.
- While in past drug epidemics family and communities could fill some of the gaps, today agencies report that family members across generations may be experiencing substance use problems forcing greater reliance on State custody and non-relative care.
- Parents using substances have multiple problems including domestic violence, mental illness, trauma history, and addressing substance abuse alone is unlikely to be effective.
- Substance use assessment is haphazard and there is a lack of “family-friendly” treatment that includes family therapy, child care, parenting classes and developmental services.
- There is a shortage of foster homes and this is exacerbated by the need to keep children longer in care which keeps existing homes full and unable to accept new placements.

FAMILY FIRST ACT

In fiscal year 2020, Families First will allow States to draw funds for children and families at risk of foster care. States taking the optional services will be limited to evidence-based services for families that need intervention, post-adoption, and reunification services. States must engage in and coordinate public-private agencies experienced with providing child and family community-based services, including mental health, substance use, and public health providers. There is a limited supply of foster homes and family-based aftercare support that can provide for post-discharge services for children leaving institutional care. Child welfare agencies need to find and support more family-based foster care homes. These four funds can help States develop evidence-based services that will meet the laws “well-supported,” “supported,” and “promising” standards and can assist the coordination of community based behavioral health and human services.

Child Welfare Services (CWS), Title IV-B part 1

We ask for \$325 million for Child Welfare Services, the full authorization and above the current total of \$269 million. Starting in fiscal year 2020, the Families First Act will allow States to draw funds for children and families at risk of foster care. CWS is flexible enough to allow States to test out and develop these services and provide the research required to meet these evidence standards.

Promoting Safe and Stable Families (PSSF), Title IV-B part 2

We also asking for full funding of \$200 million for Promoting Safe and Stable Families. Currently this appropriations is set at \$99 million despite being authorized at \$200 million. These funds supplement \$345 million in mandatory funds divided between services, the courts, substance use treatment grants and workforce development. Appropriations to \$200 million could be used for the four key services under PSSF: family reunification, adoption support, family preservation and family support. There are limited services for reunification services for children who return to their families and the same is true of post adoption services. These will all be

eligible services under Family First but there are few models now eligible for funding.

The Adoption Opportunities Act

The Adoption Opportunities program is the Nation's oldest adoption program created to develop adoption promotion, post adoption services and strategies. It has funded grants to reduce barriers to adoption, reduce disproportionality, and more recently to promote adoptions of older youth in foster care and develop post-adoption services. It is funded at \$39 million. We ask for funding at \$60 million to develop evidence-based models for post adoption services to families.

The Adoption and Kinship Incentive Fund

We ask for a continued funding level of \$75 million for the adoption incentive fund. The fund was created in the Adoption and Safe Families Act (ASFA). In 2014 it became the Adoption and Legal Guardianship Incentive Payments Program. We thank the Appropriations Committee for partially addressing a recent shortfall in this incentive fund with the 2018 appropriations of \$75 million. In recent years HHS has been not been able to fully award States because of a reduced appropriation. As a result, HHS has made up the previous year's shortfall with the following year's appropriations. The \$75 million for fiscal year 2018 was a significant step in addressing the shortfall of 2017. In the beginning years Congress would recognize this and provide an extra amount of appropriation. Your 2018 appropriation reestablished this practice. When HHS issues the latest awards for fiscal year 2018, this September, there will have \$25 million remaining. That will likely fall short to fully fund the incentives. And we again ask for an appropriation of \$75 million to fully fund 2018 awards and have enough in place for fiscal year 2019.

These funds are reinvested by States into adoption services. These funds can be used by States to build both the evidence-based adoption services include post-adoption counseling and services that can prevent and reduce adoption disruption. NWRA thanks you for this consideration and stands ready to respond to your questions and concerns.

[This statement was submitted by Kendra Morris-Jacobson, Director of Oregon Programs, Northwest Resource Associates.]

PREPARED STATEMENT OF THE NURSING COMMUNITY COALITION

The Nursing Community Coalition is comprised of 59 national professional nursing associations that build consensus and advocate on a wide spectrum of healthcare issues that intersect education, research, practice, and regulation. Collectively, we represent over one million Registered Nurses (RNs), Advanced Practice Registered Nurses (including Certified Nurse-Midwives, Nurse Practitioners, Clinical Nurse Specialists, and Certified Registered Nurse Anesthetists), nurse executives, nursing students, faculty, and researchers, as well as other nurses with advanced degrees. The Nursing Community Coalition commends Congress' investment to nursing education and research in the fiscal year 2018 Consolidated Appropriations Act [Public Law 115-141]. To continue the forward progress this will enact, our organizations respectfully request \$266 million for the Nursing Workforce Development Programs (authorized under Title VIII of the Public Health Service Act [42 U.S.C. 296 et seq.]), administered by the Health Resources and Services Administration (HRSA), and \$170 million for the National Institute of Nursing Research (NINR), one of the 27 Institutes and Centers within the National Institutes of Health (NIH) in fiscal year 2019.¹

TITLE VIII PROGRAMS: AMERICA'S PATIENTS NEED NURSING CARE

As integral members of the healthcare team, nurses collaborate with other professions and disciplines to improve the quality of America's healthcare system. RNs comprise the largest group of health professionals with almost four million licensed providers in the country.² A constant focus must be placed on education, recruitment, and retention to ensure a stable workforce as projections cite an impending

¹For Fiscal Year 2019, the Ad Hoc Group for Medical Research is recommending at least \$39.3 billion for the NIH, including funds provided to the agency through the 21st Century Cures Act for targeted initiatives. The request level of \$170 million for NINR denotes the same percentage increase for NIH applied to NINR.

²National Council of State Boards of Nursing. (2018). Active RN Licenses: A profile of nursing licensure in the U.S. as of April 18, 2018. Retrieved from: <https://www.ncsbn.org/6161.htm>.

shortage largely due to retirements within the profession.³ Investments must continue to be made in the education of new nurses and nurse faculty to ensure the Nation will have access to the services it will demand for years to come, particularly in rural and underserved areas.

According to HRSA, there were over 84.3 million individuals living in Health Professional Shortage Areas as of December 2017.⁴ The Title VIII programs provide nursing students and practicing nurses exposure to caring for underserved communities, which helps to bolster recruitment and retention in these areas. In academic year 2015–2016, a total of 3,034 nursing students were supported by the Advanced Education Nursing Traineeship, 59 percent of which were serving in medically underserved communities.⁵ Of the 2,491 nurse anesthetist students supported by the Nurse Anesthetists Traineeship, 70 percent received clinical training in medically underserved communities in the 2015–2016 academic year.⁵

Additionally, the Title VIII NURSE Corps Loan Repayment and Scholarship Programs assist students who agree to serve at least 3 years in facilities experiencing a critical shortage of nurses.⁵ In fiscal year 2016, 55 percent of recipients extended their service contracts to work in these facilities beyond the required 3 years.⁵ Clearly, these programs are instrumental to connecting current and future providers to patient populations most in need.

The Nursing Community respectfully requests \$266 million for the Nursing Workforce Development programs in fiscal year 2019, which include the following:

- Advanced Nursing Education Program (Sec. 811), including the Advanced Education Nursing Traineeships and Nurse Anesthetist Traineeships
- Nursing Workforce Diversity (Sec. 821)
- Nurse Education, Practice, Quality, and Retention (Sec. 831)
- NURSE Corps Loan Repayment and Scholarship Program (Sec. 846)
- Nurse Faculty Loan Program (Sec. 846A)
- Comprehensive Geriatric Education Program (Sec. 855)

NATIONAL INSTITUTE OF NURSING RESEARCH: FOUNDATION FOR EVIDENCE-BASED CARE

NINR funds research that lays the groundwork for evidence-based nursing practice. NINR examines ways to improve care models to deliver safe, high-quality, and cost-effective health services. Research funded through NINR stands with the larger research community by focusing on national level issues such as precision health and the opioid crisis. One of NINR's recently featured research studies focused on the relationship between opioid treatment and the rate of healing in chronic wounds. Notably, the study suggests that opioid use reduces immune activity, thus negatively impacting patients with chronic wounds.⁶ This type of timely research has implications that will drive the evidence-based care nurses, and other providers, deliver in the future.

NINR's Strategic Plan includes the themes of: symptom science for patients with chronic illness and pain; wellness to prevent illness across conditions, settings, and the lifespan; patient self-management to improve quality of life; and end-of-life and palliative care science.⁷ Nursing science offers a unique lens in finding solutions as it considers healing and symptom management, as described in NINR's Strategic Plan. Moreover, NINR allots a generous portion of its budget towards training new nursing scientists, thus helping to sustain the longevity and success of nursing research. Training programs at NINR develop future nurse researchers, many of whom also serve as faculty in our nation's nursing schools.

³"In 2015, the nursing workforce lost 1.7 million experience-years [due to retirees]." Buerhaus, Peter I., Skinner, Lucy E., Auerbach, David L., Saiger, Douglas O. et al. 2017. Four Challenges Facing the Nursing Workforce in the United States. *Journal of Nursing Regulation*. Volume 8, Issue 2, pp. 40–46.

⁴U.S. Health Resources and Services Administration. (2018). Designated Health Professional Shortage Areas Statistics. Retrieved from: https://ersrs.hrsa.gov/ReportServer?/HGDW_Reports/BCD_HPSA/BCD_HPSA_SCR50_Qtr_Smry_HTML&rc:Toolbar=false.

⁵U.S. Department of Health and Human Services. (2018). Health Resources and Services Administration Fiscal Year 2018 Justification of Estimates for Appropriations Committees. Retrieved from: <https://www.hrsa.gov/sites/default/files/hrsa/about/budget/budget-justification-2018.pdf>.

⁶Shanmugam, V K, et al. "Relationship between Opioid Treatment and Rate of Healing in Chronic Wounds." *Advances in Pediatrics*, U.S. National Library of Medicine, Jan. 2017, www.ncbi.nlm.nih.gov/pubmed/27865036.

⁷National Institutes of Health. National Institute of Nursing Research. Implementing NINR's Strategic Plan: Key Themes. Retrieved from: http://www.ninr.nih.gov/aboutninr/keythemes#VRVhGWZ_SSU.

The Nursing Community respectfully requests \$170 million for the NINR in fiscal year 2019.

Continued increased investments in the Title VIII programs and NINR will strengthen the nation's health by bolstering the workforce and the science that is foundational to the care nurses provide across the country and in every community. Thank you for your support of these crucial programs.

Members of the Nursing Community Coalition Submitting this Testimony

Academy of Medical-Surgical Nurses
 American Academy of Ambulatory Care 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 Assessment Coordination
 American Association of Nurse Practitioners
 American College of Nurse-Midwives
 American Nephrology Nurses Association
 American Nurses Association
 American Nursing Informatics Association
 American Organization of Nurse Executives
 American Pediatric Surgical Nurses Association
 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
 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 Neonatal Nurse Practitioners
 National Association of Neonatal Nurses
 National Association of Nurse Practitioners in Women's Health
 National Association of Pediatric Nurse Practitioners
 National Association of School Nurses
 National Black Nurses Association
 National Council of State Boards of Nursing
 National Forum of State Nursing Workforce Centers
 National League for Nursing
 National Nurse-Led Care Consortium
 National Organization of Nurse Practitioner Faculties
 Nurses Organization of Veterans Affairs
 Oncology Nursing Society
 Organization for Associate Degree Nursing
 Pediatric Endocrinology Nursing Society
 Preventive Cardiovascular Nurses Association
 Society of Pediatric Nurses
 Wound, Ostomy and Continence Nurses Society

PREPARED STATEMENT OF ORAL HEALTH AMERICA

Chairman Blunt, Ranking Member Murray, and distinguished Members of the Subcommittee, Oral Health America (OHA), a leading organization dedicated to changing lives by connecting communities with resources to drive access to care, increase health literacy and advocate for policies that improve overall health through better oral health for all Americans, especially those most vulnerable; is grateful to Congress for increased Federal investment for all programs administered by the Older Americans Act (OAA) (U.S. Department of Health and Human Services, Administration for Community Living) provided in the fiscal year 2018 omnibus appropriations bill. Of interest to OHA is Title III–D, Disease Prevention and Health Promotion, because of the cost-effectiveness that health education, health promotion, and disease prevention programs provide to the system. OHA applauds Congress for providing \$24,848,000 to Title III–D funding for fiscal year 2018, \$5 million above the fiscal year 2017 enacted level. OHA also applauds the \$180,586,000 fiscal year 2018 appropriation for Title III–E, National Family Caregivers Support Program, \$30 million above the fiscal year 2017 enacted level, because of the range of critical support services it provides to family caregivers, who number approximately 40 million individuals.

The fiscal year 2018 enacted levels for all OAA programs will aid their restoration following several fiscal years of decreased or plateaued funding levels. As our Nation's older adult population grows, so too, must our Nation's investment in OAA programs. Therefore, for fiscal year 2019, we request the Subcommittee—at the minimum—to preserve fiscal year 2018 funding levels for OAA programs. However, we strongly recommend the Subcommittee to continue to nurture OAA programs and build off of fiscal year 2018's appropriation with increased investment, especially for Title III–D Disease Prevention and Health Promotion and Title III–E National Family Caregivers Support Program.

The OAA provides Federal programs that serve to meet the needs of millions of older Americans. We understand the United States continues to operate amid a challenging budgetary environment. However, OHA believes that proper Federal investment in the OAA is critical to keep pace with the rate of inflation and to meet the needs of this ever-growing segment of the population through the multitude of services the OAA provides. Simply stated, proper investment in OAA saves taxpayer dollars. This is especially evident when it comes to health services. Health services that emphasize prevention and promotion will help to reduce disease, leading to the improvement of the overall health and well-being of America's older adults and resulting in the reduction of premature and costly medical interventions. OHA strongly contends that one's health and overall well-being begins with proper oral health. This core belief applies throughout the lifespan and especially with older adults.

BACKGROUND

The population of the United States is aging at an unprecedented rate. Older adults make up one of the fastest growing segments of the American population. In 2009, 39.6 million seniors were U.S. residents. This aging cohort is expected to reach 72.1 million by 2030—an increase of 82 percent.¹

The oral health of older Americans is in a state of decay. The reasons for this are complex. Limited access to dental insurance, affordable dental services, community water fluoridation, and programs that support oral health prevention and education for older Americans are significant factors that contribute to the unmet dental needs and edentulism among older adults, particularly those most vulnerable. While improvements in oral health across the lifespan have been observed in the last half century, long term concern may be warranted for the 10,000 Americans retiring daily, as it is estimated that only 9.8 percent of this “silver tsunami”—baby boomers turning age 65—will have access to dental insurance benefits.²

Dental Health and Disparities: Oral health data reveals that many older adults experience adverse oral health associated with chronic and systemic health conditions. For example, associations between heart disease, periodontitis and diabetes have emerged in recent years, as well as oral conditions such as xerostomia associated with the use of prescription drugs.^{3,4} Xerostomia, commonly known as dry

¹Administration on Aging. (2013). Aging Statistics. Retrieved from http://www.aoa.gov/Aging_Statistics/.

²Consumer Survey, National Association of Dental Plans. 2012.

³Ira B. Lamster, DDS, MMSc, Evanthia Lalla, DDS, MS, Wenche S. Borgnakke, DDS, PhD and George W. Taylor, DMD, DrPH. (2008). Journal of the American Dental Association.

mouth, contributes to the inception and progression of dental caries (cavities). For older Americans, the occurrence or recurrence of dental caries coupled with an inability to access treatment may lead to significant pain and suffering along with other detrimental health effects.

These oral conditions disproportionately affect persons with low income, racial and ethnic minorities, and those who have limited or no access to dental insurance. Older adults with physical and intellectual disabilities and those persons who are homebound or institutionalized are also at greater risk for poor oral health.⁵

As examples of these disparities, older African American adults are 1.88 times more likely than their white counterparts to have periodontitis;⁶ low-income older adults suffer more than twice the rate of gum disease than their more affluent peers (17.49 versus 8.62 respectively); and Americans who live in poverty are 61 percent more likely to have lost all of their teeth when compared to those in higher socioeconomic groups.

Aging in Place: Despite these existing conditions, recent dental public health trends demonstrate that as the population at large ages, older Americans are increasingly retaining their natural teeth.⁷ Today, many older adults benefit from healthy aging associated with the retention of their natural teeth, improvements in their ability to chew, and the ability to enjoy a variety of food choices not previously experienced by earlier generations of their peers.

Nearly 90 percent of older adults want to stay in their own homes as they age, often referred to as “Aging in Place.” Today’s older adults are living more independently than previous generations. In fact, only 9 percent of older adults live in a long-term care setting. Maintaining a healthy mouth is one of the keys to independence as we age, however resources for oral health remain conspicuously absent from home and community-based services and are largely disconnected and difficult to access.

Oral Care Provider Issues: Although a growing number of older Americans need oral healthcare, the current workforce is challenged to meet the needs of older adults. The current dental workforce is aging, and many dental professionals will retire within the next decade. A lack of geriatric specialty programs complicates this problem, and few practitioners are choosing geriatrics as their field of choice.

While these trends are favorable, adverse oral health consequences are emerging. Due to reasons stated in this report, together with increased demand for services, lack of access to dental benefits through Medicare, increased morbidity and mobility among older adults, and reduced income associated with aging and retirement, many older Americans are unable to access oral healthcare services. As a result, many older adults who have retained their natural teeth are now experiencing dental problems.

OLDER ADULTS’ ORAL HEALTH IN STATE OF DECAY

OHA’s 2018 A State of Decay, Vol. IV report is a state-by-state analysis of oral healthcare delivery and public health factors impacting the oral health of older adults. The report revealed more than two-thirds of the country received a “fair” or “poor” assessment when it comes to minimal standards affecting dental care access for older adults. The top findings of the report were:

- One-third (33 percent) of older adults have lost six or more teeth.
- 25 U.S. states received a poor overall score based six key performance measures.
- Minnesota, Wisconsin, Iowa, Connecticut and Colorado all earned an “Excellent” Composite Score. Iowa and California made big improvements, jumping from 23 and 30, respectively, in 2016, to 3 and 9 in 2018.
- The States with the lowest overall scores are Wyoming, Delaware, West Virginia, New Jersey, Arkansas, Texas, Oklahoma, Louisiana and Tennessee, with Mississippi’s score being the least favorable. Alabama improved from 50 in 2016 to 29 in 2018.

⁴Fox, Philip C. (2008). Xerostomia: Recognition and Management. Retrieved from: http://www.colgateprofessional.com/hk/LeadershipHK/ProfessionalEducation/Articles/Resources/profed_art_access-supplement-2008-xerostomia.pdf.

⁵U.S. Department of Health and Human Services. (2000). Oral Health in America: A Report of the Surgeon General. Retrieved from <http://silk.nih.gov/public/hck1ocv/www.surgeon.fullrpt.pdf>.

⁶Borrel, L.N., Burt, B.A., & Taylor, G.W. (2005, October). Prevalence and Trends in Periodontitis in the USA: from the NHANES III to the NHANES, 1988 to 2000. *Journal of Dental Research*, 84(10). Retrieved from <http://jdr.sagepub.com/content/84/10/924.abstract>.

⁷Dolan, T. A., Atchison, K., & Huynh, T. N. (2005). Access to Dental Care Among Older Adults in the United States. *Journal of Dental Education*, 69(9), 961–974. Retrieved from <http://www.jdentaled.org/content/69/9/961.long>.

- Community water fluoridation (CWF) increased from a State average of 71.9 percent in 2016 to 72.6 percent in 2018, a national increase of about 2.2 million people.
- Medicaid coverage of oral health benefits increased. Two States (Delaware and South Dakota) provided no benefits in 2016 but added some of the 13 services measured in this 2018 survey.
- More State oral health officials are including older adults in State Oral Health Plans (SOHP) and administering Basic Screening Surveys (BSS) that include seniors. The 2018 data show 34 States have SOHPs; 31 include older adults.
- Sociodemographic factors, such as income, race, gender and education play a critical role in oral health outcomes. The severe tooth loss and recent dental visit data analyzed individually on a national basis, showed an association with household income. Low household income directly correlates with predicted measures of poor oral health. As income levels rose, so did the probability of good oral health.

Moreover, poor oral health has substantial financial implications. For example, in 2010 alone, between \$867 million and \$2.1 billion was spent on emergency dental procedures.⁸ When compared to care delivered in a dentist's office, hospital treatments are nearly ten times more expensive than the routine care that could have prevented the emergency. This places a costly, yet avoidable, burden on both the individual and the health institutions that must then bear the expense.

In sum, oral health and access to preventive care significantly impact overall health and expenditure yet are difficult to maintain—particularly for older adults—in the Nation's present context of support systems and healthcare.

CAREGIVING & ORAL HEALTH

Caregiving is important to the oral health community. Family caregivers help with a myriad of activities for daily living, which include performing tasks related to oral healthcare. Moreover, family caregivers generally do not receive training or other instruction to help them provide proper oral care. Preventing oral diseases in older adults requires a caregiver's understanding of the risk factors for oral diseases and how these risk factors change over time. For example, there is a recognized association between periodontal disease and diabetes. In addition, older adults make up a small portion of the population today but consume 30 percent of all prescription medications, some of which can have a negative impact upon oral health. Therefore, oral health education of family, caregivers, and the aging network is essential if oral diseases are to be avoided later in life or if optimal oral health is to be achieved. The National Family Caregivers Support Program is quite vital to providing such training, education, and support services to family caregivers.

HOW OHA EMPOWERS OLDER ADULTS TO MEET THEIR ORAL HEALTH NEEDS

Oral Health America's Wisdom Tooth Project® aims to change the lives of older adults especially vulnerable to oral disease. Its goal is to educate Americans about the oral health needs of older adults, connect older adults to local resources, and to advocate for policies that will improve the oral health of older adults. The Wisdom Tooth Project achieves these goals through five strategies: our web portal, regional symposia, communications, advocacy and demonstration projects.

In addition to the A State of Decay report referenced above, a vital component of the Wisdom Tooth Project is Toothwisdom.org, which is a first-of-its-kind website created to connect older adults and their caregivers to local care and education around the oral health issues they face, the importance of continuing prevention as we age, and the overall impact of oral health on overall health.

IMPORTANCE OF OAA REAUTHORIZATION TO ORAL HEALTH OF OLDER ADULTS

Recognizing this current state of oral health among older adults, Oral Health America vigorously applauded the enactment of the reauthorization of the Older Americans Act in April 2016. The law includes—for the first time—a small provision that allows the Aging Network to utilize OAA funding to conduct oral health screenings. Preventive dental care that can be provided through oral health screenings can head off more expensive dental work and help prevent severe diseases. Unfortunately, dentists see older adults everyday living with infection and pain that could be easily avoided with proper care that these screenings could provide. Currently, OHA is working with partners on a pilot project to test the imple-

⁸Wall, Thomas and Nasseh, Dr. Kamyar, "Dental-Related Emergency Department Visits on the Increase in the United States," Health Policy Institute, ADA, May 2013, http://www.ada.org/~media/ADA/Science%20and%20Research/HPI/Files/HPIBrief_0513_1.ashx.

mentation of the oral health screening process. OHA is proud to play a role in its implementation. Finally, and most important, OAA now recognizes the importance of oral health and its role in disease prevention. We view this as a step toward improving the oral—and overall—health of older adults.

RECOMMENDATION

It is evident the United States' healthcare system is woefully unprepared to meet the oral health challenges of a burgeoning population of older adults with special needs, chronic disease complications, and a growing inability to access and pay for dental services. However, the benefits of proper oral hygiene and routine care for older adults to our Nation's healthcare system and economy are also quite clear. Through OHA's Wisdom Tooth Project, OHA aspires to change the lives of older adults especially vulnerable to oral disease. OHA views proper funding of the Older Americans Act as a crucial Federal investment vehicle to advance health promotion and disease prevention among our Nation's elderly as well as providing vital support to family caregivers who must look after their well-being. The increased investment provided to OAA programs for fiscal year 2018, for which OHA and its stakeholders are grateful, will help. Therefore, OHA recommends the Subcommittee—at the minimum—to preserve fiscal year 2018 funding levels for OAA programs. However, we strongly recommend the Subcommittee to continue to nurture OAA programs and build off of fiscal year 2018's appropriation with increased investment for fiscal year 2019, especially for Title III–D Disease Prevention and Health Promotion and Title III–E National Family Caregivers Support Program.

Thank you for the opportunity to present and submit our written testimony before the Subcommittee.

[This statement was submitted by Beth Truett, CEO/President, Oral Health America.]

PREPARED STATEMENT OF ORAL HEALTH AMERICA

Chairman Blunt, Ranking Member Murray, and distinguished Members of the Subcommittee, Oral Health America (OHA), a leading organization dedicated to changing lives by connecting communities with resources to drive access to care, increase health literacy and advocate for policies that improve overall health through better oral health for all Americans, especially those most vulnerable; respectfully request that funding for the Oral Health Training and Workforce Programs at the Health Resources and Services Administration (HRSA) at the U.S. Department of Health and Human Services, which have been recommended for elimination in the Administration's fiscal year 2019 Budget request, be restored and appropriated \$44 million for fiscal year 2019. We are grateful to Congress that it provided \$40,673,000 for fiscal year 2018, and we request that Congress builds off this investment to such an effective program that benefits underserved urban and rural areas of our Nation.

The Oral Health Training and Workforce Programs at HRSA include: Dental Faculty Development and Loan Repayment Program (DFDLRP), Faculty Development in Dentistry (FDD), Post-doctoral Training (PDD), Pre-doctoral Training (PD), and State Oral Health Workforce Program (SOHWP). These programs are designed to enhance access to oral health services by increasing the number of oral healthcare providers working in underserved areas and improving training programs for oral healthcare providers. Further, they serve to increase the number of medical graduates from minority and disadvantaged backgrounds and to encourage students and residents to choose primary care fields and practice in underserved urban and rural areas. Under these programs, training exists for general, pediatric, and public health dentistry students and residents; and dental hygiene students. In academic year 2016–17, Oral Health Training Programs trained 7,079 dental/oral healthcare providers in these disciplines.

Statistics that speak to the effectiveness of the Oral Health Training and Workforce Program during the 2016–17 academic year¹ include:

Dental Faculty Development and Loan Repayment Program

One example of a grant that exemplifies the effectiveness of this program provided training and educational opportunities for dentists that treat patients with special needs in community dental settings in Florida. In turn, the program pro-

¹ <https://bhwa.hrsa.gov/sites/default/files/bhw/health-workforce-analysis/program-highlights/oral-health-training-program-2017.pdf>.

vided loan repayment for the community dentists that commit to this enhanced training. The end benefit is that it leads to the treatment of more special needs patients and the students gain more experience with this population prior to graduation.

—Faculty trained 1,904 dental students, including general dentistry residents (70 percent), pediatric dentistry residents (16 percent), and public health dentistry residents (4 percent).

Faculty Development in Dentistry

Many faculty members come into dental education with no background in teaching, particularly adult learning and critical thinking. In addition, many clinical faculty members do not possess the strong scientific or educational backgrounds necessary to evaluate how well they are teaching and whether new teaching methods are better than others.

—Faculty who received direct grant support as instructors trained 2,017 dental students, general dentistry residents, and pediatric dentistry residents.

Pre-Doctoral Training

Awardees trained 5,291 dental and dental hygiene students, 15 percent of whom were from a disadvantaged background and 16 percent were from an underrepresented minority. Awardees partnered with 175 clinical training sites, 71 percent in a medically underserved community, 30 percent in a primary care setting, and 16 percent in a rural setting.

Post-Doctoral Training

A PDD training grant allowed a university's school of Dentistry to expand its 2-year Advanced Education in General Dentistry, which provided a pathway to Florida licensure for qualified internationally trained dentists. In States that are diverse in population, such as Florida, training of a workforce that mirrors the State's composition is essential to improve disparities in care. Additionally, HRSA estimates that by 2025, we will have a workforce shortage of over 1,000 dental practitioners, which will disproportionately impact access to vulnerable populations. These grants also support Dental Public Health Residency programs at universities.

—The program produced 259 newly specialized dentists who completed their dental residencies and entered the healthcare workforce. Of these new dentists, 58 percent were in General Dentistry, 37 percent in Pediatric Dentistry, and 5 percent in Public Health Dentistry.

—Awardees partnered with 140 clinical training sites, 64 percent in a medically underserved community, 53 percent in a primary care setting, and 7 percent in a rural setting.

State Oral Health Workforce Program

Furthermore, State Oral Health Workforce Program grants are critical. State governments use them to improve State dental public health programs and to test innovative new approaches to improve oral health. One HRSA Workforce Improvement grant awarded to Maryland enabled the State health department to integrate oral and primary care medical delivery systems for underserved communities and expanded community-based dental facilities, free-standing dental clinics, school-linked dental facilities, and mobile or portable dental clinics. Another Workforce Improvement grant in Alabama made a significant impact on the lives of graduating dentists, currently practicing dentists interested in additional training to treat special needs patients, and in access to dental care for a host of people in rural and underserved areas around the State. Due to the impact of the HRSA grant, nine new access points for dental services were established in rural and underserved areas of the State.

—Approximately 31 percent of SOHWP-supported students and dental residents reported coming from a rural background.

—Nearly all dentists (over 99 percent) who received SOHWP loan repayment reported practicing in dental Health Professions Shortage Areas and served 2,592 Medicaid/CHIP patients.

RECOMMENDATION

Clearly, the Oral Health Training and Workforce Programs at HRSA have proven to be effective, increase the number of medical graduates from minority and disadvantaged backgrounds and to encourage students and residents to choose primary care fields and practice in underserved urban and rural areas. Moreover, grants administered by these programs are oftentimes the primary source in this country for

training in these critical areas. Therefore, we request that you restore and appropriate \$44 million for the Oral Health Training and Workforce Programs at HRSA.

Thank you for the opportunity to present and submit our written testimony before the Subcommittee.

[This statement was submitted by Beth Truett, CEO/President, Oral Health America.]

PREPARED STATEMENT OF PATH

This testimony is submitted by Carolyn Reynolds, on behalf of PATH, an international nonprofit organization that drives transformative innovation to save lives and improve health in low- and middle-income countries. PATH is appreciative of the opportunity afforded by Chairman Blunt, Ranking Member Murray, and members of the Subcommittee on Labor, Health and Human Services, Education and Related Agencies to submit written testimony regarding fiscal year 2019 funding for global health programs within the U.S. Department of Health and Human Services (HHS). PATH acknowledges the strong leadership the Committee has shown in supporting HHS' work in this area, and recommends that support continue. Therefore, we respectfully request that this Subcommittee maintain funding to HHS in fiscal year 2019—including that the Centers for Disease Control and Prevention's (CDC's) Center for Global Health (CGH) is funded at no less than \$488.62 million, sustaining programming for research and development, malaria, and immunization. CDC's Division of Global Health Protection funding should be increased from \$108.2 million to \$208.2 million to bridge the funding gap created by the expiring Ebola supplemental in fiscal year 2019—this specific division capitalizes on the agency's technical expertise to improve health and increase security, while bolstering the ability of partner countries to lead in the future. We also request the creation of a \$70 million Emergency Reserve Fund at HHS—similar to the one established in the fiscal year 2017 Omnibus for USAID—to quickly respond to disease outbreaks, and a separate line item for Emerging Infectious Diseases (EID)s within BARDA to enable work beyond pandemic influenza, with an appropriation at a minimum of \$300 million.

The Vital Role of HHS in Global Health and Security

Disease outbreaks pose direct threats to US national security and place added burdens on fragile health systems. The recent Ebola and Zika epidemics, and emerging crises such as antimicrobial resistance, further demonstrate the influence that health security—or a lack of it—can have on American health. US investments in global health security and deployed CDC personnel are making America safer today. CDC's health security personnel and resources were indispensable in averting crisis during the 2017 responses to outbreaks of Ebola in the Democratic Republic of the Congo and Marburg in Uganda. Other departments such as National Institute of Allergy and Infectious Diseases (NIAID), the Fogarty International Center, and Biomedical Advanced Research and Development Authority (BARDA) support these efforts by building critical overseas capacity to stop the spread of deadly diseases and investing in new tools and technologies to prevent, detect and treat future outbreaks.

Yet as it currently stands, most of CDC's funding for global health security is set to expire at the end of September 2019, forcing the withdrawal of deployed capabilities to stop outbreaks at the source remain into the future. This drives the United States into a reactive position to face massive government expenditures and military interventions. The ongoing threat that infectious disease poses to American health, economic, and national security interests demands dedicated and steady funding for global health security, as much as we continue to invest in a strong military. Pulling back could result in a 100-fold more costly response later in terms of lives and treasure. Congress must ensure that the United States prioritizes investments in our global health security capability.

Immunization

HHS is also achieving complementary global health and security goals through investment in immunization, with the majority of vaccine delivery activities overseen by CDC's Global Immunization Division. Vaccines are among the most high-impact and cost-effective tools to combat infectious disease threats available today. Through 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, preventing an estimated 2.5 million deaths among children under the age of 5 each year. As well as protecting the health of children,

immunization programs further support the creation of better disease detection and health systems to help thwart other threats. As diseases do not respect borders, and travel as easily as people within countries and across continents, bolstering local systems helps safeguard Americans by containing disease outbreaks before they spread.

For example, the CDC serves as the lead US technical agency in providing scientific, research, and programmatic leadership for polio eradication. Sustained investment and policy leadership by HHS will enable the eradication and certification of a polio-free world. CDC's Strategic Framework for Global Immunization 2016—2020 builds upon CDC's 50 year history in effective immunization programming to increase vaccine coverage and protect Americans at home. We urge the committee to continue to fully fund global immunization programs, including polio and measles.

Fighting to Eliminate Malaria

CDC plays a critical role as a 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, providing technical assistance, with a focus on monitoring, evaluation, surveillance, as well as operational and implementation research. Malaria prevention and treatment programs have averted 6.8 million deaths globally since 2000. An estimated 263 million of the malaria cases averted by malaria control programs would have required care in the public sector, translating into \$900 million in savings in government healthcare spending. This progress could not have been accomplished without a sustained US commitment to combating the disease.

With incidence and death rates still unacceptably high in addition to evidence of growing insecticide and drug resistance, CDC's research to develop and evaluate interventions demonstrates new approaches to better fight this long-standing and ever-changing disease. With PMI's new strategy and expansion, CDC's mandate has grown, while its budget for malaria has been flat. In fiscal year 2019, Congress should fully fund PMI and the CDC Parasitic Diseases and Malaria (DPDM) program, to ensure prioritization of research and development of new tools. Congress should also exercise its oversight of all relevant US agencies that are implementing malaria programs to ensure that the goal of elimination is a priority and that programs are monitored and evaluated for efficiency, cost-effectiveness, and progress toward a world free from malaria.

Protecting the U.S. Through Leadership in Global Health R&D

While access to proven health interventions must be extended, it is also critical to support research and development into new technologies that can prevent emerging global health threats.

For example, new and improved vaccines, such as an effective, low-cost vaccine against meningitis A—a disease that historically caused devastating outbreaks each year in Africa's Meningitis Belt—which was developed and delivered by CDC. Zero cases of meningitis A have occurred among the more than 235 million Africans vaccinated since 2010. In response to the 2014 outbreak, US funding for Ebola R&D increased from negligible levels in 2013, to \$101 million in 2014, to \$298 million in 2015, resulting in four new products for Ebola and select viral hemorrhagic fevers being registered, and the advancement of 11 new US-supported Ebola products in the development process. These efforts were supported by the CDC as well as NIH, BARDA and agencies outside HHS, which all played unique and critical roles in the product development process.

Within HHS, the Biological Advanced Research and Development Authority (BARDA) plays an unmatched role across the U.S. Government by providing an integrated, systematic approach to the development and purchase of critical health technologies for public health emergencies. PATH has worked closely with BARDA to enhance manufacturing capacity for these products in developing countries. Continued support of BARDA's work will help ensure vaccine supplies are available worldwide to help stop the spread of pandemics and enhance American's health security. BARDA has also played a vital role in the development of urgently needed countermeasures for emerging infectious diseases (EIDs) like Ebola and Zika—developing three Ebola vaccine candidates, six diagnostics for Zika, and five Zika vaccine candidates in under 2 years. To date, BARDA's work in advancing tools to protect against the threat of EIDs has been funded through emergency funding. To ensure the continuation of this critical work, PATH supports the creation of a separate line item for EIDs within BARDA, with an appropriation at a minimum of \$300 million.

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, while at the same time investing in solutions to tomorrow's challenges. By fully funding the global health and BARDA accounts, the US can protect the health of Americans while ensuring that people everywhere have the opportunity to lead healthy lives and reach their full potential.

[This statement was submitted by Carolyn Reynolds, Vice President, Advocacy and Public Policy, PATH.]

PREPARED STATEMENT OF ANN D. PEEL

Mr. Chairman, Amyloidosis is a rare and often fatal disease. I ask that you include language in the Committee's report for fiscal year 2019 recommending that NIH expand its research efforts into amyloidosis, a group of rare diseases characterized by abnormally folded protein deposits in tissues. I also ask that the Committee direct NIH to inform the Committee 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.

Mr. Chairman, I have presented Congressional testimony related to Amyloidosis for more than a decade. I want to thank you for the language included by the Senate Appropriations Committee in the fiscal year 2018 Health and Human Services report. Your Committee over the years has been instrumental in moving forward to finding the causes and a cure for Amyloidosis.

I wish I could report to you today that the efforts of NIH and others have solved the problem. However, there is no known cure for amyloidosis. I urge you to continue the efforts of this Committee to help people with amyloidosis have hope for the future.

Current methods of treatment are risky and unsuitable for many patients. 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 15 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.

Amyloidosis remains a threat, even for people with successful treatment. After 13 years of no amyloidosis symptoms, last year I underwent 5 months of chemotherapy to address concerns that signs of amyloidosis were developing.

This additional treatment has been effective. 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 14 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.

AMYLOIDOSIS

Amyloidosis occurs when unfolded or misfolded proteins form amyloid fibrils and are deposited in organs, such as the heart, kidneys and liver. These misfolded proteins clog the organs until they no longer are able to function-sometimes at a very rapid pace. I have been treated for primary amyloidosis, a blood or bone marrow disorder.

Amyloidosis can cause heart, kidney, or liver dysfunction and failure and severe neurologic problems. Left untreated, the average survival is about 15 months from the time of diagnosis.

Amyloidosis can literally kill people before they even know that they have the disease.

Researchers have not been able to determine the root cause of the disease or an effective low-risk treatment. The patients with amyloidosis who are able to obtain treatment face challenges that can include high dose chemotherapy and stem cell transplantation or organ transplantation.

Amyloidosis is vastly under-diagnosed. Thousands of people die because they were diagnosed too late to obtain effective treatment. Thousands of others die never knowing they had amyloidosis.

In addition to primary amyloidosis, there are also thousands of cases of inherited (familial) and age-related amyloidosis. The most common familial type of amyloidosis was found to be caused by mutations in a protein made in the liver. This is

the form of amyloidosis that may be present in a significant number of African-Americans.

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.

It was not until the 1980s that research identified the most common amyloid proteins and rationales for treatment began being discussed. The first clinical trial using oral chemotherapy for primary amyloidosis was begun 28 years ago, and high dose chemotherapy with stem cell transplantation was developed in 1994. The first liver transplant in the United States for familial amyloidosis was performed in 1992.

There is no explanation for how or why amyloidosis develops. Although progress has been made in developing alternate forms of treatment for amyloidosis, there is still no known reliable cure.

All of these types of amyloidosis, left undiagnosed or untreated, are fatal.

AMYLOIDOSIS TREATMENT

The Amyloidosis Center at Boston University School of Medicine and Boston Medical Center, and other centers for amyloidosis treatment, have found that high dose intravenous chemotherapy followed by stem cell transplantation is an effective treatment in selected patients with primary amyloidosis. Abnormal bone marrow cells producing amyloidogenic precursor protein 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 treatment of individuals identified with amyloidosis varies with each patient. It depends on the type of amyloidosis, the specific organ systems involved, and the extent of involvement. An exact course of the disease is unpredictable. Some patients have achieved remission of disease and major organ system improvement. Barring a cure to amyloidosis, the current treatment goal is to provide a complete remission and if not to induce a "durable" or long remission.

The high dose chemotherapy and stem cell transplantation 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.

RESEARCH

Prior year research and equipment funding through HHS and NIH has been helpful in developing new treatment alternatives for some patients with amyloidosis. Although funding is severely limited, researchers are moving forward to develop targeted treatments that will specifically attack the amyloid proteins.

The outlook is better each year as clinical research has led to improvements in therapy, but more research and better diagnosis is necessary to save thousands of lives. Only through more research is there hope of further increasing the survival rate and finding additional treatments to help more patients.

DIAGNOSIS

Early diagnosis and treatment are the keys to success. More needs to be done in these areas 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.

CURRENT INITIATIVES

Through the leadership of this Committee and the further involvement of the U.S. Government, a number of positive developments have occurred.

—The National Institutes of Health has substantially increased its interest in amyloidosis. The Amyloidosis Research Consortium (ARC), a network of clinical centers caring for amyloidosis patients, has developed and is working with the Food and Drug Administration and pharmaceutical companies to enhance drug development for amyloidosis.

—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.

- There has been increased basic and clinical research at the Boston University Amyloidosis Center: 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 AL and familial amyloidosis are underway. A study of the age-related form of amyloid heart disease has provided natural history data.
- 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.

REQUEST FOR FISCAL YEAR 2019

Mr. Chairman, 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 ask that the Committee take the following actions in the fiscal year 2019 Committee report:

- First, include language recommending that NIH expand its research efforts into amyloidosis.
- Second, direct the NIH to keep the Committee informed 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. 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. Thank you for your consideration.

PREPARED STATEMENT OF THE PERSONALIZED MEDICINE COALITION

Chairman Blunt, Ranking Member Murray and distinguished members of the subcommittee, the Personalized Medicine Coalition (PMC) appreciates the opportunity to submit testimony on the National Institutes of Health (NIH) fiscal year 2019 appropriations. PMC is a nonprofit education and advocacy organization comprised of more than 200 institutions from across the healthcare spectrum. As the subcommittee begins work on the fiscal year 2019 Labor, Health and Human Services, Education and Related Agencies appropriations bill, we ask that you include at least \$39.3 billion in funding for the NIH. Our request would raise NIH's base funding by \$2 billion over the final fiscal year 2018 funding level and add \$215 million from the 21st Century Cures Act Innovation Account scheduled for NIH in fiscal year 2019.

Personalized medicine, also called precision or individualized medicine, is an evolving field in which physicians use diagnostic tests to identify specific biological markers, often genetic, that help determine which medical treatments will work best for each patient. By combining this information with an individual's medical records, circumstances, and values, personalized medicine allows doctors and patients to develop targeted treatment and prevention plans. Personalized healthcare promises to detect the onset of and pre-empt the progression of disease as well as improve the quality, accessibility, and affordability of healthcare.¹

I. THE ROLE OF NIH IN PERSONALIZED MEDICINE

Accounting for more than one of every four new drugs approved by the U.S. Food and Drug Administration (FDA) over the past 4 years,² personalized medicine is a rapidly growing field. Biopharmaceutical companies nearly doubled their R & D investment in personalized medicines over 5 years, and expect to increase their investment by an additional third over the next 5 years.³ According to the same survey, leading manufacturers also identified scientific discovery as the biggest challenge facing personalized medicine, followed closely by regulatory and reimbursement barriers.

As the primary Federal agency conducting and supporting basic and translational research investigating the causes, treatments and cures for both common and rare

¹ <http://www.personalizedmedicinecoalition.org/Userfiles/PMC-Corporate/file/The-Personalized-Medicine-Report1.pdf>.

² http://www.personalizedmedicinecoalition.org/Resources/Personalized_Medicine_at_FDA_An_Annual_Research_Report.

³ <http://www.personalizedmedicinecoalition.org/Userfiles/PMC-Corporate/file/pmc-phrma-personalized-medicine-investment-21.pdf>.

diseases, NIH is leading scientific discovery for personalized medicines. Many institutes and centers at the NIH are supporting basic and translational research informing the discovery of personalized treatments, including the National Human Genome Research Institute (NHGRI), the National Cancer Institute (NCI), and the National Center for Advancing Translational Sciences (NCATS). An increase for NIH in fiscal year 2019 would protect its foundational role in the identification and development of personalized medicines.

II. THE CURES INNOVATION FUND: ACCELERATING PERSONALIZED MEDICINE RESEARCH

By passing the 21st Century Cures Act (The Cures Act), Congress acknowledged the need for NIH to accelerate basic research and provided funding for long-term initiatives, two of which will benefit personalized medicine. First, the All of Us™ Research Program will provide an unprecedented dataset of genetic information that promises to improve our understanding of the genetic basis of common and rare diseases. The program awarded its first four community partner awards this year to organizations well-positioned to engage and enroll communities usually underrepresented in biomedical research.⁴ This was an initial step the All of Us Program took to collect genetic and health information from one million diverse volunteers. Second, the Cancer Moonshot initiative aims to make a decade's worth of cancer research progress in 5 years by transforming how cancer research is conducted. The initiative granted 142 awards, including grants in five areas of precision oncology, and established cancer research collaborations, including the Partnership for Accelerating Cancer Therapies (PACT). PACT is a public-private collaboration between the NIH and 11 biopharmaceutical companies to standardize the biological markers of cancer for new immunotherapy treatments. Immunotherapies have provided new treatment options for many patients who do not respond to other cancer therapies. Discoveries through PACT will help scientists understand why immunotherapies work for some but not all patients.

The Cures Act authorizes funding for these initiatives through the Cures Innovation Fund over the next 10 years for a total of \$4.8 billion; however, funding must be appropriated each year. An increase of \$215 million to the Cures Innovation Fund in fiscal year 2019, as scheduled for NIH, would ensure these programs can continue their important research.

III. NIH BASE FUNDING: SUSTAINING BASIC AND TRANSLATIONAL RESEARCH

While the initiatives funded by the Cures Act are important for the growth of personalized medicine, scientific discovery begins with basic research that gathers fundamental knowledge about the genetic basis of a disease and with translational research aimed at applying that knowledge to develop a treatment or cure. From 2003 to 2015, NIH lost more than 20 percent of its purchasing power.⁵ This loss of purchasing power, coupled with biomedical inflation, leaves NIH funding for basic and translational research short of where it needs to be to sustain the discovery and development of new personalized medicines.

Discovering New Biological Markers for Disease:

Basic research has led to the development of over 130 personalized medicines currently on the market and available for patients.⁶ This includes novel cancer immunotherapies that harness a patient's immune system to fight cancer. This treatment is only possible thanks to the decades of basic research to understand how the immune system functions at the molecular level and the genetic characteristics of specific cancers. Basic genomics research also offers opportunities beyond oncology, especially with rare diseases. Rare diseases affect an estimated 25 to 30 million Americans, and with advances in genomics, the molecular cause of 6,500 rare diseases has been identified. However, only 500 of these rare diseases have approved treatments.⁷

Even though NIH's budget saw a major appropriations increase in fiscal year 2018, at least 40 percent was designated to specific programs,⁸ limiting the increase in funds available for basic and translational research. Reliable and consistent fund-

⁴ <https://www.nih.gov/about-nih/who-we-are/nih-director/testimony-implementation-21st-century-cures-act-progress-path-forward-medical-innovation>.

⁵ <https://www.nih.gov/about-nih/who-we-are/nih-director/fiscal-year-2016-budget-request>.

⁶ <http://www.personalizedmedicinecoalition.org/Userfiles/PMC-Corporate/file/The-Personalized-Medicine-Report1.pdf>.

⁷ <https://www.nih.gov/about-nih/who-we-are/nih-director/fiscal-year-2018-budget-request>.

⁸ https://appropriations.house.gov/uploadedfiles/03.21.18_fy18_omnibus_labor_health_and_human_services_summary.pdf.

ing across all NIH institutes and centers will ensure basic research continues to identify new biological markers for disease.

Translating Discovery into Development:

Translational researchers require new resources and tools to bridge basic research discoveries with activities to develop treatments or cures. After decades of NIH-funded basic research, gene editing is enabling researchers to “correct” a genetic mutation causing a disease. The NIH launched the Somatic Cell Genome Editing program led by NCATS to accelerate the utilization of this technology by researchers in the development of new therapies. NIH has also recently released the PanCancer Atlas, a data set of molecular and clinical information from over 10,000 tumors representing 33 types of cancer. The project involved 150 researchers at more than two dozen institutions and was led by the NHGRI and NCI. The PanCancer Atlas provides an unparalleled resource for understanding the genetics of why, where, and how tumors arise. An increase in NIH base funding in fiscal year 2019 will ensure translational research like this can continue for personalized medicine.

DE-RISKING RESEARCH AND DEVELOPMENT:

Developing a new treatment takes well over a decade; has a failure rate of more than 95 percent; and costs more than \$1 billion.⁹ Not all discoveries lead to effective drug targets, and choosing the wrong biological target can result in costly failures late in the drug development process. The NIH’s Small Business Innovation Research (SBIR) and Small Business Technology Transfer (STTR) programs invest in companies to incentivize high-risk research on new drugs and therapies.

NIH also establishes collaborations to reduce the risk of developing new personalized medicines. As a public-private partnership between the NIH, the FDA, 12 biopharmaceutical and life science companies, and 13 nonprofit organizations, the Accelerating Medicines Partnership (AMP) seeks to change the current model for the development of new diagnostics and treatments starting with Alzheimer’s disease, type 2 diabetes, lupus, and Parkinson’s disease. Industry and nonprofit participants only account for 26 percent of the program’s funding. AMP promises to shorten timelines, cut costs, and increase the success rates of treatment development by pinpointing the right biological targets early in drug development. Robust funding will empower NIH to continue de-risking research and supporting industry through collaborations like these that have the potential to improve clinical trials success rates, including those for personalized medicines.

IV. CONCLUSION

PMC appreciates the opportunity to highlight the NIH’s important contributions to the success of personalized medicine. The subcommittee’s support for a \$2 billion increase in base funding, plus the \$215 million increase scheduled through the Cures Act’s Innovation Account, will bring us closer to a future in which every patient benefits from an individualized approach to healthcare.

[This statement was submitted by Cynthia A. Bens, Senior Vice President, Public Policy, Personalized Medicine Coalition.]

PREPARED STATEMENT OF THE PEW CHARITABLE TRUSTS

Chairman Blunt, Ranking Member Murray, and distinguished Members of the Subcommittee:

Thank you for this opportunity to submit prepared testimony in support of fiscal year 2019 appropriations funding for certain programs and activities at the U.S. Department of Health and Human Services (HHS) with the potential to have a meaningful impact on public health. Pew is a nonprofit, nonpartisan research and policy organization with programs that touch on many areas of American life. We appreciate the critical investments the Subcommittee has already made on a bipartisan basis in recent years to help scientists, physicians, and public health officials combat antibiotic resistance (AR) and strengthen the implementation of health information technology. The Agencies and programs discussed below are vitally important to strengthening public health for all Americans, and we urge you to increase the appropriated Budget Authority for these crucial investments. We appreciate your consideration.

⁹ <https://www.nih.gov/research-training/accelerating-medicines-partnership-amp>.

ANTIBIOTIC RESISTANCE

Each year, CDC estimates that over two million illnesses and about 23,000 deaths are caused by antibiotic resistance in the United States alone; this leads to approximately \$20 billion in excess direct healthcare costs. Both the U.S. Centers for Disease Control and Prevention and the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Preparedness and Response play integral roles in detecting and responding to antibiotic resistance.

Within the CDC's Emerging and Zoonotic Infectious Diseases (EZID) budget line:

Antibiotic Resistance Solutions Initiative (ARSI)

CDC's ARSI supports a national infrastructure to detect, respond, and contain antibiotic resistant infections across healthcare, food, and the community. This nationwide antibiotic resistance infrastructure provides fundamental public health capabilities, combined with specialized programs, for the country to effectively prevent, detect, and respond to potentially life threatening AR pathogens such as carbapenem-resistant Enterobacteriaceae (CRE), *C. auris*, and resistant *Salmonella*. Laboratory and epidemiological expertise in all 50 States, six large cities, and Puerto Rico is vital to rapidly identify, contain, and prevent transmission of AR threats in healthcare, in the food supply and in the community. In addition, CDC's Antibiotic Resistance Laboratory Network (ARLN) supported by ARSI funding, provides specialized capabilities that serve as a critical resource for cutting-edge lab support to States, and fosters innovations in antibiotic and diagnostic development. Finally, ARSI-funded programs in 25 States and 3 cities prevent and contain hospital-acquired and antibiotic resistant threats through the targeted prevention intervention efforts of State and local public health officials and healthcare facilities.

We respectfully request \$200 million for CDC's Antibiotic Resistance Solutions Initiative in fiscal year 2019.

Advanced Molecular Detection (AMD)

Advanced molecular detection introduces rapid technological innovation, such as genomic sequencing of pathogens, to allow for better prevention and control of infectious diseases. AMD technologies incorporate newer, more powerful pathogen and resistance detection methods, often replacing more costly, time-consuming methods. As a result, AMD is obtaining higher quality data, detecting outbreaks sooner, and responding more effectively—ultimately saving lives and reducing costs. Additionally, AMD is helping to understand, characterize, and control antibiotic resistance and develop and target prevention measures, including vaccines. Additional funding for AMD will strengthen CDC's ability to further implement AMD protocols and technologies at CDC and State and local health departments; update IT infrastructure; and promote workforce modernization through additional training for CDC scientists and State public health staff in pathogen genetic sequencing, analysis, and interpretation.

We respectfully request \$40 million for CDC's Advanced Molecular Detection in fiscal year 2019.

National Healthcare Safety Network (NHSN)

Healthcare facilities identify and prevent healthcare-associated infections (HAI) and other health events using CDC's NHSN—the Nation's most comprehensive and widely used HAI/antibiotic resistance surveillance system. Currently, 36 States, the District of Columbia and the City of Philadelphia have implemented HAI reporting requirements using NHSN, and over 22,000 healthcare facilities nationwide use NHSN as the cornerstone of their HAI elimination strategies. Public health and healthcare partners—including healthcare facilities (e.g., hospitals, dialysis facilities, and nursing homes), State and local health departments, and Federal partners (e.g., the Centers for Medicare and Medicaid Services (CMS), HHS, the Food and Drug Administration (FDA), the Department of Defense (DoD), and the Department of Veterans Affairs (VA))—have used NHSN data and system tools to identify problem areas, measure and benchmark the success of prevention efforts, and ultimately drive progress toward elimination of HAIs. Increased funding for NHSN will support CDC's efforts to measure antibiotic use in hospitals and target efforts to reduce inappropriate use and stop unnecessary antibiotic exposure, which puts patients at risk of highly resistant infections and secondary complications such as *C. difficile* infections.

We respectfully request \$31 million for CDC's National Healthcare Safety Network in fiscal year 2019.

Within the Office of the HHS Assistant Secretary for Preparedness and Response:

Biomedical Advanced Research and Development Authority (BARDA)

BARDA has taken a unique partnership approach to address the challenging market for antibacterials by engaging industry through its Broad Spectrum Antimicrobials program. This highly unique program supports late-stage development of novel antibacterial and antiviral drugs to treat or prevent diseases caused by biological threats and to address the public health threat of antibiotic resistance. BARDA support through this program has been critical for the advancement of several antibiotics in clinical development leading to several new drug applications and a recent approval. BARDA also engages in strategic partnerships, through its use of Other Transaction Authority, to support a portfolio of antibacterial candidates with several companies.

In 2015, to address the lack of antibiotic on the market, the U.S. National Action Plan on Combatting Antibiotic-Resistant Bacteria called for the development of a biopharmaceutical accelerator to spur pre-clinical product development. In fiscal year 2016, and in response to the Action Plan's recommendations, BARDA created CARB-X—a biopharmaceutical accelerator to spur pre-clinical antibiotic development that focuses on a critical gap in the antibiotic pipeline (pre-clinical through investigational new drug (IND) filing). CARB-X has already shown initial success with three products in their portfolio entering into clinical development. Sustained funding for this BARDA initiative is needed to ensure success so that novel and impactful products can ultimately reach patient bedsides. Additional funding would allow BARDA to expand its portfolio of partnerships and set up CARB-X for success.

We respectfully request \$392 million for BARDA's Broad Spectrum Antimicrobial Program and CARB-X in fiscal year 2019.

Within the Office of the National Coordinator for Health Information Technology (ONC):

Health Information Technology

Electronic health records have revolutionized modern medicine through improvements to safety and efficiency. However, the design, customization and use of these systems—or usability—can also contribute to unexpected patient harm, such as incorrect drug dosages or missed laboratory results. In the 21st Century Cures Act (Public Law 114-255 (2016)), Congress instructed ONC to both develop new voluntary criteria for electronic health records used in the care of children and to specify reporting requirements to evaluate the usability of health IT generally. These provisions offer a meaningful opportunity to improve patient safety. For example, many uses of EHRs are more prevalent in pediatric care, such as dosing medications based on the patient's weight. Requested report language has been submitted under separate cover. The requested language would ensure that the Office prioritizes issues that affect patient safety to further enhance how health IT can reduce medical errors.

[This statement was submitted by Allan Coukell, Senior Director, Health Programs, The Pew Charitable Trusts.]

PREPARED STATEMENT OF THE PHYSICIAN ASSISTANT EDUCATION ASSOCIATION

The Physician Assistant Education Association (PAEA), on behalf of the 235 accredited PA programs in the United States, is pleased to submit the following testimony in support of sustained investment in Title VII health workforce programs under the Public Health Service Act in fiscal year 2019. PAEA joins with our health professions education colleagues in requesting \$690 million in fiscal year 2019 for Title VII health workforce and Title VIII nursing workforce programs. PAEA also requests that \$12 million be directed to support innovation in primary care education and the ongoing development of PA programs under the Primary Care Training and Enhancement (PCTE) program in fiscal year 2019. Of note, PAEA wishes to commend the Subcommittee for its long-time support of the 15 percent funding floor for PA training in the PCTE program. At a time of rapid growth in both PA education and the PA profession, continued Federal investment is essential to the development of a well-prepared PA workforce capable of providing high-quality care to patients throughout the country.

PA EDUCATION: PROMOTING PUBLIC HEALTH

For more than 50 years, PAs have been on the frontlines of healthcare delivery in the United States and have played a crucial role in expanding access to care in rural and medically underserved areas. PA programs are designed in the medical

training model and are second only to physician education in requiring more than 2,000 hours of rigorous clinical training, in addition to didactic instruction. Our member programs graduate more than 8,000 new PAs each year, with a plurality of students going on to serve in primary care capacities following graduation.¹ PAs currently constitute a significant portion of the primary care workforce, with more than 25,000 PAs practicing in primary care capacities.²

A major challenge to the ability of PA programs to prepare enough graduates to meet the Nation's healthcare needs is clinical site capacity, particularly in primary care and behavioral health. This shortage of clinical sites will become even more significant as PAs in primary care play an increasingly crucial role in addressing the opioid epidemic through the use of medication-assisted treatment (MAT) and other behavioral health interventions. Continued Federal investment in primary care training for PA programs is critical to meet these public health and workforce demands.

THE OPIOID CRISIS: PA EDUCATION IS PART OF THE SOLUTION

The national opioid epidemic that is ravaging communities throughout the United States presents a clear and compelling challenge to both policymakers and the health professions community. The Centers for Disease Control and Prevention estimates that 42,000 people died in 2016 as the result of opioid-related overdoses—a tragic figure that calls for a marked shift in strategy among educators tasked with preparing the future health workforce.³ While Congress has already acted boldly to implement short-term measures by expanding access to treatment through State Targeted Response grants and improving the capacity of PAs to prescribe MAT through the Comprehensive Addiction and Recovery Act, this deep-rooted crisis also requires long-term workforce solutions.

Currently, there are not enough clinical training sites to train the number of PAs needed to treat those suffering from opioid use disorder (OUD), particularly in the fields of primary care and behavioral health, and funding is inadequate to facilitate instructional innovation in preparing students to provide care to those with OUD. To help PAs contribute optimally to the long-term solution to the national opioid crisis, PAEA urges Congress to implement a comprehensive strategy to improve clinical training site availability and quality, while increasing investments in existing Title VII workforce programs.

CLINICAL TRAINING SITES: INVESTMENT NEEDED

One component of a broader national response to the opioid epidemic must be improving both the availability and quality of behavioral health clinical training sites. In a 2014 survey of PA programs, behavioral and mental health clinical training sites and preceptors were found to be the third most difficult to recruit.⁴ We are deeply concerned about the impact of limited clinical site capacity on the ability of PA programs to provide the best possible training to students. According to PAEA's most recent Student Report, regarding clinical rotations, students were least likely to give psychiatry and behavioral medicine rotations—those with the most direct bearing on OUD training—an “excellent” rating.⁵ Furthermore, increased demand for providers with the skills necessary to treat OUD will be a growing source of pressure on the Nation's already limited supply of clinical training sites in primary care. Continuing support of Title VII health workforce programs, which benefit PA training in primary care, remains a crucial step Congress can take to improve the capacity of PA programs to prepare practice-ready graduates.

TITLE VII FUNDING

As the PA education community grapples with existing structural barriers to building the PA workforce in response to the national opioid epidemic, current Federal initiatives have a significant role to play in the development of workforce solutions. Recognizing the importance of a well-trained PA workforce in primary care,

¹Physician Assistant Education Association. (2017). *By the Numbers: Program Report 32: Data from the 2016 Program Survey*, Washington, DC: PAEA. doi: 10.17538/PR32.2017.

²National Commission on Certification of Physician Assistants. (2016). *2016 Statistical Profile of Certified Physician Assistants by Specialty*. Johns Creek, GA: NCCPA. <https://prodcmststorage.blob.core.windows.net/uploads/files/2016StatisticalProfilebySpecialty.pdf>.

³Opioid Overdose. (2017). Retrieved April 02, 2018, from <https://www.cdc.gov/drugoverdose/index.html>.

⁴Physician Assistant Education Association. (2014). *2014 PAEA Program Survey*. Alexandria, VA: PAEA.

⁵Physician Assistant Education Association. (2017). *By the Numbers: Student Report 1*. Washington, DC: PAEA. doi: 10.17538/SR2017.0001.

Congress enacted a 15 percent allocation requirement for PA education under the PCTE program beginning in 2010. This funding has been an invaluable tool for stimulating innovation in PA primary care education—with demonstrable positive implications for student training and patient care. For example, the PA program at James Madison University has used PCTE funding to operate a Physician Assistant Student-Engaged Medical Clinic focusing on primary care training with a medically underserved patient population. Moreover, citing the most recent outcomes data available as of fiscal year 2016, the Health Resources and Services Administration has found that the PCTE program significantly exceeds targets both in the number of PAs graduating from funded programs as well as those trained in and going on to practice in underserved areas.⁶ To encourage continued innovation in primary care instruction among PA education programs, especially as we work to address the opioid epidemic, PAEA urges the Subcommittee to protect the 15 percent funding floor in the PCTE program in fiscal year 2019.

DIVERSITY AND CARE FOR UNDERSERVED POPULATIONS

In addition to the innovation in primary care instruction made possible through PCTE grants, PAEA also strongly supports increased funding for Scholarships for Disadvantaged Students, the National Health Service Corps, and the Health Careers Opportunity Program. These initiatives help increase the diversity of the healthcare workforce and expand access to essential healthcare services. Federal investments in the training and subsequent retention of PA students from underserved areas, which are often those hardest hit by the opioid epidemic, are crucial and a vital part of the long-term solution to this public health crisis.

RECOMMENDATIONS FOR FISCAL YEAR 2019 APPROPRIATIONS

To facilitate continued innovation in PA education, PAEA urges the Subcommittee to reinforce its commitment to Title VII health workforce programs in fiscal year 2019. Along with our partners in the health professions, we support funding Title VII and Title VIII programs at a total level of \$690 million for fiscal year 2019. Regarding specific funding for PA education under the PCTE programs, we request \$12 million to continue enhancing the long-standing track record of PA graduates providing high-quality primary care to patients.

PAEA thanks the Subcommittee for its ongoing support of Title VII health workforce programs and their role in supporting PAs as a vital component of long-term solutions to the opioid epidemic. We look forward to continuing to work with members to educate and develop the PA workforce necessary to combat the opioid epidemic and to promote public health across the country.

[This statement was submitted by Lisa Mustone Alexander, EdD, MPH, PA-C, President, Physician Assistant Education Association.]

PREPARED STATEMENT OF THE POLYCYSTIC KIDNEY DISEASE FOUNDATION

The PKD Foundation appreciates the opportunity to present our support for increasing fiscal year 2019 spending for the National Institutes of Health (NIH) in general and the National Institute of Diabetes and Digestive Diseases and Kidney Disease (NIDDK) in particular and for recognizing PKD in NIH's next list to Congress on updated research activities.

Autosomal dominant polycystic kidney disease (ADPKD) is a genetic disease that causes fluid-filled cysts to grow uncontrolled in the kidneys and can eventually lead to kidney failure. It is a painful disease that significantly impacts quality of life, causing a host of other issues including cysts in other organs such as the liver, chronic hypertension and increased risk for cerebral aneurysms. A parent with ADPKD has a 50 percent chance of passing it to each child. ADPKD affects 1 in 500 to 1 in 1,000 live births, but many cases go undiagnosed due to death by related or unrelated causes prior to end stage renal disease. Over 600,000 Americans have ADPKD.

The recessive form of the disease, autosomal recessive polycystic kidney disease (ARPKD), is a rare disease, affecting 1 in 20,000 live births. It is often life-threatening and can cause death shortly after birth. If both parents have the ARPKD gene, there is a 25 percent chance that each offspring will inherit the disease. There is no treatment for ARPKD.

⁶Health Resources and Services Administration. (2018). fiscal year 2019 Congressional Budget Justification. Rockville, MD: HRSA.

PKD is the fourth leading cause of kidney failure with about 50 percent of PKD patients entering end stage renal disease in their 50's. Very few treatment options exist for PKD patients, and once their kidneys fail they must undergo dialysis or a kidney transplant. While these options are life-saving, they are both associated with excess morbidity and mortality. The very first treatment for PKD was approved in April 2018. This treatment, although groundbreaking, is not going to work for every single PKD patient. Having additional treatment options to preserve and extend native kidney function is clearly the best option, particularly because there are far more patients in need of a transplant than there are available kidneys. Research is the path to additional treatments that stop or slow the progression of the disease with the ultimate goal of keeping the kidneys from failing.

The PKD Foundation is the only organization in the U.S. solely dedicated to finding treatments and a cure for PKD and to improve the lives of those it affects. We do this through promoting programs of research, education, advocacy, support and awareness on a national level, along with direct services to local communities across the country. We are the largest private funder of PKD research. Since our founding in 1982, we have invested almost \$50 million in basic and clinical research, nephrology fellowships and scientific meetings with a simple goal: to discover and deliver treatments and a cure for PKD.

The PKD Foundation appreciates your interest in NIH research efforts and thanks Congress for increasing funds for the NIH over the past few years. NIH will devote \$21 million for PKD research in fiscal year 2018. In fiscal year 2013, that figure was \$40 million. Unfortunately, it is notable that PKD receives less funding from the NIH than other significantly less prevalent genetic diseases. It is also notable that, unlike non-renal diseases, Medicare pays for dialysis and care of PKD patients in end stage renal disease (ESRD) regardless of age. According to a 2015 GAO report, in 2013 Medicare spent about \$11.7 billion on dialysis care for about 376,000 patients, some of whom had PKD. The cost of this care is significantly greater than Federal research support.

Although the NIH received nearly a 9 percent budget increase in fiscal year 2018, research in the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) received just over a 5 percent increase. Yet, since fiscal year 2013 NIDDK funding for PKD research has fallen by nearly 50 percent. By having NIDDK invest more in PKD research, a significant proportion of the PKD population could be converted from recipients of Medicare into more productive citizens.

The Appropriations Committees have expressed interest in specific health research areas. In recent years, appropriations bills have requested NIH to provide Congress with an update for a large number of listed diseases, conditions or topics, and a description of the latest efforts ongoing and planned for the following fiscal year. Unfortunately, PKD was not listed in any of these requests.

PKD patients and advocates have two requests for Congress as it develops the fiscal year 2019 funding bill for NIH:

- First, provide \$2.165 billion for NIDDK and direct that 10 percent of the additional funds be used for increased PKD research.
- Second, include PKD in the next NIH update list in the final fiscal year 2019 appropriations bill.

[This statement was submitted by Ms. Alexis Denny, Director of Governmental Relations, Polycystic Kidney Disease Foundation.]

PREPARED STATEMENT OF THE POPULATION ASSOCIATION OF AMERICA AND
ASSOCIATION OF POPULATION CENTERS

Thank you, Chairman Blunt and Ranking Member Murray for this opportunity to express support for the National Institutes of Health (NIH), National Center for Health Statistics (NCHS), and Bureau of Labor Statistics (BLS). These agencies are important to the members of the Population Association of America (PAA) and Association of Population Centers (APC) because they provide direct and indirect support to population scientists and the field of population, or demographic, research overall. In fiscal year 2019, we urge the Subcommittee to adopt the following funding recommendations: \$39.3 billion for the NIH, including funds provided to the agency through the 21st Century Cures Act for targeted initiatives; \$175 million for the NCHS; and \$650 million, for the BLS.

NATIONAL INSTITUTES OF HEALTH

Demography is the study of populations and how or why they change. A key component of the NIH mission is to support biomedical, social, and behavioral research

that will improve the health of our population. 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).

NATIONAL INSTITUTE ON AGING

By 2030, there will be 72 million Americans aged 65 and older. To inform the implications of our rapidly aging population, policymakers need objective, reliable data about the antecedents and impact of changing social, demographic, economic, health and well being characteristics of the older population. The NIA Division of Behavioral and Social Research (BSR) is the primary source of Federal support for basic population aging research.

In fiscal year 2018, the BSR Division expanded its Alzheimer's disease research portfolio to include the population sciences. Some primary examples of this activity include enhanced collection of nationally representative data via the Health and Retirement Study to measure cognitive function to inform our understanding of national trends and differences. In addition to enhancing data collection, NIA developed a dementia care research agenda and added an Alzheimer's disease research component as part of the Roybal Centers of Translation Research in Behavioral and Social Sciences of Aging, Resource Centers for Minority Aging Research, and Demography and Economics of Aging Centers program. In addition to continuing these activities in fiscal year 2019, the Division seeks to encourage more research, especially the population sciences, related to the underlying causes of regional health disparities, including differences in U.S. adult mortality rates.

EUNICE KENNEDY SHRIVER NATIONAL INSTITUTE ON CHILD HEALTH AND HUMAN DEVELOPMENT

Since 1968, NICHD has supported research on population processes and change. This research is housed in the Institute's Population Dynamics Branch, which supports research and research training in demography, reproductive health, and population health and funds major national studies that track the health and well-being of children and their families from childhood through adulthood. These studies include Fragile Families and Child Well Being, the first scientific study to track the health and development of children born to unmarried parents, and the Panel Study of Income Dynamics Child Development Supplement, an intergenerational study that yields extensive family data about the linkages that exist between children, their parents, and grandparents.

In addition to supporting individual research grants and surveys, NICHD supports the Population Dynamics Centers Research Infrastructure Program. These highly productive centers, based at U.S. universities and private research institutions nationwide, have advanced U.S. science by fostering groundbreaking interdisciplinary research on human health and development, and increased the scientific pipeline by nurturing the careers of junior researchers. With additional funding in fiscal year 2019, the Institute will be able to maintain its strong commitment to these centers of research excellence as well as the rest of the Population Dynamics Branch's impressive research portfolio. As members of the Friends of NICHD, PAA and APC request that NICHD receive \$1.5 billion in fiscal year 2019.

NATIONAL CENTER FOR HEALTH STATISTICS

NCHS is the Nation's principal health statistics agency, providing data on the health of the U.S. population. NCHS funds and manages the National Vital Statistics System (NVSS), which contracts with the states to collect birth and death certificate information. NCHS also funds several complex large surveys to help data users understand the population's health, influences on health, and health outcomes. In the last year, critical research findings, including the number of deaths attributable to the opioid epidemic, decreased life expectancy in the U.S., and the percentage of children affected by head injuries, including concussions, were informed by NCHS data. NCHS health data are an essential part of the Nation's statistical and public health infrastructure.

Since 2011, NCHS has been essentially flat funded, greatly diminishing the agency's purchasing power. Current base funding remains below fiscal year 2010 levels, adjusted for inflation, and the agency does not expect to recover the roughly \$25 million in supplemental Prevention and Public Health Fund dollars it lost in 2013. NCHS also faces increasing costs on the horizon associated with state and vendor contracts and other infrastructure challenges related to survey redesign and systems improvements that will require additional resources far beyond current levels.

Any cuts below the agency's fiscal year 2018 level, however seemingly minor, would have a demonstrably negative effect on the agency's programs, survey data, and staff. For example, if NCHS's budget is reduced below its fiscal year 2018 funding level, NCHS will need to consider eliminating or radically altering one of its two seminal surveys: the National Health Interview Survey (NHIS)—the principal data source for studying demographic, socioeconomic, and behavioral differences in health and mortality outcomes since 1957—or the National Health and Nutrition Examination Survey (NHANES), which has assessed the health and nutritional status of adults and children in the United States since the early 1960s. Despite making marginal adjustments to accommodate years of budget cuts, including reducing sample size and delaying necessary survey innovations, the agency has stated it cannot responsibly sustain these surveys if its funding level dips below its fiscal year 2018 level, \$160 million.

As members of the Friends of NCHS, PAA and APC request that NCHS receive \$175 million in fiscal year 2019. NCHS needs this \$15 million increase to make essential investments in the agency, including restoring survey sample sizes, filling numerous vacant staff positions, and to pursue technical innovations such as a redesign of NHIS (to reduce respondent burden and boost response rates), and facilitate ongoing implementation of electronic death records.

BUREAU OF LABOR STATISTICS

BLS produces essential economic information for public and private decision-making. Population scientists who study and evaluate labor and related economic policies use its data extensively.

As members of the Friends of Labor Statistics, PAA and APC are very grateful for the minor funding increase (\$3 million) BLS received in fiscal year 2018. However, the agency is struggling to overcome years of insufficient support. Between fiscal year 2009 and fiscal year 2015, the purchasing power of BLS appropriations decreased every year. Given the importance and unique nature of BLS data, we urge the Subcommittee to provide BLS with \$650 million in fiscal year 2019. This funding would allow BLS to support its core programs and surveys and to launch initiatives, such as overdue efforts to update the Consumer Expenditure Survey and Occupational Employment survey, that have been postponed due to budget shortfalls. BLS would also be able to sustain support for its large-scale surveys, namely the American Time Use Survey and National Longitudinal Surveys, which are unique sources of data used by population scientists in academic and applied research settings to understand how work, unemployment, and retirement influence health and well-being outcomes across the lifespan.

Thank you for considering our organization's positions on these agencies under your subcommittee's jurisdiction.

[This statement was submitted by Mary Jo Hoeksema, Director, Government and Public Affairs, Population Association of America/Association of Population Centers.]

PREPARED STATEMENT OF POWER TO DECIDE

Dear Chairman Blunt, Ranking Member Murray, and members of the Subcommittee:

We respectfully request the following funding levels for programs administered by the Office of Adolescent Health and the Office of Population Affairs within HHS in the fiscal year 2019 LHHS appropriations bill, as well as language ensuring that these programs are implemented in the same high quality manner that they have been in the past.

Specifically, we request: \$110 million for the evidence-based Teen Pregnancy Prevention (TPP) Program and language that ensures continuation of the evidence-based approach that has been a hallmark of the program since its inception, and that continues to undergird the work of the current fiscal year 2015—fiscal year 2019 grantees; \$6.8 million under the Public Health Services Act for evaluation of teenage pregnancy prevention approaches; and \$327 million for the Title X Family Planning Program.

Power to Decide believes that all young people should have the opportunity to pursue the future they want, realize their full potential, and follow their intentions. These beliefs guide our work to ensure that everyone has the power to decide, if, when, and under what circumstances to get pregnant. Providing a system of support that enables young people to have this power not only benefits the young people themselves, but also leads to significant savings in publicly funded programs. New research from Power to Decide shows that the public savings associated with de-

clines in teen births amount to more than \$4 billion annually, and that is only factoring in medical and economic supports during pregnancy and infancy. Moreover, if all teens were able to avoid unplanned pregnancy and childbearing, we estimate that the U.S. could save an additional \$1.9 billion each year.¹

Without question, we as a society must support women, prenatal care, and healthy childbirth. But it's also essential, and cost effective, to provide evidence-based sex education and high quality, publicly funded contraceptive care that empower young people to decide if and when to get pregnant in the first place. All totaled, researchers estimate a savings of roughly \$7 in medical costs for every \$1 spent on contraceptive services.²

We recognize that Congress faces tough budget decisions. In this context, making modest investments in high quality programs that reduce unplanned pregnancy makes fiscal sense and can pay great dividends for individuals and communities.

Teen Pregnancy Prevention (TPP) Program

We request that funding for the TPP Program be restored to \$110 million—its original funding level. This competitive grant program is funded at \$101 million in the Consolidated Appropriations Act, 2018. We also request that language be included that ensures the continuation of the current evidence-based approach, such as the language included in the fiscal year 2018 Senate Appropriations Committee bill that passed on a bipartisan basis in September 2017.

The TPP Program is currently funding 84 competitive grants in a wide variety of communities and settings across the country, using a variety of approaches. It is on track to serve 1.2 million youth if projects are able to continue for 5 years as intended. This program is making a vital contribution to building a body of knowledge of what works for whom and under what circumstance to prevent teen pregnancy through high quality implementation, rigorous impact evaluations (primarily randomized control trials), innovation, and learning from results. The first round of TPP Program grants yielded evaluation results showing 1 in 3 programs changed behavior, far better than what experts say is typically expected from rigorous evaluations in other fields.³ The TPP Program is a gold-standard example of evidence-based policymaking—just the type of investment that independent experts and members of Congress on both sides of the aisle have called for. The September 2017 unanimously-agreed-to-report from the bipartisan Commission on Evidence-Based Policymaking established by House Speaker Paul Ryan and Senator Patty Murray highlighted the TPP Program as an example of a Federal program developing increasingly rigorous portfolios of evidence.⁴

Yet HHS sent notices dated July 1, 2017 informing 81 TPP Program grantees that their 5-year projects will end after year three (July 1, 2017—June 30, 2018)—preceding congressional action on fiscal year 2018 LHHHS appropriations (the remaining three grantees received notice in September). To date, explanations from HHS for these actions have included numerous false characterizations of the program and the evaluation results. On April 20, HHS released two new funding opportunity announcements (FOAs) for the TPP Program that raise concern. The Administration's implementation shifts away from the strong focus on rigorous evidence, results, and evaluation that have been hallmarks of the program since its start, and deviates from the expectations in the legislative language for replication of rigorously-evaluated programs. We are pleased that the final fiscal year 2018 omnibus appropriations bill continued funding for the TPP Program, and we urge you to further continue this funding and to add language protecting the structure and implementation of the program in fiscal year 2019 appropriations.

Evaluation of Teenage Pregnancy Prevention Approaches

As part of the growing bipartisan commitment to evidence-based policymaking there's a recognition of supporting high quality evaluation within Federal agencies. Congress has historically provided a modest amount of funding to evaluate teen pregnancy prevention approaches, including longitudinal evaluations. This funding, in conjunction with the TPP Program, has contributed to deepening our knowledge of what works to reduce teen pregnancy. This smart investment should be continued in fiscal year 2019.

¹ <https://powertodecide.org/what-we-do/information/why-it-matters/progress-pays>.

² <https://powertodecide.org/what-we-do/information/resource-library/everyone-loves-birth-control>.

³ <http://thehill.com/blogs/pundits-blog/the-administration/343908-trump-team-doesnt-understand-evidence-based-policies>.

⁴ <https://www.cep.gov/cep-final-report.html>.

Title X Family Planning Program

We request \$327 million in funding for the Title X program for fiscal year 2019 and language that ensures the integrity of the program. For more than four decades, Title X has played a critical role in preventing unplanned pregnancy by offering low-income and uninsured individuals access to high-quality contraceptive services, preventive screenings, and health education and information. The majority (66 percent) of patients served by Title X have income at or below 100 percent of the Federal poverty level (FPL) and receive services free of charge. Another 22 percent of patients have incomes between 101 percent and 250 percent FPL and receive services on a sliding fee scale. In 2015, the contraceptive care delivered by Title X—funded providers helped women avoid 822,000 unintended pregnancies, which would have resulted in 387,000 unplanned births and 278,000 abortions.⁵

Despite the significant return on investment, the current \$286.5 million funding level in the Consolidated Appropriations Act, 2018 is \$31 million lower than the fiscal year 2010 level, which was already inadequate to meet the need. Reduced funding over the last several years has resulted in fewer patients served and more clinic closings. For example, in 2016, Title X clinics served 4 million women and men, down 23 percent or 1.2 million patients from the 5.2 million patients served in 2010. The need for publicly funded contraception is already far greater than the supply. Any cuts to Title X only increase this need. Research from Power to Decide shows that more than 19 million women in need of publicly funded contraception live in contraceptive deserts, where they do not have reasonable access to a public clinic that offers the full range of methods in their county.⁶

In 2017, HHS shortened Title X grants so that all grants expire in 2018, and the Department recently issued a new FOA. The FOA raises concerns that the Administration's shift in program priorities towards less effective methods could result in funding going to providers that offer a limited range of contraceptive methods, and away from the providers who are able to offer high quality contraceptive care.

The TPP Program and the Title X Family Planning Program enjoy broad bipartisan support. Eighty-five percent of adults support continued funding for the TPP Program, and 75 percent favor continuing the Title X program. These programs make common sense. Helping to ensure that all young people have the power to decide if, when, and under what circumstances to get pregnant will improve opportunities for them and for the country. We appreciate the budget constraints facing the Committee and respectfully urge you to support this request. If you have questions or need additional information, please contact me at rfey@powertodecide.org.

Sincerely,

[This statement was submitted by Rachel Fey, Director, Public Policy.]

PREPARED STATEMENT OF PREVENT BLINDNESS

Prevent Blindness appreciates the opportunity to submit testimony to the Subcommittee and respectfully requests the following allocation and support in fiscal year 2019 to promote eye health and prevent eye disease and vision loss in the United States:

- Provide at least \$3,300,000 to expand vision and eye health efforts at the Vision Health Initiative of the Centers for Disease Control and Prevention (CDC);
- Provide at least \$3,500,000 to the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB) to establish a children's vision and eye health programs in ten States, and a technical assistance coordinating center;
- Provide at least \$4,000,000 for the Glaucoma Project at CDC to allow the program to continue to improve glaucoma screening, referral, and treatment by reaching populations that experience the greatest disparity in access to glaucoma care.

In September 2016, the National Academies of Sciences, Engineering, and Medicine (NASEM) issued its report, "Making Eye Health a Population Health Imperative: Vision for Tomorrow," outlining recommendations to address vision and eye health through Federal investments, coordination with States and local governments and other stakeholders, and actions to integrate vision into current public health interventions. NASEM recognizes that, for too long, vision and eye health have not received the attention and investment they warrant, especially given their

⁵ www.gutmacher.org/gpr/2017/01/why-we-cannot-afford-undercut-title-x-national-family-planning-program.

⁶ <https://powertodecide.org/what-we-do/access/access-birth-control>.

importance to public health. With an aging population and rise in chronic diseases, now is the time to invest in our collective eye health.

Good vision is an integral component to health and economic well-being. Vision affects nearly all activities of daily living and impacts an individual's physical, emotional, social, and financial status. Loss of vision has a devastating impact on individuals and their families. Vision-related conditions affect people across the lifespan from refractive errors to chronic disease that warrants lifestyle changes, disease management, and adaption to treatment and rehabilitation. An estimated 80 million Americans have a potentially blinding eye disease, 3 million have low vision, more than 1 million are legally blind, and 200,000 are more severely visually blind. Vision impairment in children is a common condition that affects 5 to 10 percent of preschool age children, and is a leading cause of impaired health in childhood.

Recent research showed that the economic burden of vision loss and eye disorders is \$145 billion each year, and could rise to as much as \$717 billion by the year 2050 if we don't increase attention to vision and eye health. Alarming, while half of all incidents of vision impairment and blindness can be prevented through education, early detection, and treatment, the Vision Health Initiative at the Centers for Disease Control and Prevention reports that, due to a rapidly aging population and epidemic of diabetes and chronic disease, "the number of Americans with age-related eye disease and the vision impairment that results is expected to double within the next three decades."¹

Prevent Blindness—the Nation's leading non-profit, voluntary organization committed to preventing blindness and preserving sight—maintains a long-standing commitment to working with policymakers at all levels of government, organizations and individuals in the eye care and vision loss community, and other interested stakeholders to develop, advance, and implement policies and programs that prevent blindness and preserve sight.² To curtail the increasing incidence of vision loss in America, and its accompanying economic burden to the patient and our country, Prevent Blindness is requesting sustained and meaningful Federal investment in programs that promote eye health and prevent eye disease, vision loss, and blindness.

We thank the Subcommittee members for working to ensure the Vision Health Initiative and Glaucoma Project at the CDC received additional investments totaling nearly \$1.2 million in the fiscal year 2018 omnibus legislation. These increases are a critical first step to addressing the burden of vision impairment. However, there is much more to be done to understand the burden of vision impairment, eye diseases, and vision loss. Therefore, we strongly urge Members of the Subcommittee to increase the Vision Health Initiative's funding level to \$3.3 million and maintain the fiscal year 2018 level of \$4 million for the Glaucoma Project at the CDC for fiscal year 2019. Vision loss is often preventable; however, without the necessary funding to better understand eye health conditions, expand access to care, develop treatment options, and expand public health systems and infrastructure to disseminate good science and prevention strategies, millions of Americans face the loss of healthy eyesight and a potential decline of their independence, physical, social, and emotional wellbeing, and their economic livelihoods as a result of vision impairment and eye disease.

Vision and Eye Health at the CDC: Helping to Save Sight and Save Money

The CDC serves a critical role in promoting vision and eye health. Since 2003, the CDC and Prevent Blindness have collaborated, along with other partners, to create a more effective public health approach to vision loss prevention and eye health promotion. CDC has also been able to explore a few model programs to promote early detection of glaucoma. However, severely constrained financial resources have limited the CDC's ability to take the work of the Vision Health Initiative (VHI) to the next level.

The NASEM report acknowledges the essential role of the CDC in addressing the challenges that exist for vision and eye health. This report also calls on the U.S. Department of Health and Human Services to prioritize and expand CDC's vision and eye health program, in partnership with State-based chronic disease programs and other clinical and non-clinical stakeholders, to:

- Develop, implement, and evaluate evidence-based public health programs for the prevention of conditions leading to visual impairment;

¹"The Burden of Vision Loss" Vision Health Initiative, Centers for Disease Control and Prevention, 2009 (Referenced May 31, 2018). https://www.cdc.gov/visionhealth/basic_information/vision_loss_burden.htm.

²For more information about Prevent Blindness and our Federal government relations and public policy efforts, please visit www.preventblindness.org.

- Develop and evaluate programs and models that facilitate access to, and utilization of, patient-centered vision care and rehabilitation services, including integration and coordination among healthcare providers;
- Develop and evaluate initiatives to improve environments and socioeconomic conditions that underpin good eye and vision health in communities and reduce eye health disparities;
- Develop a coordinate public health surveillance system to monitor eye and vision health in the U.S.

The requested fiscal year 2019 resources will allow the CDC to apply previous vision and eye health research findings to develop effective prevention and early interventions, with an initial focus on early detection of diabetic retinopathy. These investments will additionally provide for much-needed and overdue surveillance work necessary to understand the range and depth of vision impairment and eye disease, and implement targeted public health interventions that allow for Americans to receive and understand the importance of caring for their vision and eyes.

Investing in the Vision of Our Nation's Most Valuable Resource: Children

In addition to acknowledging the essential, yet underfunded, role of the Vision Health Initiative at the CDC, the NASEM report committee acknowledged the HRSA-funded quality improvement work being led by the National Center for Children's Vision and Eye Health as a leading example of the importance of continuous quality improvement among diverse stakeholders in advancing eye health in the U.S. Early detection and intervention for vision problems are incorporated into national goals and healthcare standards. For example, Healthy People 2020 includes the following vision objectives:

- “Increase the proportion of preschool children aged 5 years and under who receive vision screening” (Objective V-1);
- “Reduce blindness and visual impairment in children and adolescents aged 17 years and under” (Objective V-20); and
- “Increase the use of personal protective eyewear in recreational activities and hazardous situations around the home among children and adolescents aged 6 to 17 years” (Objective V-6.1).

While the risk of eye disease increases after the age of 40, eye and vision problems in children are of an equal and time-sensitive concern. If left undiagnosed and untreated, eye diseases in children can lead to permanent and irreversible visual loss and/or cause problems socially, academically, and developmentally. Studies have demonstrated that optical correction of significant refractive error may be related to improved child development and school readiness,^{3,4,5} yet only 52 percent of children ages three through five are screened for vision problems,⁶ and only one-third of all children receive eye care services before the age of six.⁷ But early detection can help prevent vision loss and blindness as many serious ocular conditions in children are treatable if identified at an early stage.

In 2009, Prevent Blindness established the National Center for Children's Vision and Eye Health (the Center). The Center is a national vision health collaborative effort aimed at developing the public health infrastructure necessary to address issues surrounding children's vision screening with funding support from a HRSA-MCHB grant opportunity. Through their work, the Center has established a National Advisory Committee to provide recommendations toward national guidelines for quality improvement strategies, vision screening, and developing a continuum of children's vision and eye health. With this support the Center, will continue to:

- Provide national leadership in dissemination of best practices, infrastructure development, professional education, and national vision screening guidelines that ensure a continuum of vision and eye healthcare focused on children ages birth to 6 years old;
- Advance State-based performance improvement systems and screening guidelines;
- Promote family education and engagement in their child's vision health; and

³ Ibranke JO, F. D. (2011). Child Development and Refractive Errors in Preschool Children. *Optometry and Vision Science*, 252-8.

⁴ Roch-Levecq AC, B. B. (2008). Ametropia, preschoolers' cognitive abilities, and effects of spectacle correction. *Arch Ophthalmol*, 187-98.

⁵ Atkinson J, A. S. (2002). Infant vision screening predicts failures on motor and cognitive tests up to school age. *Strabismus*, 187-98.

⁶ O'Connor, K. (2012). Overview of Health Cre Access, Use, Unmet Needs and Key System Performance Measures for CSHCN by Vision Status. Children's Vision and Eye Health Federal Intra-Agency Task Force Meeting, Washington D.C.

⁷ “Our Vision for Children's Vision: A National Call to Action for the Advancement of Children's Vision and Eye Health, Prevent Blindness America,” Prevent Blindness America, 2008.

—Provide technical assistance to States in the implementation of strategies for vision screening, establishment of quality improvement measures, and promotion of State-to-State sharing of promising practices.

The National Survey of Children's Health for 2016–2017, which included questions pertaining to children's vision screening, revealed important information on the rate that children's vision is being conducted by age, site, State, socioeconomic status, child health status, and other barriers to eye care as well as important trends to consider in terms of the eye care workforce, access to eye care providers in community health centers, and disparities in access to eye care between rural and urban communities, income levels, and other factors. While there are some existing regulations related to the vision of school aged children in 2/3 of the States, only 34 percent of U.S. States address the vision health of children younger than 5 years old. Currently, there is a lack of data on the proportion of children screened, and there is no effective system to ensure that children who fail screenings ultimately access appropriate comprehensive eye examinations and follow-up care.

To address this issue, our request for a \$3.5 million program would establish within MCHB–HRSA a 10 State grant system for States and local governments needing technical assistance with setting up children's vision screenings and eye health programs as well as coordinate programmatic efforts across Federal agencies. In the first year of this program the MCHB would award up to 10 competitive grants to States and territories and fund technical assistance, allowing for the opportunity to identify and develop resources as a part of vision health outreach and awareness. We believe that the appropriation would integrate vision into a holistic approach for children's health given the essential role that healthy vision plays in school readiness and learning as well as other developmental areas. We ask for the Subcommittee's support of our request.

CONCLUSION

On behalf of Prevent Blindness, our Board of Directors, and the millions of people at risk for vision loss and eye disease, we thank you for the opportunity to submit written testimony regarding fiscal year 2019 funding for the CDC's Vision Health Initiative and Glaucoma Project, and the MCHB at HRSA in support of the work of the National Center for Children's Vision and Eye Health. Please know that Prevent Blindness stands ready to work with the Subcommittee and other Members of Congress to advance policies that will prevent blindness and preserve sight.

[This statement was submitted by Jeff Todd, President & CEO, Prevent Blindness.]

PREPARED STATEMENT OF PREVENT CHILD ABUSE AMERICA

The future of America depends on our next generation. Together, we can strengthen American families and help every child live the American dream. To support the next generation of entrepreneurs, innovators and creators, we urge Congress to increase funding for key programs in fiscal year 2019 to help ensure we reduce child abuse and neglect, promote healthy child development, improve parental education and increase job prospects for all families. These programs lead families to self-sufficiency and away from government services and are critical to our success as a Nation. Prevent Child Abuse America humbly recommends the following for the fiscal year 2019 Labor, Health and Human Services, Education and Related Services appropriations:

CAPTA: Fund the Child Abuse Prevention and Treatment Act (CAPTA) at \$200 Million

Prevent Child Abuse America appreciates the \$60 million increase provided in fiscal year 2018 to help States improve their response to infants and families affected by substance use disorder. We urge Congress to maintain this increase in fiscal year 2019 and increase funding so that States can place greater emphasis on prevention-related activities.

CAPTA is currently funded at less than half its authorization level. By fully funding CAPTA at \$200 million, Congress can help strengthen the network of support in States focused on prevention, investigation and treatment activities for families.

CCDBG: Fund the Child Care Development Block Grant (CCDBG) at \$5.8 Billion

The 2018 bipartisan agreement to expand the Child Care Development Block Grant (CCDBG) by \$2.4 billion will create new and expanded opportunities for States to fully implement the 2014 reauthorization of the CCDBG Act. We actively support what is stated in the 2018 Consolidated Appropriations Act Agreement:

“This funding will help improve the quality of child care programs, including increasing provider rates and ensuring health and safety standards are met; and expanding working families’ access to quality, affordable child care.”

We believe that the availability of subsidized child care, as provided to eligible families via CCDBG, is associated with reduced maltreatment of children. These services improve parental education and job prospects, increase upward mobility and enable families to become self-sufficient.

21st Century Cures Act

We supported the passage of the 21st Century Cures Act (Public Law 114–255) and are pleased Congress included funding in fiscal year 2018 for all major programs authorized under the law. We urge Congress to press forward and maintain this funding in fiscal year 2019.

Infant and Early Childhood Mental Health. We encourage continued funding at \$5 million to provide grants to develop, maintain or enhance infant and early childhood mental health promotion, intervention, and treatment programs. Children from birth to age 12 who are at risk or have been diagnosed with a mental illness (including a serious emotional disturbance) will be eligible for services. Services can be provided by eligible entities with specialized training and experience in infant and early childhood mental health assessment, diagnosis and treatment.

Screening and Treatment for Maternal Depression. We urge continued funding at \$5 million to provide grants to States to establish, improve, or maintain programs to train professionals to screen, assess and treat for maternal depression in women who are pregnant or who have given birth within the preceding 12 months. Depression can lead to negative effects on cognitive development, social-emotional development and children’s behavior.

CDC: Fund the Centers for Disease Control and Prevention’s Essentials for Childhood Framework

We encourage ongoing funding for the Centers for Disease Control and Prevention’s Essentials for Childhood Framework. These funds support the implementation of statewide comprehensive strategies and approaches designed to reduce adverse childhood experiences, morbidity, mortality, and related health disparities associated with childhood abuse and neglect.

SSBG: Fund the Social Services Block Grant (SSBG) at \$1.7 Billion

We support current funding for the SSBG so that States can provide essential social services that help achieve a myriad of goals to reduce dependency, promote self-sufficiency and protect children from abuse, neglect and exploitation.

Science has proven that child abuse and neglect during a child’s first 5 years of life can limit brain development and decrease the size and weight of an individual’s brain. Child abuse and neglect have profound and far-reaching effects that impact a child’s social, emotional and cognitive development. Research is clear, evidenced-based prevention programs reduce the likelihood of costly ailments to the individual and to society, including mental illness, criminal justice, child welfare, substance abuse and addiction, and the perpetuation of abuse and neglect. Prevention services strengthen families and give families the tools they need to succeed and thrive.

Thank you for your consideration. If Prevent Child Abuse America can assist you in any way as you complete the fiscal year 2019 appropriations process, please do not hesitate to contact me or our Senior Director of Public Policy at mmorabito@preventchildabuse.org.

Sincerely,

[This statement was submitted by Dan Duffy, President & CEO, Prevent Child Abuse America.]

PREPARED STATEMENT OF THE PULMONARY HYPERTENSION ASSOCIATION

THE ASSOCIATIONS'S FISCAL YEAR 2019 L-HHS APPROPRIATIONS RECOMMENDATIONS

-
- \$8.56 billion in program funding for the Health Resources and Services Administration (HRSA).
 - \$8 billion in program funding for the Centers for Disease Control and Prevention (CDC)
 - \$750,000 for a pulmonary hypertension awareness and early diagnosis campaign at CDC.
 - At least \$39.3 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).
-

Chairman Blunt, Ranking Member Murray and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the pulmonary hypertension (PH) community as you work to craft the fiscal year 2019 L-HHS Appropriations bill.

ABOUT PULMONARY HYPERTENSION

Pulmonary hypertension (PH) is a disabling and often fatal condition characterized by high blood pressure in the lungs. The World Health Organization (WHO) has classified PH into five groups. Treatment and prognosis vary depending on the type of PH. In WHO Group 1 PH, pulmonary arterial hypertension, the arteries in the lungs become narrow and stiff causing the heart to work harder to handle the amount of blood that must be pumped through the lungs. The resulting increase in pressure strains the right side of the heart, causing it to enlarge and ultimately fail. Fourteen targeted treatment options are available to help patients manage their disease and feel better day to day but the common symptoms of the disease—breathlessness and fatigue—cause it to be frequently misdiagnosed as asthma or other conditions. Even with the more modern targeted therapies, life expectancy with PAH is thought to be 7–9 years on average. While PAH is rare—15 to 50 cases per million—other types of PH are much more common. PH associated with left heart disease (WHO Group 2) and lung disease (WHO Group 3) impact significantly more individuals but these forms require additional research to identify the role for targeted therapies.

ABOUT PHA

Headquartered in Silver Spring, Md., the Pulmonary Hypertension Association (PHA) is the country's leading PH organization. PHA's mission is to extend and improve the lives of those affected by PH. PHA achieves this by connecting and working together with the entire PH community of patients, families, healthcare professionals and researchers. The organization supports more than 200 patient support groups; a robust national continuing medical education program; a PH clinical program accreditation initiative; and a national observational patient registry.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

Due to the serious and life-threatening nature of PH, it is common for patients to face drastic health interventions, including heart-lung transplantation. To ensure HRSA can continue to make improvements in donor lists and donor-matching please provide HRSA with \$8.56 billion in discretionary budget authority in fiscal year 2019.

CENTERS FOR DISEASE CONTROL AND PREVENTION

Please provide \$750,000 for a pulmonary hypertension program at CDC. While PH remains incurable, investment in medical research and sustained scientific progress in this area has led to fourteen Food and Drug Administration-approved targeted treatment options for two forms of the disease. It currently takes an average of two and a half years to receive a diagnosis and three quarters of patients have severe PH when they are finally diagnosed. Without treatment, historical studies have shown a mean survival time of 2.8 years after diagnosis for pulmonary arterial hypertension (PAH). Patients with advanced PH cannot benefit as greatly

from available therapies and often face dramatic and costly medical interventions, including 24-hour IV infused medication, increased risk for hospitalization and in some cases heart-lung transplantation. Considering the availability of effective therapies for early-stage PH, a CDC program focusing on education, awareness, and epidemiology activities that promote early and accurate diagnosis and treatment of PH would not only save countless lives but save the American healthcare system from spending on avoidable medical outcomes.

NATIONAL INSTITUTES OF HEALTH

Please provide NIH with meaningful increases—including at least \$39.3 billion in program funding in fiscal year 2019—to facilitate expansion of the PH research portfolio so we can continue to improve diagnosis and treatment. NHLBI and PHA have partnered on a groundbreaking clinical study, the Redefining Pulmonary Hypertension through Pulmonary Vascular Disease Phenomics (PVDOMICS) program (RFA-HL-14-027 and RFA-HL-14-030). By collecting information from one thousand participants with various types of PH, and 500 participants without or at risk for PH, PVDOMICS hopes to find new similarities and differences between the current WHO classifications of PH, which could be a major step in learning about the disease and advancing patient care. This research is intended to lead to identification of both endophenotypes of lung vascular disease and biomarkers of disease that may be useful for early diagnosis or for assessment of interventions to prevent or treat PH.

PROPER HEALTH COVERAGE AND ACCESS

The PH community is concerned that the Centers for Medicare and Medicaid Services (CMS) is allowing insurance payers to refuse to accept charitable copay and premium assistance on behalf of patients with complex, chronic and life-threatening conditions like PH. Because of breakthroughs in research, PH patients are able to utilize life-sustaining treatments that allow them to manage this potentially 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 are aware of the Subcommittee's continued requests for an explanation of this practice targeting rare disease patients. We ask that this Subcommittee once again ask CMS to explain this decisions and also encourage them to fix this problem that is greatly affecting the rare disease community.

PATIENT PERSPECTIVES

Before developing pulmonary hypertension, *Doug* was an architect specializing in historic preservation. Being an architect was the only thing he had ever wanted to do “when he grew up.” Doug spent 2 years seeking an accurate diagnosis for his shortness of breath. During that time, he was misdiagnosed with depression, sleep apnea, altitude sickness and asthma. Ultimately Doug was diagnosed and treated, however he had to give up his career due to his PH.

Edith is a 71-year-old Medicare recipient who was diagnosed with pulmonary hypertension about 5 years ago. Edith says, “If I didn't have the medication I wouldn't be around. I would have passed away. And I don't want to do that because I have great grandchildren and I want to see them grow up.” Edith's husband adds, “without her medications she cannot breathe. Without these drugs I would lose my wife in a day.”

Aine's parents heard over and over that there was nothing wrong with their daughter. When they relayed her shortness of breath with exertion to physicians they were ignored or told she was just anxious. Aine was 8 years-old when she died.

Thank you again for your consideration of the PH community's priorities as you develop the fiscal year 2019 L-HHS Appropriations bill.

[This statement was submitted by Mr. Brad A. Wong, President and CEO, Pulmonary Hypertension Association.]

PREPARED STATEMENT OF REBUILDING AMERICA'S MIDDLE CLASS

Dear Chairman Blunt and Ranking Member Murray:

On behalf of Rebuilding America's Middle Class (RAMC), a coalition of State and individual community college systems from across the Nation—representing over 120 colleges and 1.5 million students, I am providing written comments on the fiscal year 2019 Appropriations Bill. We are specifically writing in regards to the \$22.4

billion Pell Grant program, \$1.1 billion for Career Technical Education (CTE) State Grants, the elimination of the Strengthening Institutions Program (SIP) within the Department of Education and \$200 million for the Apprenticeship Program within the Department of Labor's budget.

Community colleges have an unparalleled commitment to accessibility, which encourages traditionally underrepresented audiences to pursue a college degree. We serve 45 percent of all first-time freshmen, 40 percent of our students are the first in their family to attend college, and a significant proportion of our Nation's minority undergraduates attend community colleges, including 42 percent of all African American undergraduates, nearly half of all Hispanic undergraduates, and 56 percent of Native American undergraduates. Community colleges have historically existed to make higher education accessible for everyone and match our employers' need for a large, diverse workforce. Accordingly, we believe that the Federal Government needs to make sure that financial aid policies work for nontraditional students who work and have families and are increasingly turning to community colleges for access to higher education.

Increase the Maximum Pell Grant.

RAMC members believe that the Pell Grant program is the key to ensuring low-income students can afford college. Community colleges are the most affordable of the many options facing students; yet, even at our institutions, low-income community college students overwhelmingly rely on this critical Federal student aid program. For these reasons we appreciate the \$175 increase in the maximum Pell grant as part of the fiscal year 2018 appropriations bill. While the fiscal year 2019 request sets the maximum Pell Grant award at \$5,920 for the 2019–20 award year, we believe that the maximum Pell Grant should be increased.

Support Career Technical Education State Grants.

The fiscal year 2019 request proposes to level fund CTE State Grants at \$1.1 billion level funded to the fiscal year 2017 level. In the 2018 Omnibus appropriations bill RAMC very much appreciated the \$75 million increase to this program. RAMC believes that there is a need to prioritize career and technical education certificates and degrees, and provide them the same value as baccalaureate and advanced degrees. Accordingly, RAMC believes that Congress should again provide an increase in funding to the CTE grant program as part of the fiscal year 2019 appropriations process.

Do Not Eliminate the Title III Strengthening Institutions Program.

The fiscal year 2019 budget request includes no funding for the Strengthening Institutions Program and asserts that the program is duplicative of other program funding for institutional support activities. RAMC utilizes SIP funds to increase student retention, provide enhanced faculty professional development and expand access to high-demand STEM programs through the conversion of high-demand courses. RAMC believes that the consolidation of SIP would be detrimental to providing much needed student services and urges the Subcommittee to consider an increase for this program in fiscal year 2019.

Focus Workforce Innovation and Opportunity Act (WIOA) Funding on Training

The goal of WIOA is to provide more Americans with the skills, knowledge, and training they need for the jobs of today and tomorrow. Unfortunately, too little funding provided through WIOA programs makes its way down to actually paying for actual job training. Accordingly, RAMC requests that the Subcommittee consider requiring that the Department of Labor to mandate a minimum percentage of WIOA funding be used to pay for actual job training services versus administrative overhead. Such a provision would ensure that funding benefits those who need additional skills and training to acquire or upgrade their employment.

Support Apprenticeships and Innovative Partnerships.

As community college leaders, RAMC members are at the forefront of working to expand apprenticeships and create opportunities for students to earn while they learn. As such we applaud the fiscal year 2019 proposal that includes \$200 million for the Apprenticeship Program, an increase of \$5 million above the fiscal year 2017 funding level. In addition, we very much appreciate the recognition of the Subcommittee for this program by increasing funding in fiscal year 2018 by \$50 million. For fiscal year 2019 we would urge the Subcommittee to consider another increase for this program.

Thank you for your consideration of our comments. RAMC members stand ready and willing to help you in any way we can as the Fiscal Year 2019 Appropriations process moves forward.

Sincerely.

[This statement was submitted Joe May, Board Chair, Rebuilding America's Middle Class.]

PREPARED STATEMENT OF THE REFUGEE COUNCIL USA

On behalf of the twenty-five member organizations of Refugee Council USA (RCUSA)¹ dedicated to refugee protection, assistance and welcome, and representing the interests of hundreds of thousands of refugees, their families, and the millions of volunteers and community members across the country who support refugee resettlement, I thank you for the opportunity to submit these funding recommendations for fiscal year 2019. RCUSA recommends fiscal year 2019 funding levels of \$2.056 billion for the Department of Health and Human Services' Refugee and Entrant Assistance (REA) account.

The REA account funds the Office of Refugee Resettlement (ORR) within the Administration of Children and Families. ORR funding provides critical Federal investments in the States and local communities that welcome refugees, and is a crucial component of fostering refugee integration and economic contributions. In addition to new refugee arrivals, ORR funding provides essential services to refugees who arrived in recent years, unaccompanied refugee minors, asylees, Cuban and Haitian entrants, Special Immigrants Visa (SIV) holders from Afghanistan and Iraq who served the U.S. mission in those countries, victims of human trafficking, survivors of torture, and unaccompanied children. Through ORR programs and associated public-private partnerships, in fiscal year 2019 ORR anticipates serving 119,000 individuals, including 45,000 refugees.²

RCUSA supports a continuance of the funding provided in the fiscal year 2018 omnibus appropriations bill with three exceptions. RCUSA recommends an increase for the Transitional Medical Assistance (TAMS) program; domestic and foreign-born trafficking victim services; and, torture survivor assistance. TAMS funds critical initial assistance to refugees and other new arrivals; programs for vulnerable unaccompanied refugee children; and the highly effective Matching-Grant program, which leverages public funds with private donations, empowering refugees to secure employment within 6 months. The trafficking program has seen a 962 percent increase in identified victims in need of trauma-informed case management services since 2002,³ and funding has not kept pace with this increase, jeopardizing the ability of the program to enroll all identified new clients. Finally, torture survivors currently face long wait lists for services due to chronic, systemic underfunding.

The U.S. is one of roughly 37 resettlement countries. The U.S. Refugee Admissions Program (USRAP) process begins with rigorous screening to determine that applicants qualify for refugee status and are not a security risk. The U.S. admits a small percentage of the world's refugees, often the most vulnerable, for resettlement (including unaccompanied refugee minors) through the USRAP. Refugees arriving through the USRAP, along with Iraqi and Afghan SIV recipients, are placed with one of nine voluntary nonprofit resettlement agencies that have signed a Cooperative Agreement with the State Department and have local affiliates in over 200 sites in communities around the country. Six of the nine voluntary agency networks are faith-based, and harness the energy of many faith communities to help welcome newcomers to their new communities. These community organizations ensure that a core group of services are provided during the first 30–90 days after a refugee's arrival, including the provision of food, housing, clothing, employment services, follow-up medical care, and other necessary services. After this initial period, ORR funds integration services through both the States and community partners around the country.

Once refugees arrive to the U.S., they are supported to become oriented to the community, learn English, enroll their children in school, and find employment. With this crucial support, they often are not only able to support themselves and their families but also become contributors to their new communities, integrating with and bringing innovation to our neighborhoods. The following highlights critical programs within the REA account, but does not include all program activities:

¹A list of RCUSA member organizations can be viewed at RCUSA.org.

²The fiscal year 2019 refugee admissions ceiling has not been set. This figure also does not include unaccompanied children, predominantly from Central America, in ORR's care.

³This is based on the 2002 ORR report to Congress and the 2016 TIP report.

TRANSITIONAL & MEDICAL SERVICES

Matching Grant Program.—The Matching Grant Program, a public-private partnership, is ORR's most successful program to help refugees achieve early self-sufficiency. It empowers refugees and other eligible individuals to become self-sufficient within 6 months without needing to access Federal or State assistance programs. The program leverages public funds with private donations at a 2:1 ratio, with non-governmental agencies working hand-in-hand with local communities to match Federal Government contributions with private resources.

Refugee Cash and Medical Assistance (CMA).—CMA provides time-limited (eight months maximum) services including cash assistance, coverage for health expenses, and medical screening. ORR reimburses States for 100 percent of services provided to refugees and other eligible persons, as well as associated administrative costs.

Unaccompanied Refugee Minors.—Unaccompanied refugee minors (URM) are among the most vulnerable of refugees, and the U.S. is the only country that permanently resettles them. URM have been lost or separated from their parents and families and have often suffered greatly not only in their home country but also in countries near their homelands where they have sought refuge. This is a small but crucial U.S. program to protect the most vulnerable of these at-risk children and provide them a new life in the U.S.

Refugee Support Services (RSS).—RCUSA is concerned with the proposed 22 percent cuts to the programs funded by RSS, which promote refugee employment and fiscal contributions to U.S. communities; these cuts will result in greater burdens placed on States and localities to fund benefits rather than proven employment services.

Refugee Social Services.—RSS supports initial employability services and other integration services that address initial barriers to employment. It is provided to States and non-profit organizations based on formula pertaining to anticipated refugee and other arrivals and competitive grants. Additionally, school Impact funding, provided through a formula in the RSS program, supports impacted school districts with the funds necessary for activities, like English as a Second Language instruction, that will lead to the effective integration and education of vulnerable children.

Targeted Assistance Program (TAG).—TAG is a discretionary grant program that provides support to States with particularly high refugee arrivals, including via secondary migration, and services to refugees requiring longer term employment support. It also provides specialized services to meeting the unique needs of certain groups, such as youth programming and career development for higher skilled refugees looking to recertify in their field.

Refugee Health Promotion (RHP).—The Administration's fiscal year 2019 budget again proposes eliminating this vital program, which helps refugees navigate the U.S. healthcare system. It is awarded competitively and helps fund State Refugee Health Coordinators, provide language access at Federal healthcare centers, and supports mental health screening of refugees, among other things. RCUSA strongly opposes the proposed elimination of RHP.

Survivors of Trafficking.—Since the passage of the Trafficking Victims Protection Act in 2000, victims of human trafficking have received case management services through HHS's partnership with NGO providers, including assistance obtaining and referrals to medical and psychological treatment, housing, educational programs, life skills development, legal services, and other assistance. Funding is also utilized to promote public awareness, training, and coalition building to raise awareness about human trafficking among law enforcement, social services, medical staff, and other potential first responders, in addition to other faith-based and community groups. These grants are crucial to providing victims, including children, integrative aid and services once they have been identified as a victim of trafficking. Increased funding to \$20 million for each domestic and foreign-born victim is requested to adequately serve trafficking survivors. This funding is critical due to the increases in victim identification efforts. In fact, there has been a 843 percent increase in the number of foreign-born individuals served by the program from 2003 to fiscal year 2016.

Survivors of Torture.—The Torture Victims Relief Act authorizes funding for domestic programs that address the long-term impacts of torture on survivors and their families. Effective rehabilitation programs address a survivor's physical, psychological, legal and social needs to reduce their suffering and restore functioning as quickly as possible. RCUSA's proposed \$16 million for torture survivor assistance reflects that many treatment programs have long wait lists, and that at current funding levels demand will continue to exceed availability as programs serve not only refugees, but also (and in some cases predominantly) asylees and asylum seek-

ers. An estimated 9,000 survivors and their families from 125 countries benefited from these services in fiscal year 2017.

Unaccompanied Children (UCs).—In fiscal year 2017, 40,894 children were referred to the custody and care of the Office of Refugee Resettlement (ORR). ORR’s provides children in its care with food, shelter, and clothing as well as educational, medical, mental health, and case management services. For a limited number of children, ORR provides family reunification services by social services providers; specifically, “home studies” to help ensure children are released into safe placements and “post-release services” to facilitate family and community integration after reunification. Post-release social services by providers are an important means of assuring the continued well-being and adjustment of the children and preventing such dangers as human trafficking. Post-release services also help families to understand the child’s legal obligations as well as provide critical protection and support to the families themselves as the children are integrated into their new communities. These practices not only promote child safety, but they can help reduce the need for involvement with the public child welfare system post-release. RCUSA supports the fiscal year 2018 funding level for these programs that promote successful family reunification and stability, which serve the best interest of the children. RCUSA does not support an expansion of detention, including through use of large-scale institutional facilities, or efforts to support forced family separation.

Our Nation’s historic commitment to refugees through domestic resettlement provides lifesaving support and protection to the world’s most vulnerable. Our Nation’s historic commitment to displaced populations helps us build strategic alliances and stabilize those regions most affected by the largest displacement crisis in global history. This helps keep America safe. Thank you for considering our funding recommendations for fiscal year 2019.

**Fiscal Year 2019 Office of Refugee Resettlement Funding Needs for
the Refugee and Entrant Assistance (REA) Account**

| Program Areas | Fiscal Year 2018 Enacted Funding | Fiscal Year 2019 | |
|--|-------------------------------------|------------------------------|-------------------------------|
| | | President’s Request | RCUSA Request |
| Transitional & Medical Assistance (TAMS) | \$320,000,000 | \$354,000,000 | \$490,000,000 |
| Refugee Social Services | ⁴ \$207,201,000 | ⁵ \$161,000,000 | \$155,000,000 |
| Targeted Assistance | | | \$47,601,000 |
| Refugee Health Promotion | | \$0 | \$4,600,000 |
| Subtotal (Resettlement Services) | \$527,201,000 | \$515,000,000 | \$697,201,000 |
| Foreign-Born Trafficking Victims | \$17,000,000 | \$18,755,000 | ⁶ \$20,000,000 |
| Domestic Trafficking Victims | \$6,755,000 | | ⁷ \$20,000,000 |
| Torture Survivor Assistance | \$10,735,000 | \$10,735,000 | ⁸ \$16,000,000 |
| Unaccompanied Children | \$1,303,245,000 | ⁹ \$1,148,000,000 | ¹⁰ \$1,303,245,000 |
| Total | \$1,864,936,000 | \$1,692,000,000 | \$2,056,446,000 |

⁴The fiscal year 2018 omnibus explanatory statement indicates that Congress is supportive of combined administration of these three programs, but requires that all three programs continue in fiscal year 2018 to be funded at fiscal year 2017 levels, which were reflected in RCUSA’s asks

⁵The Administration proposes merging the administration of Refugee Social Services and Targeted Assistance into one new program, Refugee Support Services. Congress has not allocated less than \$200 million for these programs in at least 15 years, not even taking inflation into account.

⁶An increase is requested to serve trafficking survivors, given the 962 percent increase in the number of victims identified and certified in need of services since 2002, based on the 2002 ORR report to Congress and the 2016 Trafficking in Persons (TIP) report.

⁷See #4.

⁸An increase is requested because many of the torture treatment centers in the Center for Victims of Torture (CVT) network have lengthy wait lists, some as long as 8 months, even without outreach. Additionally, in some areas asylum seekers comprise more than 80 percent of treatment center clients; given the administration’s plans to more rapidly increase asylum claims there will likely be an increased demand for torture survivor services. Finally, ORR estimates up to 44 percent of refugees are torture survivors.

⁹This request includes a scored \$100 million contingency fund for unaccompanied children, and authorization for an additional \$100 million as needed based on certain triggers, which RCUSA supports.

¹⁰RCUSA supports continued funding at the level enacted by Congress for fiscal year 2018 but stresses that the funding increase should not be used to support forced family separation at the southern border or increased use of large-scale institutional shelter facilities.

PREPARED STATEMENT OF REFUGEE COUNCIL USA

On behalf of the twenty-five member organizations of Refugee Council USA (RCUSA)¹ dedicated to refugee protection, assistance and welcome, and representing the interests of hundreds of thousands of refugees, their families, and the millions of volunteers and community members across the country who support refugee resettlement, I thank you for the opportunity to submit these funding recommendations for fiscal year 2019. RCUSA recommends fiscal year 2019 funding levels of \$2.056 billion for the Department of Health and Human Services' Refugee and Entrant Assistance (REA) account.

The REA account funds the Office of Refugee Resettlement (ORR) within the Administration of Children and Families. ORR funding provides critical Federal investments in the States and local communities that welcome refugees, and is a crucial component of fostering refugee integration and economic contributions. In addition to new refugee arrivals, ORR funding provides essential services to refugees who arrived in recent years, unaccompanied refugee minors, asylees, Cuban and Haitian entrants, Special Immigrants Visa (SIV) holders from Afghanistan and Iraq who served the U.S. mission in those countries, victims of human trafficking, survivors of torture, and unaccompanied children. Through ORR programs and associated public-private partnerships, in fiscal year 2019 ORR anticipates serving 119,000 individuals, including 45,000 refugees.²

RCUSA supports a continuance of the funding provided in the fiscal year 2018 omnibus appropriations bill with three exceptions. RCUSA recommends an increase for the Transitional Medical Assistance (TAMS) program; domestic and foreign-born trafficking victim services; and, torture survivor assistance. TAMS funds critical initial assistance to refugees and other new arrivals; programs for vulnerable unaccompanied refugee children; and the highly effective Matching-Grant program, which leverages public funds with private donations, empowering refugees to secure employment within 6 months. The trafficking program has seen a 962 percent increase in identified victims in need of trauma-informed case management services since 2002,³ and funding has not kept pace with this increase, jeopardizing the ability of the program to enroll all identified new clients. Finally, torture survivors currently face long wait lists for services due to chronic, systemic underfunding.

The U.S. is one of roughly 37 resettlement countries. The U.S. Refugee Admissions Program (USRAP) process begins with rigorous screening to determine that applicants qualify for refugee status and are not a security risk. The U.S. admits a small percentage of the world's refugees, often the most vulnerable, for resettlement (including unaccompanied refugee minors) through the USRAP. Refugees arriving through the USRAP, along with Iraqi and Afghan SIV recipients, are placed with one of nine voluntary nonprofit resettlement agencies that have signed a Cooperative Agreement with the State Department and have local affiliates in over 200 sites in communities around the country. Six of the nine voluntary agency networks are faith-based, and harness the energy of many faith communities to help welcome newcomers to their new communities. These community organizations ensure that a core group of services are provided during the first 30-90 days after a refugee's arrival, including the provision of food, housing, clothing, employment services, follow-up medical care, and other necessary services. After this initial period, ORR funds integration services through both the States and community partners around the country.

Once refugees arrive to the U.S., they are supported to become oriented to the community, learn English, enroll their children in school, and find employment. With this crucial support, they often are not only able to support themselves and their families but also become contributors to their new communities, integrating with and bringing innovation to our neighborhoods. The following highlights critical programs within the REA account, but does not include all program activities:

Transitional & Medical Services

Matching Grant Program: The Matching Grant Program, a public-private partnership, is ORR's most successful program to help refugees achieve early self-sufficiency. It empowers refugees and other eligible individuals to become self-sufficient within 6 months without needing to access Federal or State assistance programs. The program leverages public funds with private donations at a 2:1 ratio, with non-

¹A list of RCUSA member organizations can be viewed at RCUSA.org.

²The fiscal year 2019 refugee admissions ceiling has not been set. This figure also does not include unaccompanied children, predominantly from Central America, in ORR's care.

³This is based on the 2002 ORR report to Congress and the 2016 TIP report.

governmental agencies working hand-in-hand with local communities to match Federal Government contributions with private resources.

Refugee Cash and Medical Assistance (CMA): CMA provides time-limited (eight months maximum) services including cash assistance, coverage for health expenses, and medical screening. ORR reimburses States for 100 percent of services provided to refugees and other eligible persons, as well as associated administrative costs.

Unaccompanied Refugee Minors: Unaccompanied refugee minors (URM) are among the most vulnerable of refugees, and the U.S. is the only country that permanently resettles them. URM have been lost or separated from their parents and families and have often suffered greatly not only in their home country but also in countries near their homelands where they have sought refuge. This is a small but crucial U.S. program to protect the most vulnerable of these at-risk children and provide them a new life in the U.S.

Refugee Support Services (RSS)

RCUSA is concerned with the proposed 22 percent cuts to the programs funded by RSS, which promote refugee employment and fiscal contributions to US communities; these cuts will result in greater burdens placed on States and localities to fund benefits rather than proven employment services.

Refugee Social Services: RSS supports initial employability services and other integration services that address initial barriers to employment. It is provided to States and non-profit organizations based on formula pertaining to anticipated refugee and other arrivals and competitive grants. Additionally, school Impact funding, provided through a formula in the RSS program, supports impacted school districts with the funds necessary for activities, like English as a Second Language instruction, that will lead to the effective integration and education of vulnerable children.

Targeted Assistance Program (TAG): TAG is a discretionary grant program that provides support to States with particularly high refugee arrivals, including via secondary migration, and services to refugees requiring longer term employment support. It also provides specialized services to meeting the unique needs of certain groups, such as youth programming and career development for higher skilled refugees looking to recertify in their field.

Refugee Health Promotion (RHP): The Administration's fiscal year 2019 budget again proposes eliminating this vital program, which helps refugees navigate the U.S. healthcare system. It is awarded competitively and helps fund State Refugee Health Coordinators, provide language access at Federal healthcare centers, and supports mental health screening of refugees, among other things. RCUSA strongly opposes the proposed elimination of RHP.

Survivors of Trafficking: Since the passage of the Trafficking Victims Protection Act in 2000, victims of human trafficking have received case management services through HHS's partnership with NGO providers, including assistance obtaining and referrals to medical and psychological treatment, housing, educational programs, life skills development, legal services, and other assistance. Funding is also utilized to promote public awareness, training, and coalition building to raise awareness about human trafficking among law enforcement, social services, medical staff, and other potential first responders, in addition to other faith-based and community groups. These grants are crucial to providing victims, including children, integrative aid and services once they have been identified as a victim of trafficking. Increased funding to \$20 million for each domestic and foreign-born victim is requested to adequately serve trafficking survivors. This funding is critical due to the increases in victim identification efforts. In fact, there has been a 843 percent increase in the number of foreign-born individuals served by the program from 2003 to fiscal year 2016.

Survivors of Torture: The Torture Victims Relief Act authorizes funding for domestic programs that address the long-term impacts of torture on survivors and their families. Effective rehabilitation programs address a survivor's physical, psychological, legal and social needs to reduce their suffering and restore functioning as quickly as possible. RCUSA's proposed \$16 million for torture survivor assistance reflects that many treatment programs have long wait lists, and that—at current funding levels—demand will continue to exceed availability as programs serve not only refugees, but also (and in some cases predominantly) asylees and asylum seekers. An estimated 9,000 survivors and their families from 125 countries benefited from these services in fiscal year 2017.

Unaccompanied Children (UCs): In fiscal year 2017, 40,894 children were referred to the custody and care of the Office of Refugee Resettlement (ORR). ORR's provides children in its care with food, shelter, and clothing as well as educational, medical, mental health, and case management services. For a limited number of children, ORR provides family reunification services by social services providers; specifically,

“home studies” to help ensure children are released into safe placements and “post-release services” to facilitate family and community integration after reunification. Post-release social services by providers are an important means of assuring the continued well-being and adjustment of the children and preventing such dangers as human trafficking. Post-release services also help families to understand the child’s legal obligations as well as provide critical protection and support to the families themselves as the children are integrated into their new communities. These practices not only promote child safety, but they can help reduce the need for involvement with the public child welfare system post-release. RCUSA supports the fiscal year 2018 funding level for these programs that promote successful family reunification and stability, which serve the best interest of the children. RCUSA does not support an expansion of detention, including through use of large-scale institutional facilities, or efforts to support forced family separation.

Our Nation’s historic commitment to refugees through domestic resettlement provides lifesaving support and protection to the world’s most vulnerable. Our Nation’s historic commitment to displaced populations helps us build strategic alliances and stabilize those regions most affected by the largest displacement crisis in global history. This helps keep America safe. Thank you for considering our funding recommendations for fiscal year 2019.

**FISCAL YEAR 2019 OFFICE OF REFUGEE RESETTLEMENT FUNDING NEEDS FOR
THE REFUGEE AND ENTRANT ASSISTANCE ACCOUNT**

| Program Areas | Fiscal Year | | |
|--|----------------------------|-------------------------------|-----------------------------|
| | 2018 Enacted Funding | 2019 President’s Request | 2019 RCUSA Request |
| Transitional & Medical Assistance (TAMS) | \$320,000,000 | \$354,000,000 | \$490,000,000 |
| Refugee Social Services | ⁴ \$207,201,000 | ⁵ \$161,000,000 | \$155,000,000 |
| Targeted Assistance | | | \$47,601,000 |
| Refugee Health Promotion | | \$0 | \$4,600,000 |
| Subtotal (Resettlement Services) | \$527,201,000 | \$515,000,000 | \$697,201,000 |
| Foreign-Born Trafficking Victims | \$17,000,000 | \$18,755,000 | ⁶ \$20,000,000 |
| Domestic Trafficking Victims | \$6,755,000 | | ⁷ \$20,000,000 |
| Torture Survivor Assistance | \$10,735,000 | \$10,735,000 | ⁸ \$16,000,000 |
| Unaccompanied Children | \$1,303,245,000 | ⁹ \$1,148,000,000 | ¹⁰ 1,303,245,000 |
| Total | \$1,864,936,000 | ¹¹ \$1,692,000,000 | \$2,056,446,000 |

⁴ The fiscal year 2018 omnibus explanatory statement indicates that Congress is supportive of combined administration of these three programs, but requires that all three programs continue in fiscal year 2018 to be funded at fiscal year 2017 levels, which were reflected in RCUSA’s asks.

⁵ The Administration proposes merging the administration of Refugee Social Services and Targeted Assistance into one new program, Refugee Support Services. Congress has not allocated less than \$200 million for these programs in at least 15 years, not even taking inflation into account.

⁶ An increase is requested to serve trafficking survivors, given the 962 percent increase in the number of victims identified and certified in need of services since 2002, based on the 2002 ORR report to Congress and the 2016 Trafficking in Persons (TIP) report.

⁷ See #4.

⁸ An increase is requested because many of the torture treatment centers in the Center for Victims of Torture (CVT) network have lengthy wait lists, some as long as 8 months, even without outreach. Additionally, in some areas asylum seekers comprise more than 80 percent of treatment center clients; given the administration’s plans to more rapidly increase asylum claims there will likely be an increased demand for torture survivor services. Finally, ORR estimates up to 44 percent of refugees are torture survivors.

⁹ This request includes a scored \$100 million contingency fund for unaccompanied children, and authorization for an additional \$100 million as needed based on certain triggers, which RCUSA supports.

¹⁰ RCUSA supports continued funding at the level enacted by Congress for fiscal year 2018 but stresses that the funding increase should not be used to support forced family separation at the southern border or increased use of large-scale institutional shelter facilities.

PREPARED STATEMENT OF RESEARCH!AMERICA

On behalf of Research!America, the Nation’s largest not-for-profit education and advocacy alliance working to accelerate medical progress and strengthen our Nation’s public health system, thank you for this opportunity to share our views on fiscal year 2019 appropriations under the jurisdiction of the Subcommittee on Labor, Health and Human Services, Education, and Related Agencies. We are grateful that for fiscal year 2018, the committee not only bolstered the base budgets of the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and the Agency for Healthcare Research and Quality (AHRQ), but also provided dedicated funding for such escalating threats as the opioid crisis and antibiotic resistance and unique needs like the development of a universal flu vaccine. Our appropriations requests for fiscal year 2019 focus on continuing to rebuild the base budgets of these agencies, since the dollars needed to address the opioid crisis and other discreet research and public health issues could well change over the course of fiscal year 2018.

In that context, we request a discretionary budget increase of at least \$2.215 billion for the National Institutes of Health, agency-wide funding of \$8.445 billion for the Centers for Disease Control and Prevention, and agency-wide funding of \$454 million for the Agency for Healthcare Research and Quality.

The National Institutes of Health Drives the Discovery of New Treatments and Cures

NIH is the world's leading funder of basic biomedical research, and Americans recognize the value this research delivers. Since 1992, Research!America has commissioned national and State-level surveys to gauge public sentiment on issues related to health research and innovation. One of the most consistent findings over time has been Americans' support for basic research. In a recent survey, 64 percent of respondents agreed that "even if it brings no immediate benefits, basic scientific research that advances the frontiers of knowledge is necessary and should be supported by the Federal Government."

More than 80 percent of NIH funding is awarded through almost 50,000 competitive grants to 300,000 researchers at more than 2,500 universities, medical schools, and other research institutions in every State and around the world. Research supported by NIH is typically at the early, non-commercial stages of the research pipeline; therefore, NIH funding complements critical private sector investment and development. The NIH also plays an essential role in educating and training America's future scientists and medical innovators by sponsoring training grants and fellowships for biomedical- and health-focused graduate and medical students, postdoctoral researchers and young investigators— a pivotal investment in America's future research workforce.

NIH advances the interests of America and Americans in other crucial ways. For example, the All of Us Research Program at NIH seeks to collect data from one million people to help researchers uncover paths toward delivering precision medicine, accelerating research and improving health. The National Institute of Aging supports research on the health and well-being of older Americans and, through its Alzheimer's Disease Education and Referral Center, provides information on age-related cognitive changes and neurodegenerative disease. The National Cancer Institute's Cancer Moonshot aims to accelerate research and improve our ability to prevent and detect cancer. NIH also plays a pivotal role in the public-private research and development of countermeasures when epidemics and other global public health threats emerge.

We believe it is in the strategic interests of the United States to increase annual discretionary funding for NIH by at least \$2.215 billion in fiscal year 2019, and to supplement that increase by accelerating progress in key areas of opportunity and threat. Research!America believes this powerful infusion of funds is merited by the magnitude of our health challenges, the tangible and intangible costs of inaction, and the extraordinary return on medical progress.

The Centers for Disease Control and Prevention Safeguards the Nation's Health

CDC is tasked with protecting and advancing the Nation's health, and over the past 70 years it has worked diligently to thwart deadly outbreaks, costly pandemics and debilitating disease. Moreover, CDC plays a key role in research that leads to life-saving vaccines, bolsters defenses against bioterrorism and improves health tracking and data analytics. CDC's work has benefited America and Americans in myriad ways, including dramatically reducing the incidence of child lead poisoning, reducing deaths from motor vehicle accidents, containing dangerous pandemic and epidemics, achieving a significant expansion of newborn hearing tests and other screening measures and preventing millions of hospitalizations.

Ebola, Zika, Dengue fever, flu and other emerging health threats have shown just how critical CDC is to our Nation, and have also revealed the enormity of the challenge the agency faces as it works to safeguard American lives. To protect our Nation, CDC scientists must be on-the-ground fighting public health challenges wherever and whenever they occur. But there is an imbalance between the funding provided to CDC and its increasingly growing mission demands. We request that CDC receive at least \$8.445 billion in fiscal year 2019 to carry out its crucially important responsibilities.

AHRQ Provides Best Practices to Keep Healthcare Costs Under Control

AHRQ is the lead Federal agency responsible for ensuring that medical progress translates into better patient care. The value of medical discovery and development hinge on smart healthcare delivery. Out of the \$3 trillion annual spending on healthcare, an estimated 30 percent could be prevented by addressing error and inefficiency. AHRQ-funded research identifies and addresses this diversion of limited healthcare dollars, empowering patients to receive the right care at the right time in the right settings. One out of every 25 hospital patients are affected by

healthcare-associated infections. AHRQ-funded research highlighted best practices for identifying methicillin-resistant *Staphylococcus aureus* (MRSA) in long-term care facilities as part of an infection control strategy that limits the exposure of MRSA-free residents.

From ensuring new medical discoveries reach doctors and patients as quickly as possible in rural as well as urban areas to deploying telemedicine and other health IT to address challenges in healthcare access and delivery, to cutting the number of deadly and preventable medical errors, AHRQ serves many critical purposes. If we underinvest in AHRQ, we are inviting unnecessary healthcare spending and squandering the opportunity to ensure patients receive the quality care they need. We ask that you commit to investing in life- and cost-saving health services research by funding AHRQ at \$454 million in fiscal year 2019.

CONCLUSION

There are few Federal investments that convey benefits as important and far-reaching as funding for NIH, CDC and AHRQ: new cures, new businesses, new jobs; innovative solutions that improve healthcare delivery and optimize the use of limited health dollars; and a public health system nimble and sophisticated enough to meet daunting challenges to the health and safety of the American people. We appreciate your consideration of our funding requests and thank you for your stewardship over such critically important Federal spending priorities.

Sincerely,

[This statement was submitted by Mary Woolley, President and CEO, Research!America.]

PREPARED STATEMENT OF RESTLESS LEGS SYNDROME FOUNDATION

Chairman Blunt, Ranking Member Murray, and distinguished members of the Subcommittee, thank you for considering the views of the Restless Legs Syndrome Foundation as you begin work on fiscal year 2019 appropriations for the NIH and all related research and public health activities across the Department of Health and Human Services, especially those aimed at combating the opioid crisis.

ABOUT THE RLS FOUNDATION

The Restless Legs Syndrome Foundation is a nonprofit §501(c)(3) organization dedicated to improving the lives of men, women, and children living with this often-devastating neurological condition. The Foundation works to increase awareness, improve treatments, and support research to find a cure. From a few volunteers meeting in a member's home in 1992, the Foundation has grown steadily; it now has members in every State, local support groups, and a track record that includes over \$1.6 million provided to support fundamental 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 2019 APPROPRIATIONS RECOMMENDATIONS

The RLS Foundation joins the broader medical research community in thanking Congress for providing a \$3 billion funding increase for NIH for fiscal year 2018 and in requesting at least a subsequent \$2 billion funding increase for fiscal year 2019 to bring NIH's budget up to \$39.3 billion, which is consistent with the necessary level of funding identified through the 21st Century Cures Act.

In this regard, please provide proportional funding increases for all NIH Institutes and Centers, including, but not limited to the National Institute of Neurological Disorders and Stroke (NINDS), the National Heart, Lung, and Blood Institute (NHLBI), the National Institute on Drug Abuse (NIDA), and the National Institute of Mental Health (NIMH). Research on RLS and similar neurological movement disorders is directly related to efforts targeting the opioid epidemic, as many patients with these disorders utilize very low total daily doses of opioid therapies to manage their condition. Additionally, related sleep disorders research activities impact many conditions and are studied across various Institutes and Centers at NIH.

RLS AND THE OPIOID CRISIS

While you debate the Committee's response to the opioid epidemic, the RLS Foundation asks that you protect the needs of patient communities who depend on appropriate access to low total daily dose 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 dose 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 Tim Thornton from Boise, Idaho. Tim suffers from RLS, and he participated in the Foundation's awareness campaign earlier this year to educate members of Congress and the public about the daily struggles that accompany this devastating disorder:

"I was one of the unfortunate individuals who developed restless leg syndrome in my 30s. After developing RLS and having a sleep study, my doctor placed me on so many different medications that I cannot recount the exact number. Out of sheer desperation and complete exhaustion, I felt as though I was at a dead end. I literally thought my life as I knew it was over. My wife all the while had been doing her own research online and came across a doctor practicing out of Downey, California. I called him that afternoon. He called me back that day and the next week I flew down to Los Angeles to meet with him. During the period [before] seeing [this doctor], I paced my hallways every night, my wife almost took me to the emergency room twice, and I literally could not function nor go to work due to sleep deprivation. Once I agreed to go on Methadone, my life has quite literally turned around. I have actually been on it almost 5 years, and my dosage has gone down a bit. My life is back again. I attribute my ability to live a normal life to Methadone, as without it, I can tell you that I would probably be in some ward somewhere, not working, not being able to be the parent that I am, and not contributing to society. It simply takes away the unbelievably uncomfortable feeling in my legs and arms, allowing me to sleep at night and function normally during the day. If this medication were taken away from RLS sufferers, you would be doing a disservice that is of a magnitude to sufferers like me that cannot be comprehended. This medication has had such a huge benefit in the quality of my life that I don't know what I would do without it. We are contributing members of society who happen to have a disease that leaves us with virtually no alternative. This is not a disease I asked for when I was born, and if any of the people considering doing away with the regular prescribing of this medication to sufferers like me were to spend a few nights with our condition, I guarantee that they would reverse their decision for certain diseases and not lump us all into the class of people that are abusers. I am pleading with you to consider those of us with RLS before acting on this agenda item to do away with prescribing this for our community as long as it is working."

Thank you for the opportunity to testify before your committee and for your time and consideration of our requests.

[This statement was submitted by Karla M. Dzienkowski, RN, BSN, Executive Director, Restless Legs Syndrome Foundation.]

PREPARED STATEMENT OF ROTARY INTERNATIONAL

Chairman Blunt, Ranking Member Murray, members of the Subcommittee: Rotary appreciates the opportunity to encourage continuation of funding for fiscal year 2019 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), which is an unprecedented model of cooperation among national governments, civil society and UN agencies working together to reach the most vulnerable children through the safe, cost-effective public health intervention of polio immunization. We appeal to this Subcommittee for continued leadership to ensure we seize the opportunity to conquer polio once and for all. Rotary International requests that \$176 million be provided for the polio eradication activities of the CDC—level funding—to ensure we end polio transmission, protect polio free areas, and leverage the resources developed through this global effort for value-added impact.

The United States is the leading public sector donor to the Global Polio Eradication Initiative. The 325,000 members of Rotary clubs in the U.S. appreciate the United States' generous support and longstanding leadership. Rotary, including matching funds from the Gates Foundation, has contributed more than U.S. \$1.8 billion and thousands of hours of volunteer service to protect children from polio. Rotarians are committed to fundraising for the program until the world is certified polio free. Continued U.S. leadership remains vital to achieve the goal of a polio free world and ensure that the investment in polio eradication infrastructure and resources lives on to benefit other health efforts.

PROGRESS IN THE GLOBAL PROGRAM TO ERADICATE POLIO

Since the launch of the GPEI in 1988, eradication efforts have led to more than a 99 percent decrease in cases. Thanks to this committee's funding for the polio eradication activities of the CDC, 2017 saw only 22 cases of wild polio confirmed in just two countries: Afghanistan and Pakistan. Nigeria, which experienced an outbreak in 2016, has not confirmed any new cases since August of 2016 despite humanitarian crises. Continued progress to reach every child and stop polio virus transmission in these most complex environments reinforces the fact that polio eradication is feasible. While the primary focus of global efforts is on stopping transmission of endemic polio, this is followed closely by work to immunize the more than 400 million children in up to 70 countries which remain at risk for polio outbreaks. Since 2001, more than 40 countries which were polio free experienced outbreaks. While these outbreaks were stopped, they are a reminder that as long as the wild polio virus circulates anywhere, children everywhere, including the United States, remain at risk and must continue to be protected through immunization.

Only wild poliovirus type 1 (WPV1) is still causing cases of paralysis. Type 2 (WPV2) was declared eradicated in September 2015. Type 3 (WPV3) has not been seen since November 2012. Eradicating strains of the polio virus is further proof that a polio-free world is achievable.

CDC'S VITAL ROLE IN GLOBAL POLIO ERADICATION PROGRESS

The United States is the leader among donor nations in the drive to eradicate polio globally. Congressional support has enabled CDC to:

- Provide strategic, technical expertise through the international assignment of 14 technical staff on direct, 2-year assignments to WHO and UNICEF to assist polio-endemic and re-infected countries; and support for three international polio consultants in Pakistan and eight national polio consultants in Afghanistan;
- Expand environmental surveillance to detect and respond to vaccine-derived poliovirus outbreaks in Syria, Democratic Republic of the Congo, Somalia, and Kenya;
- Continue focused response to following 2016 outbreak of wild poliovirus (WPV) in Borno, Nigeria;
- train and deploy 70 national epidemiologists from CDC's Field Epidemiology Training Program (FETP) to the highest risk districts in Pakistan to improve the quality of surveillance and immunization activities there and to strengthen routine immunization systems. This initiative was undertaken in collaboration with the Pakistan Ministry of Health and in coordination with WHO and the USAID's mission in Islamabad;
- provide \$ 54.3 million (in fiscal year 2017) to WHO for surveillance, technical staff and immunization activities' operational costs, primarily in Africa.

- provide \$ 24.2 million (in fiscal year 2017) to UNICEF for approximately 40 million doses of oral polio vaccine, 2.7 million doses of inactivated polio vaccine, and \$15.5 million for operational costs for NIDs in all polio-endemic countries and other high-risk countries in Asia, the Middle East and Africa. Most of these NIDs would not take place without the assurance of CDC's support.
- train virologists from around the world in advanced poliovirus research and public health laboratory support. CDC's Atlanta laboratories serve as a global reference center and training facility, and leading specialized polio reference lab in the world.
- provide the largest volume of operational (poliovirus isolation) and technologically sophisticated (genetic sequencing of polio viruses) lab support to 146 laboratories of the global polio laboratory network;
- continue CDC's Stop Transmission of Polio (STOP) program, which trains and deploys public health professionals to improve vaccine-preventable disease surveillance and to help plan, implement, and evaluate vaccination campaigns in countries of higher-risk for poliovirus transmission to support critical national immunization functions. STOP has trained and deployed more than 2,000 public health professionals to work on polio surveillance, data management, campaign planning and implementation, program management, and communications in high-risk countries. In 2017, the STOP program sent 489 professionals on assignments to 40 countries. In 2018, the first STOP team currently in the field numbers 241 in 42 countries. The second STOP team is being finalized for training and deployment in June 2018;
- train 252 staff at the Local Governing Area level in the highest risk states of Nigeria through CDC's National STOP. Nigeria's polio legacy planning will transition those workers to build lasting improvements in Nigeria's immunization system.
- lead efforts to raise awareness of the importance and urgency of transition planning among donors, country governments and other stakeholders to begin polio legacy planning to ensure that key polio functions, including immunization, surveillance, outbreak response and biocontainment, will be in place post-eradication. Presently, the global polio eradication staff is the single largest source of external technical assistance for immunization and surveillance in low-income countries, and polio eradication efforts are responsible for reaching the world's most vulnerable children with vaccines and other health interventions;
- support global polio eradication by participating in technical advisory groups, EPI manager and other key global meetings. The CDC also published 14 articles, with five more planned for the remainder of 2018, on the progress toward polio eradication in the Morbidity and Mortality Weekly Report (MMWR); and
- provide scientific and technical expertise to WHO on research issues regarding: (1) laboratory containment of wild poliovirus stocks following polio eradication, and (2) when and how to stop or modify polio vaccination worldwide following global certification of polio eradication.

FISCAL YEAR 2019 BUDGET REQUEST

We respectfully request \$176 million in fiscal year 2019 for the polio eradication activities of CDC, the level that was recommended by the House and Senate Appropriations subcommittees for fiscal year 2018. With Congress' continued support for polio eradication in fiscal year 2019, CDC's priorities are to stop wild transmission in the three remaining polio endemic countries and countries at-risk by strengthening surveillance, reaching all children with vaccine, and rapid case response. CDC will also continue to work to strengthen surveillance for polioviruses in all areas currently below certification standard. CDC has also begun planning for a post-polio transition to advance additional global vaccine-preventable diseases (VPD) control and elimination/eradication targets as outlined in CDC's Strategic Framework for Global Immunization 2016–2020.

BENEFITS OF POLIO ERADICATION

Since 1988, 16 million people who would otherwise have been paralyzed are walking because they have been immunized against polio. Tens of thousands of public health workers have been trained to manage massive immunization programs and investigate cases of acute flaccid paralysis. Cold chain, transport and communications systems for immunization have been strengthened. The global network of 146 laboratories and trained personnel established by the GPEI also tracks measles, rubella, yellow fever, meningitis, and other deadly infectious diseases and will do so long after polio is eradicated.

In financial terms, the global effort to eradicate polio has saved more than \$27 billion in health costs since 1988. Polio eradication is a cost-effective public health investment with permanent benefits. On the other hand, as many as 200,000 children could be paralyzed annually in the next 10 years if the world fails to capitalize on the more than \$15 billion already invested in eradication. Success will ensure that the significant investment made by the U.S., Rotary International, and many other countries and entities, is protected in perpetuity.

PREPARED STATEMENT OF THE RYAN WHITE MEDICAL PROVIDERS COALITION

My name is Ernie-Paul Barrette, MD, thank you for considering my record testimony. I serve as Medical Director of the HIV Clinic for the Washington University School of Medicine, in St. Louis, Missouri, the largest providers of medical care for patients with HIV/AIDS in Missouri. I am pleased to submit this testimony on behalf of the Ryan White Medical Providers Coalition (RWMP) of the HIV Medicine Association (HIVMA). HIVMA represents nearly 5,000 HIV clinicians and researchers, and its RWMP 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). I thank the Subcommittee for the \$201.1 million provided in fiscal year 2018 for the Ryan White Part C program. While grateful for this support, I request \$225.1 million, or a \$24 million increase, for Ryan White Part C in fiscal year 2019.

Part C clinics are responding to the opioid epidemic and co-occurring substance use disorders in patients living with HIV. Increased Ryan White Part C funding, and additional non-Ryan White funding for substance use disorder (SUD) treatment and supportive services such as case management, would provide SUD treatment to patients living with HIV who also have co-occurring SUD. This strategy of leveraging the experience and expertise of Ryan White Part C clinics nationwide in treating both infectious diseases and SUD will support the Nation in more rapidly and effectively responding to the opioid epidemic, while also helping prevent the spread of HIV and other infectious diseases, such as hepatitis C, sexually transmitted diseases, and heart infections.

WASHINGTON UNIVERSITY IN MISSOURI IS LEADING THE WAY

Washington University's Ryan White-funded clinic has served as the leading source of HIV primary care in Missouri for over 30 years. Each year our Ryan White clinic serves more patients with more complex needs. In 2017, the HIV Clinic at Washington University experienced a 7.0 percent increase from 2016 in its number of patients living with HIV. Over the last 10 years the clinic has seen a 56 percent increase in patients with HIV. Additionally, approximately 1 in 3 were fully uninsured and relied heavily on the Ryan White Program to fund their care, and a significant portion experienced housing insecurity. Washington University, 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, such as dental services; and support services, such as mental health, case management and transportation—all key components of the comprehensive Ryan White care model that produces outstanding outcomes.

Due to increased rates of hepatitis C infection which is in part driven by the opioid epidemic, the Washington University HIV Clinic has started a hepatitis C clinic in order to treat this infection earlier. In addition, the Washington University HIV Clinic has been a leader in expanded HIV testing to identify cases, improved linkage-to-care services, and use of social media to improve engagement, retention, and medical outcomes among youth and young adult patients. However, the opioid epidemic is hitting Missouri and other parts of the U.S. hard. Washington University patients struggle not only with HIV, but also with substance use disorder and related infectious diseases, such as hepatitis C. In fact, Missouri has seen a recent dramatic increase in cases of hepatitis C.¹

RYAN WHITE PART C CLINICS ARE EFFECTIVE MEDICAL HOMES AND PUBLIC HEALTH PROGRAMS

Part C directly funds approximately 350 community health centers and clinics that provide comprehensive HIV medical care nationwide, serving more than

¹Missouri Department of Health and Senior Services. Online at: <https://health.mo.gov/data/hivstdaids/pdf/HepCKnownRisksFactSheets.pdf>.

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. Access to Ryan White Part C clinics has helped to dramatically decrease AIDS-related mortality and morbidity over the last decade. However, HIV treatment also benefits public health by reducing HIV transmission to virtually zero when individuals are virally suppressed. In 2016, 85 percent of Ryan White patients were virally suppressed. Washington University is doing even better than this national average—in 2017, 87 percent of Washington University patients were virally suppressed. The Ryan White Part C program's comprehensive services help to engage and keep people in HIV care and treatment. For example, 88 percent of HIV patients remain in care at Washington University—a critical fact since HIV disease is infectious, so identifying, engaging, and retaining persons living with HIV in effective care and treatment is an essential public health outcome.

PART C CLINICS ARE ON THE FRONTLINES OF THE OPIOID EPIDEMIC AND PROVIDE SUD TREATMENT

Ryan White Part C clinics are experienced in effectively responding to the opioid epidemic because many clinics already provide both HIV and substance use disorder (SUD) treatment. Ryan White Part C clinics deliver a range of medical and support services needed to prevent and treat SUD, as well as related infectious diseases, such as hepatitis C. Part C clinics also are responding to increases in new HIV cases linked to the opioid epidemic by working with community-based providers and public health systems to provide access to needed HIV and SUD prevention, treatment, and support services. Additional Ryan White funding and non-Ryan White funding for SUD services for Part C clinics would increase access to SUD treatment and comprehensive support services for both individuals living with HIV as well as those without HIV. Such funding would increase access to SUD treatment more rapidly nationwide through the Ryan White Part C clinic network, which would help prevent the spread of HIV and other infectious diseases.

PART C CLINICS ARE SAVING LIVES AND REDUCING COSTS

Early and reliable access to HIV care and treatment helps patients with HIV live healthy and productive lives and is more cost effective. A study from the Part C clinic at the University of Alabama at Birmingham found that patients treated at later stages of HIV disease required 2.6 times more healthcare dollars than those receiving earlier treatment meeting Federal HIV treatment guidelines. These principles also apply when addressing SUDs. Kaiser Permanente Northern California analyzed the average medical costs during the 18 months pre- and post-SUD treatment and found that the SUD treatment group had a 35 percent reduction in inpatient costs, 39 percent reduction in ER costs, and a 26 percent reduction in total medical costs, as compared to a matched control group.^{2,3} Engaging Ryan White Part C clinics to expand access to SUD services will help meet the urgent need for this care nationwide and reduce medical and emergency care costs for people living with SUD and other communicable diseases such as viral hepatitis.

INCREASED FUNDING FOR PREVENTION AT CDC AND RESEARCH AT NIH ALSO IS CRITICAL

While my testimony is focused on HRSA's Ryan White Program, the ability to effectively respond to the interconnected HIV and opioid epidemics also depends heavily on CDC funding to enhance surveillance and prevention activities, and on NIH to continue to improve the tools that we have to prevent and treat HIV and SUD and to learn how to effectively implement them. I appreciated the increase of \$5 million in funding for sexually transmitted diseases (STD) and for viral hepatitis for fiscal year 2018, but a significant boost in funding of \$303 million is needed for the Division of HIV, Viral Hepatitis, STD and Tuberculosis to scale up activity relative to the size and scope of the epidemics we face. The \$3 billion increase for NIH for fiscal year 2018 was a critical investment in supporting the scientific discoveries that will help to end both the HIV and opioid epidemics. I urge you to sustain and grow NIH funding.

²Weisner C. Cost Studies at Northern California Kaiser Permanente. Presentation to County Alcohol & Drug Program Administrators Association of California Sacramento, California. January 28, 2010.

³Weisner C, Mertens J, Parthasarathy S, et al. Integrating primary medical care with addiction treatment: A randomized controlled trial. *Journal of the American Medical Association*, 2001; 286: 1715–1723.

CONCLUSION

Thank you for your consideration of these requests and your leadership on these pressing public health issues. As discussed in this testimony, I urge to you to provide robust fiscal year 2019 funding for the Ryan White HIV/AIDS Program, substance use disorder treatment and the treatment and surveillance of related infectious diseases, and NIH research.

[This statement was submitted by Ernie-Paul Barrette, MD, Medical Director, HIV Clinic for the Washington University School of Medicine and Member, Ryan White Medical Providers Coalition of the HIV Medicine Association.]

PREPARED STATEMENT OF SAC AND FOX NATION

Chairman Blunt and esteemed members of the Committee, on behalf of the Sac and Fox Nation I thank you for the opportunity to submit this testimony for the record of our requests for the fiscal year 2019 Budgets and matters for consideration for Health and Human Services and Education. The Sac and Fox Nation looks forward to building a positive relationship with your committee and enhancing the future of our Tribal citizens.

We are in need of a renewed commitment to Native education. The Federal trust responsibility will continue to be undermined until the Federal Government fully appropriates funding to bridge the educational attainment gap. Implementing the following requests would ensure this trust responsibility is upheld by reinvesting critical resources to improve the education systems serving Native students. We appreciate Congress working across the aisle to better fund and support Native education and we hope that Congress provides full appropriations to authorized programs which Native students desperately need.

The Sac and Fox Nation currently has an enrollment of over 3,000 people, with a jurisdictional area covering all or parts of Payne, Pottawatomie and Lincoln counties. We are a Self-Governance Tribe in both the Department of the Interior and the Department of Health and Human Services. The Sac and Fox Nation is home of Jim Thorpe, one of the most versatile athletes of modern sports who earned Olympic gold medals for the 1912 pentathlon and decathlon.

I. DEPARTMENT OF EDUCATION REQUESTS

A. *\$5 million for the State-Tribal Education Partnership Program (STEP) Increase in funding directly to education departments to allow more money for programs.* The Sac and Fox Nation supports direct funding for Tribal Education Agencies (TEA) because it would provide more money for programs which are seriously underfunded. For more than a decade we have advocated and fought for greater Tribal participation in educating Native students. STEP promotes increased collaboration between Tribal, State and local education agencies and building the capacity of TEAs to conduct certain administrative functions under ESEA formula grants for eligible schools. The enactment of Public Law 114-95, Every Student Succeeds Act (ESSA) places emphasis on State and local innovation and highlights a new era, providing a great deal of flexibility to our States and local districts and includes several Native specific provisions.

B. *\$25 billion for Title I, Part A, Local Education Agency (LEA) Grants—Support Investing in Tribally Driven Education.* Title I of ESSA provides critical financial assistance to local educational agencies and schools with high percentages of children from low income families that ensure all children meet challenging State academic standards. Currently, there are over 600,000 Native students across the country with nearly 93 percent of those students attending non-Federal institutions, such as traditional public schools in rural and urban locations. In order to address annual inflation, CR's and sequestration, a substantial increase in funding is needed to meet the needs of Native students and students from low-income families. However, the President's budget proposal for fiscal year 2019 cuts funding for all ESSA programs by almost \$3.4 billion (-14 percent) compared to fiscal year 2017; and underfunds ESSA programs by nearly \$5.1 billion (-20 percent) compared to authorized levels.

II. DEPARTMENT OF HEALTH AND HUMAN SERVICES REQUESTS

A. *\$9.6 billion for Head Start which includes Indian Head Start—*Head Start has been and continues to play an instrumental role in Native education by providing early education to over 24,000 Native children. This vital program combines education, health, and family services to model traditional Native education, which ac-

counts for its success rate. Current funding dollars provide less for Native populations as inflation and fiscal constraints increase, even though research shows that there is a return of at least \$7 for every single dollar invested in Head Start. Congress should increase funds to Head Start and Early Head Start to ensure Indian Head Start can reach more Tribal communities and help more Native recipients by activating the Indian special expansion funding provisions (after a full Cost of Living Allowance has been paid to all Head Start programs). We are proud of our programs, but they are located in major areas like Shawnee, Norman and Cushing Oklahoma. More funding and more opportunities in this area would allow programs like ours to grow and expand to make sure that all Tribal youth are being served when it comes to early education.

B. Increase Funding to Social Services in Indian Country through Health and Human Services. Our children are a critical resource that we must protect and the great work that is done by the Administration of Children and Families and all the Indian Child Welfare departments across the Nation should be properly funded. With the expansion of Indian Child Welfare, the BIA Guidelines and possible regulations these programs are in dire need of funding to ensure that they are running at the best capacity and efficiency possible. Protecting our Native youth from birth, through school and their trying years of finding themselves and their purpose is something that is paramount in our eyes. We strongly encourage you to consider this increase and to help us fight to make sure that critical services are reaching those who are most in need. In fiscal year 2019, we recommend the following:

1. *Restore \$281 million to Child Welfare Services Program (Pre-sequestration level).* Tribes need to have access to increased flexible Child Welfare Service Program funds for their child welfare programs. Of the 573 Federal-recognized Tribes less than 400 have been able to access this funding. Studies show that culturally tailored programs, resources and case management result in better outcomes for AI/AN children and families involved in the child welfare system. The median Tribal grant is merely \$13,300, an insufficient amount to provide the level of program services needed by Tribes.

2. *Increase to \$38 million Child Abuse Discretionary Activities, Innovation Evidence-Based Community Prevention Program.* Tribes are now eligible for these funds through a competitive grant process. An accurate understanding of successful child abuse and neglect interventions for American Indian and Alaska Native (A/AN) families allows child abuse prevention programs to target the correct issues, provide the most effective services and allocate resources wisely.

3. *Increase to \$45 million—Community-based Child Abuse Prevention.* Tribes have access to this program but share a one-percent set-aside of the total funding with migrant populations through a competitive grants program. Currently only two Tribal grantees are funded in each 3-year cycle. This is the only program appropriated funds for prevention programs in Tribal communities.

4. *Increase to \$50 million for Tribal Behavioral Health program.* AI/AN youth are more likely than other youth to have an alcohol or substance abuse disorder. There is growing evidence that Native youth who are culturally and spiritually engaged are more resilient than their peers. These funds must be used for effective and promising strategies to address the problems of substance abuse and suicide and promote mental health among AI/AN Tribal Leaders of tomorrow.

C. Increase Funding for Part A, Grants for Indian Programs and Part B, Grants for Native Hawaiian Programs. Increase the Level of Funding for Programs like the Title VI Elders Program Food Delivery. At the Sac and Fox Nation, just as throughout Indian Country, we are seeing a great increase in the number of elders who need help getting meals. However, not all of elders are medically homebound. Some don't have transportation or vehicles, some have issues with being able to drive properly and others are too far from the kitchens where meals are served. We request an increase in funding for this program and implementation of more flexibility. With an increase in funding more kitchens or meals centers could be opened to provide for the care of our growing population of elders. While this may seem small compared to the other major issues we know you are dealing with, it is no small issue to us. For a lot of our elder population, who may live in rural areas or communities, a meal delivery may provide them the only opportunity with human interaction on any given day. Moreover, it allows them to have a good, nutritious meal which is not a possibility for a lot of them on their own. Our meal delivery staff is critical to the health of our elders to make sure they are eating, taking care of themselves and can get help when it is needed. In a rural community, a meal delivery could save a life and allows our elders to receive consistent care.

Again, thank you for allowing us to advance these requests and recommendation from the Sac and Fox Nation.

[This statement was submitted by Kay Rhoads, Principal Chief, Sac and Fox Nation.]

PREPARED STATEMENT OF THE SAFER FOUNDATION

My name is Victor Dickson and I submit testimony on behalf of the Safer Foundation. For 46 years, Safer has provided a comprehensive continuum of workforce development and reentry services for individuals with arrest and conviction records seeking employment. There is dignity in work, and Safer Foundation believes that individuals who have made mistakes in the past should have the opportunity to be self-sufficient and contribute to their families and communities through gainful, living wage employment. Clients come to Safer because they want and need to work. Safer Foundation helps clients discover career paths that provide personal fulfillment while allowing them to earn a living. A critical Federal program that supports these efforts is the Reintegration of Ex-Offenders (RExO) program within the Employment & Training Administration of the U.S. Department of Labor. I thank the Subcommittee for providing RExO with \$93 million in fiscal year 2018. Given the persistent skills gap and significant need to help employers identify qualified workers nationwide, I request \$100 million for the RExO program in fiscal year 2019.

Employment Reduces Recidivism and Improve Reentry Outcomes

Research shows that sustained, living wage employment and life skills are critical components to long-term reentry success. One study found that individuals who were employed and earning higher wages after release were less likely to return to prison within the first year.¹ Unfortunately, finding this type of employment can be prohibitively difficult for Americans who have any history of justice system involvement. The National Employment Law Project estimates that 1 in 3 American adults has a criminal record that interferes with their ability to find a job.² The RExO program helps individuals overcome employment barriers by preparing participants for jobs in local high-demand industries through career pathways and industry-recognized credentials.

Increasing RExO funding would expand access to comprehensive workforce development and reentry services that assist individuals with criminal records in navigating obstacles to employment while improving employment and reentry outcomes. Authorized by section 169 of Workforce Innovation and Opportunity Act (WIOA), the RExO program provides critical workforce preparation services for both adults and young people. RExO includes a \$25 million set-aside to provide services to prepare formerly incarcerated youth for employment, including those who have not completed school or other educational programs. In light of the significant costs of the criminal justice system at the State, local, and Federal levels, the RExO program is crucial to incubating community-based models of successful reentry through employment.

Safer's RExO Services Increase Employment by Working with Employers and Employees

Safer Foundation offers a full spectrum of workforce development and reentry services that train individuals, address their reentry obstacles and needs, and help them obtain sustained employment. This holistic approach has rendered outstanding results for participants and employers. In 2006, decades of experience and success led Safer to become one of the original RExO grantees. This year, Safer expects to provide employment services to nearly 6,000 individuals with arrest and conviction records, with RExO funding providing critical support for these services.

However, in addition to working with reentering individuals and their communities, Safer also works closely with employers to identify what types of trained employees they need. Safer can be responsive to employer needs by tailoring its programs to develop skilled workers for specific employment sectors. For example, Safer's Training to Work (T2W) program, funded by a RExO grant, has improved long-term employment prospects for clients at Safer's Adult Transition Centers (ATC). Program participants receive case management, education, and training that lead to industry-recognized credentials for in-demand employment such as forklift operation, foodservice and sanitation, welding, computer numerically control (CNC), CDL training, and Microsoft technologies. Given the program's strong employer and

¹Visher, C., Debus, S., & Yahner, J. *Employment After Prison: A Longitudinal Study of Releasees in Three States*. Washington, DC: Urban Institute (2008).

²"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>.

credentialing components, RExO is uniquely positioned to assist local organizations in developing and providing services that meet the needs of both the local business community and reentering individuals.

Safer's RExO Grant Produced Outstanding Employment Outcomes and Reduced Recidivism

Safer's RExO grant for the Training to Work (T2W) program significantly outperformed employment targets and dramatically reduced recidivism. For the first cohort of RExO T2W participants, 69 percent of participants obtained employment—15 percent higher than the grant's employment target. Given the success of this first cohort of participants, T2W was extended to a second cohort who did even better with an employment rate of 78 percent—30 percent higher than the grant's target.

Safer's RExO T2W grant also reduced recidivism rates beyond original targets. A 2014 report published by the Bureau of Justice Statistics, which studied recidivism across 30 States for 5 years, determined that the recidivism rate 1 year after release from prison was 43.4 percent.³ T2W's first participant cohort had an 11 percent recidivism rate, and its second participant cohort had a 9 percent recidivism rate—respectively 75 percent and 80 percent lower than the national recidivism rate.

Program evaluation has shown that such successful outcomes are related to the comprehensive service model that grantees such as Safer provide. Effective, comprehensive services can include interventions such as relationship building between staff and participants, employment verification, trauma informed training, life skills training, employment preparation, mentoring, intensive case management, strong training provider relationships and support, family involvement, and post-release follow-up and support.

U.S. Economic Success Requires Increased Employment of Individuals with Criminal Records

As the U.S. economy continues to rebound from the last recession, the labor market is tightening and the skills gap is growing. While currently the U.S. is experiencing a period of economic expansion, experts warn that this expansion will end prematurely if the U.S. does not relieve structural constraints on labor force participation, including over-expansive bans on employment of individuals with criminal records. Employment barriers faced by individuals with criminal records combined with the opioid epidemic have deflated the U.S. labor force participation rates, which are as low today as they were over 30 years ago.⁴ As labor markets continue to tighten, employers are increasingly ready to give people with criminal records a fair shot, and increasingly need to do so to find and employ skilled workers. Safer has partnered with hundreds of employers to meet their workforce needs. Increased RExO funding in fiscal year 2019, including the funding of earn and learn apprenticeship opportunities for in demand skill development, would allow these efforts to expand, and could help match more employers with qualified employees who are trained, talented, motivated to work.

CONCLUSION

By making effective workforce development and reentry services a priority, we fulfill labor market demands, contribute to a growing 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 \$100 million to the RExO program in fiscal year 2019. Thank you so much for your time and consideration of this important program.

[This statement was submitted by Victor Dickson, President and CEO, Safer Foundation.]

PREPARED STATEMENT OF SAVE THE CHILDREN ACTION NETWORK

Chairman Blunt, Ranking Member Murray, and honorable Members of the Subcommittee, thank you for the opportunity to provide testimony about the critical investments that must be made in early childhood education (ECE). My name is Kris Perry and I am the President of Save the Children Action Network (SCAN). SCAN

³Durose, 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.

⁴Bureau of Labor Statistics, US Department of Labor. Available at <https://data.bls.gov/timeseries/LNS11300000>.

is a national, non-profit organization that aims to mobilize all Americans to support investments in ECE, for children birth to five and their parents. We advocate for robust appropriations for the Department of Health and Human Services programs of Head Start/Early Head Start, Child Care and Development Block Grants, and Preschool Development Grants, as well as the Department of Education programs, 21st Century Community Learning Centers and Promise Neighborhoods.

BACKGROUND

The changing demands of our Nation's economy, the stresses of our labor market and the challenge created by an increasing number of children being raised in single-parent families have all left low-income parents struggling with the burdens of work and parenting. By supporting critical early learning programs, not only are we investing in the lives of children, but their parents also have the ability to enter into the workforce and become productive, taxpaying members of society. This increases the economic stability of families and improves the foundation for the children's future wellbeing. Ensuring access to ECE is the most effective way to break the cycle of poverty. These investments lay the foundation for children's success later in school, career and life—and they also offer tangible returns on investment to the country as a whole, such as increased tax revenue later in life, lower justice system costs, and reduced reliance on government assistance.

Disadvantaged children who don't participate in high-quality early education programs are:

- 70 percent more likely to be arrested for a violent crime;
- 60 percent more likely to never attend college;
- 50 percent more likely to be placed in special education;
- 40 percent more likely to become a teen parent; and
- 25 percent more likely to drop out of school.¹

When America invests in kids, it is investing in its own economic future as well. Nobel Prize-winning economist James Heckman released a report in December 2016 indicating that the annual rate of return on investments in high-quality early childhood development for children from low-income backgrounds can be up to 13 percent, per child per year, due to improved outcomes in education, health, sociability, economic productivity and reduced crime.²

Despite this evidence, fewer than half of low-income children in the U.S. have access to quality ECE programs. Without access to high-quality early learning programs, children fall behind. Making matters worse, many never catch up. By age five, more than half of all American children are not prepared for school.³ For the benefit of our Nation, it is critical to ensure that access to high-quality early education and family engagement programs are available for all children, regardless of their income.

We recognize that difficult budget decisions that need to be made. However, balancing the budget on the backs of children, who are our greatest investment and hope for the future, is not the right path forward and it is not supported by an overwhelming majority of Americans.⁴ The research is clear that doing so is against our economic interest.

SAVE THE CHILDREN'S WORK ON EARLY CHILDHOOD EDUCATION

Save the Children has years of experience and has long been a part of the movement to provide high-quality ECE in the United States. To advance early learning, Save the Children runs education programs for children at home and in the classroom. Our child experts work to ensure that our Nation's most under resourced children have the best chance for success. Every day, we help children get ready to learn, do well in school, and live healthy, active lives.

Save the Children's Early Steps to School Success (ESSS)

ESSS has been serving children in the United States since 2006. During the 2015–2016 school year, 7,400 children and their families across 14 States participated in Save the Children's ESSS program. These children are growing up in rural poverty and facing many hurdles due to their unique geographic locations. Despite

¹“Early Childhood Education in the U.S.,” Save the Children USA, (2015), Print.

²Jorge Luis Garcia, James J. Heckman, Duncan Ermini Leaf, and Maria Jose Prados, “The Life-Cycle Benefits of an Influential Early Childhood Program,” The Heckman Equation, (2016), <https://heckmanequation.org/resource/lifecycle-benefits-influential-early-childhood-program/>.

³Julia B. Isaacs, “Starting School at a Disadvantage: The School Readiness of Poor Children,” Center on Children and Families at Brookings, (March 2012).

⁴First Five Years Fund 2016 National Poll results- <http://ffyf.org/resources/2016-poll-research-summary/>.

their challenges, 87 percent of the children in the program score at or above the normal range for vocabulary acquisition and enter kindergarten on par with their middle-income peers, ready to succeed in school and in life.

Save the Children Early Head Start and Head Start Programs

Children who participate in federally-funded Head Start and Early Head Start have a higher likelihood of graduating high school and a lower likelihood of being charged with a crime than similar children who do not participate in Head Start.⁵ Furthermore, participation in high-quality Head Start programs has been shown to close over one-third of the gap in test scores between children who participate in Head Start and their more advantaged peers.⁶ Three-year-olds who participate in Early Head Start perform significantly better on cognitive, language and social-emotional measures than their peers.⁷ In 2016, through these programs, Save the Children directly reached 2,563 American children with these comprehensive early education services.

APPROPRIATIONS PRIORITIES

Child Care and Development Block Grant (CCDBG)

We are incredibly grateful for Congress' historic demonstration of support for ECE programs in its fiscal year 2018 appropriations. The unprecedented increase in funding for CCDBG in fiscal year 2018 showed, once again, the bipartisan support of this program. To guarantee that no children lose child care slots and providers can meet the quality standards from the bipartisan 2014 reauthorization of CCDBG, SCAN supports a fiscal year 2019 appropriations level of at least \$5.8 billion for CCDBG. This funding level would ensure that Congress follows through on its commitment under the Bipartisan Budget Act of 2018 to double CCDBG funding.

As the major Federal child care program, CCDBG provides vouchers directly to working families to help them afford the licensed child care provider of their choice. Unfortunately, it is only serving one out of six children eligible for help. Federal and State child care spending has fallen to an 11-year low and the number of children receiving assistance is at a 16-year low. In 2017, only West Virginia and South Dakota reimburse child care providers serving CCDBG-eligible children at the federally recommended level.⁸ Increased funding should be used to expand the supply of child care, upgrade and expand existing child care centers, build new child care centers, cover start-up costs for small family child care businesses, and improve the quality of child care jobs—these jobs currently pay, on average, \$9.62 an hour.⁹ When child care professionals are well-paid, are offered professional development opportunities, and have good working conditions, child care is more likely to be high-quality, safer and more enriching.

Head Start and Early Head Start (HS/EHS)

HS/EHS are key to providing and expanding comprehensive early care and education to our poorest children. We are grateful for the substantial funding that HS/EHS received in fiscal year 2018 appropriations and, therefore, urge the subcommittee to support robust funding in fiscal year 2019 of at least \$11.3 billion to ensure the new, outcomes-driven HS Program Performance Standards are implemented properly. We also support the Early Head Start-Child Care Partnerships, which have shown promising results in States and communities by assisting in the expansion of high-quality early learning opportunities for infants and toddlers. These partnerships build the capacity of the community and providers, while also incorporating EHS' high standards.

HS has served over 32 million children and families in communities across the country since 1965, and continues to serve nearly a million children every year. At the current level of funding though, HS is only able to serve two out of every five

⁵ Eliana Garces, Duncan Thomas, and Janet Currie, "Longer-Term Effects of Head Start," *The American Economic Review*, 92.4, (Sept. 2002), http://www.jstor.org/stable/3083291?seq=1#page_scan_tab_contents.

⁶ Janet Currie and Duncan Thomas, "Does Head Start Make a Difference?" *The American Economic Review*, (1995): 359, <http://www.econ.ucla.edu/people/papers/Currie/Currie14.pdf>.

⁷ Early Head Start Benefits Children and Families, Early Head Start National Resource Center, An Office of the Administration for Children and Families, (June 2015), <http://www2015.fecikc.ohs.acf.hhs.gov/2Fhslc%2Fta-system%2Fehsnrc%2Fabout-ehs%23benefits>.

⁸ National Women's Law Center State Child Care Assistance Policies 2017- <https://nwlc-ciw49tixgw5lbab.stackpathdns.com/wp-content/uploads/2017/10/NWLC-State-Child-Care-Assistance-Policies-2017-1.pdf>.

⁹ National Women's Law Center, Undervalued: A Brief History of women's Care Work and Child Care Policy in the United States https://nwlc-ciw49tixgw5lbab.stackpathdns.com/wp-content/uploads/2017/12/final_nwlc_Undervalued2017.pdf.

eligible preschoolers. Moreover, some of the HS programs can only offer partial day and/or partial year programming. These shortfalls in service delivery hamper the development, interrupt stable care of children and add an extra burden on caregivers to find alternative care options, which may be costly or lower quality. Proposals for more HS programs to provide full-day, full-year services would ensure our lowest-income children receive a strong early learning experience. This change, however, will require additional investments so that the increased hours and days of programming do not result in cuts in the number of children participating in HS, the number of staff employed by programs or impact the quality of programming.

Preschool Development Grants (PDG)

States' commitment to increasing access to high-quality preschool opportunities is extremely strong, as is their eagerness to partner with the Federal Government in this endeavor. Therefore, Congress should match States' enthusiasm and continue current levels of funding of \$250 million so that States have the resources they need to achieve our shared goal of increasing access to high-quality preschool.

Unfortunately, fewer than three in ten 4-year-olds participate in a high-quality preschool program. PDG funding encourages States to establish or expand their own pre-kindergarten programs to serve more children and bolster the quality of these programs. The current PDG grantees are working in over 200 communities to expand access to high-quality preschool opportunities in 18 States. Since its inception 4 years ago, this program has already served over 170,000 children who otherwise would not have had access to preschool.

21st Century Community Learning Centers (CCLC)

We urge Congress to support this important program with funding of \$1.3 billion so that afterschool programming may continue and the academic and developmental outcomes of children be improved.

Every day 11.3 million children are alone after school and are unsupervised for an average of seven hours per week. Parents of more than 19.4 million youth say their children would participate in an afterschool program if one were available in their community. Programs like CCLC help working families, keep young people safe during the hours after school when juvenile crime peaks, and improve academic achievement. The CCLC program supports community learning centers that provide academic enrichment opportunities during non-school hours for children, particularly students who attend high-poverty and low-performing schools. The program helps students meet State and local student standards in core academic subjects and offers students a broad array of enrichment activities that can complement their regular academic programs. Under the Every Student Succeeds Act (ESSA), funds can also be used to pay for additional time, support and enrichment activities during the school day. Without funding for afterschool and summer learning programs, students will lose out on essential learning opportunities that help them prepare for school, college, and careers.

Promise Neighborhoods

Created in 2010, Promise Neighborhoods is an innovative program that continues to fund communities with demonstrated success as well as award funding to new communities who create thoughtful plans for change. This program is a strategic investment in high-needs communities, so we ask Congress to make the smart investment of \$78.3 million.

The Promise Neighborhoods program is authorized under the Elementary and Secondary Education Act of 1965, as amended by ESSA.¹⁰ The program supports the implementation of innovative strategies that improve outcomes for children in the Nation's most distressed communities and build a continuum of supports for children. This program increases the capacity of community leaders and organizations to plan, implement and track progress toward specified outcomes. These outcomes include students prepared to enter kindergarten, ready to graduate and feel safe at school. The program also tracks 15 indicators to measure success, including attendance, graduation and student mobility rates, and participation in daily physical activity. This holistic approach to improving the educational achievement of low-income students ensures sustainable, community-driven changes and interventions.¹¹

¹⁰ <https://innovation.ed.gov/what-we-do/parental-options/promise-neighborhoods-pn/>.

¹¹ <https://www.brookings.edu/research/the-harlem-childrens-zone-promise-neighborhoods-and-the-broader-bolder-approach-to-education/>.

CONCLUSION

On behalf of Save the Children Action Network, and our advocates across the country, I want to thank the Subcommittee for its continued leadership ECE programs and its demonstrated bipartisan support of these programs in the fiscal year 2018 appropriations process. I ask that you now continue to make a robust investment in ECE in fiscal year 2019. We ask for your continued partnership in investing in children, increasing access to opportunity, and ensuring a more prosperous America for generations to come.

[This statement was submitted by Kris Perry, President, Save the Children Action Network.]

PREPARED STATEMENT OF THE SCLERODERMA FOUNDATION

THE FOUNDATION'S FISCAL YEAR 2019 L-HHS APPROPRIATIONS RECOMMENDATIONS

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- \$8 billion in program level funding for the Centers for Disease Control and Prevention (CDC), which includes budget authority, the Prevention and Public Health Fund, Public Health and Social Services Emergency Fund, and PHS Evaluation transfers.
 - A proportional fiscal year 2019 funding increase for CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP).
 - At least \$39.3 billion in program funding for the National Institutes of Health (NIH).
 - Proportional funding increases for NIH's National Heart, Lung, and Blood Institute (NHLBI); National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS); National Center for Advancing Translational Sciences (NCATS).
-

Chairman Blunt, Ranking Member Murray and distinguished members of the Subcommittee, thank you for your time and your consideration of the scleroderma community's priorities while working to craft the fiscal year 2019 L-HHS Appropriations Bill.

ABOUT SCLERODERMA

Scleroderma, or systemic sclerosis, is a chronic connective tissue disease generally classified as one of the autoimmune rheumatic diseases. The word "scleroderma" comes from two Greek words: "sclero" meaning hard, and "derma" meaning skin. Hardening of the skin is one of the most visible manifestations of the disease. The disease is also known as "systemic sclerosis," a subset of the disease in which internal organ systems (such as kidneys, lungs, heart, and gastrointestinal tract) and skin, or internal organ systems only, are affected. It is estimated that about 300,000 Americans have scleroderma with one-third of those having the systemic form of the disease. Scleroderma varies from patient to patient and often presents with symptoms similar to other autoimmune diseases, making diagnosis and treatment extremely complicated. There may be many misdiagnosed or undiagnosed cases. Currently, there is no cure for scleroderma.

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 affected individuals, 2) promote education and public awareness, and 3) advance critical research and improve scientific understanding to improve treatment options and find cures. The Foundation has a research program that funds clinical research 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.

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 and pulmonary fibrosis that occurs during a heart attack. Scleroderma is a prototypical manifestation of fibrosis as it impacts multiple organ systems. In this way, it is important to promote cross-cutting research across such Institutes as NIAMS and NHLBI.

Please provide NIH with a significant funding increase to the scleroderma research portfolio can continue to expand and facilitate key breakthroughs.

- NIH continues to support the Trans-NIH Working Group on Fibrosis which is working to promote cross-cutting research across Institutes.
- NHLBI, which is leading Scleroderma Lung Study II, is comparing the effectiveness of two drugs in treating pulmonary fibrosis in scleroderma.
- NIAMS, is leading efforts to discover whether three gene expression signatures in skin can serve as accurate biomarkers predicting scleroderma, and investigations into progression and response to treatment to clarify the complex interactions of T cells and interleukin-31 (IL-31) in producing inflammation and fibrosis, or scarring in scleroderma.

Patient Perspective

My constantly aching hands begged for mercy of just one day without pain. My joints started to feel like they were being torn away from my body. Anytime I touched something cold, my hands would tingle and burn. Painful sores started appearing on my knuckles. You stole my skin color and with that went my confidence. It was like I was turning into a mummy as my skin tightened with collagen, day by day. I was beginning to need help performing small tasks. Opening a water bottle or turning a key in the door started to become difficult. Standing for long periods of time made my hips radiate with pain. In 2012 I had to stop working, at 24 years old. The definition of normal as I knew it was being torn down and built into something completely new. And so was my soul.

I now need help with everything! Getting dressed, washing my hair, cleaning, doing laundry; pretty much anything I have to use my hands for. You stole my independence. I had to learn to swallow my pride and ask for help. It's a tough thing to do, especially when you're at an age that's supposed to be your prime. Friends and family around me have blossomed into caregivers and helping me has become second nature to them. It's a beautiful thing when those surrounding you automatically adapt to your disability. Support is the lifeboat that keeps me afloat."

—Excerpt from *"My Letter to Scleroderma"*
 Jessica Messingale
 Coconut Creek, Florida

[This statement was submitted by Mr. Robert J. Riggs, Chief Executive Officer, Scleroderma Foundation.]

PREPARED STATEMENT OF THE SLEEP RESEARCH SOCIETY
 FISCAL YEAR 2019 APPROPRIATIONS RECOMMENDATIONS

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- SRS joins the broader medical research community in thanking Congress for providing a \$3 billion funding increase for NIH (National Institutes of Health) for fiscal year 2018 and in requesting a subsequent increase of at least \$2 billion for fiscal year 2019 to bring NIH's total funding up to \$39.1 billion annually.
 - Please provide proportional funding increases for all NIH Institutes and Centers, including, particularly the National Heart, Lung, and Blood Institute (NHLBI), which houses the National Center on Sleep Disorders Research (NCSDR). Sleep impacts nearly every body system, and many diseases and disorders. As a result, almost every NIH Institute and Center conducts sleep research, and NCSDR helps coordinate sleep research activities across the Federal Government.
 - SRS joins the broader public health community in asking Congress to provide CDC (Disease Control and Prevention) with a meaningful funding increase for fiscal year 2019.

—Please also provide a dedicated, line-item appropriation of at least \$250,000 to ensure the National Health Sleep Awareness Project can continue.

Chairman Blunt, Ranking Member Murray, and members of the Subcommittee, thank you for considering the views of the Sleep Research Society (SRS) as you work on fiscal year 2019 appropriations for sleep-related medical research and public health programs. Most crucially, thank you for providing meaningful investment in fiscal year 2018 for NIH and CDC. It is the sleep community's hope that this important prioritization of NIH and CDC activities will continue moving forward.

ABOUT SRS

SRS was established in 1961 by a group of scientists who shared a common goal to foster scientific investigations on all aspects of sleep 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 research has expanded into areas such as psychology, neuroanatomy, pharmacology, cardiology, immunology, metabolism, genomics, and healthy living. SRS recognizes the importance of educating the public about the connection between sleep and health outcomes. SRS promotes training and education in sleep research, public awareness, and evidence-based policy, in addition to hosting forums for the exchange of scientific knowledge pertaining to sleep and circadian rhythms.

NIH RESEARCH ACTIVITIES

Over recent years, NIH has seen a meaningful infusion of essential funding. This investment has improved grant funding pay lines, led to significant scientific advancements, and helped to prepare the next generation of young investigators. Due to quality science, the sleep research portfolio has done well as a result of this additional funding. In fact, NIH supported research was critical to the circadian research project that received the 2017 Nobel Prize in Physiology and Medicine. However, while the sleep portfolio overall is strong, one area of potential improvement is investment in individual sleep disorders.

The research portfolios for specific conditions at NIH including Restless Legs Syndrome and Narcolepsy remain relatively modest. The research done in these portfolios has a direct and sometimes immediate impact on patient health and wellness. Moreover, additional resources will support the full spectrum of medical research activities and initiate important clinical and translational research activities that will ensure breakthroughs in basic science become diagnostic, treatment, and healthcare improvements for patients battling various rare, complex, and debilitating sleep disorders.

On an annual basis, the Committee Report accompanying the annual House L–HHS Appropriations Bill features important instructions that emphasize the value and importance of sleep, sleep disorders, and circadian research. In fiscal year 2018 alone, Committee recommendations correctly identified the importance of this research to cancer care, Alzheimer's, and other conditions. Please continue to actively support various sleep research efforts moving forward.

CDC PUBLIC HEALTH ACTIVITIES

For the past 5 years, CDC has supported the National Healthy Sleep Awareness Project (NHSAP) with discretionary resources at about \$250,000 annually. Despite the severity and prevalence of sleep-related health issues, NHSAP represents the only public health activity at CDC devoted to sleep. This project has been highly successful and generated numerous research advancements, professional publications, and peer-reviewed articles.

Appropriators have been supportive of this program, but CDC is likely unable to continue to engage in ongoing activities without dedicated resources. Each year, NHSAP conducts surveillance, public awareness, and professional education public health activities on a variety of conditions. From a public health standpoint, NHSAP is both cost-effective and incredibly valuable. Please ensure NHSAP's important work can continue as you advance spending priorities for fiscal year 2019.

SAM'S STORY, COURTESY OF PROJECT SLEEP

Sam DeJesus, age 19, is about to finish his freshman at the University of Massachusetts, Amherst. He was diagnosed with narcolepsy and cataplexy at the young age of 10 (after 4 years of mysterious symptoms developing including excessive daytime sleepiness and muscle weakness with emotion, called cataplexy). To manage the terrifying and serious symptoms of his condition, Sam takes a significant

amount of medication daily and nightly, while also taking several naps a day. He is unable to function without medication, and misses activities frequently due to daytime sleepiness. He is unable to drive, so he is dependent on public transportation. Sam plans to major in anthropology and is very proud to be a member of UMass Amherst's Minutemen Marching Band, where he plays the mellophone. Advancements in research are critical to improve the lives of people like Sam who are overcoming invisible but real daily challenges of living with sleep disorders.

[This statement was submitted by Sean P.A. Drummond, PhD, Sleep Research Society.]

PREPARED STATEMENT OF THE SOCIETY FOR MATERNAL-FETAL MEDICINE

On behalf of the Society for Maternal-Fetal Medicine (SMFM), I am pleased to submit testimony in support of the important work related to women's and infants' health being conducted at the U.S. Department of Health and Human Services. As the rates of maternal mortality are rising in the U.S., investment in these public health programs and research opportunities will help address this important public health problem. We urge Congress to ensure adequate funding in fiscal year 2019 for the Centers for Medicare and Medicaid Services (CMS), Centers for Disease Control and Prevention (CDC), National Institutes of Health (NIH), Health Resources and Services Administration (HRSA) and Agency for Healthcare Research and Quality (AHRQ). Specifically, we support at least an additional \$2 billion for the NIH, including a proportionate amount for the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), \$8.445 billion for the CDC, \$660 million for the Maternal and Child Health Block Grant program at HRSA, \$175 million for the National Center for Health Statistics (NCHS), \$454 million for AHRQ, and continued broad support for the U.S. Department of Health and Human Services and programs relevant to pregnant and post-partum women and their children.

Established in 1977, SMFM is the medical professional society for obstetricians who have additional training in the area of high-risk, complicated pregnancies. Our members see the sickest and most complex patients, with the goal of optimizing care for pregnant women and their children. The complex problems faced by some mothers may lead to death as well as short-term or life-long problems for both mothers and their babies. Such complications can be understood, treated, prevented and eventually solved through research, quality improvement and sustained healthcare across the lifespan with adequate research and public health services.

Evidence to manage the complicated pregnancies is limited and more clinical research is needed, particularly in light of the rising rates of maternal mortality and morbidity. Basic research can lead to useful discoveries, however, without clinical research these discoveries cannot be translated into improvement in clinical care. Funding for clinical research in pregnancy is limited and mostly dependent on the NIH. We strongly urge Congress to prioritize clinical research in pregnancy and guides agencies, including NIH, to fund such research to decrease maternal mortality and morbidity.

Specific to the NIH, we support the following:

Task Force Specific to Pregnant Women and Lactating Women (PRGLAC).—SMFM urges Congress to continue its strong support for the PRGLAC Task Force, housed at NICHD. We look forward to the task force's report to Congress in the fall of 2018 and encourage Congress to carefully examine and support the recommendations contained in the report. We hope that this will lead to broader inclusion of pregnant and lactating women in research, so that lifesaving interventions and treatments can be known for this population.

Preterm Birth.—Delivery before 37 weeks' gestation is associated with increased risks of death in the immediate newborn period as well as in infancy and can cause long-term complications. About 20 percent of premature babies die within the first year of life, and although the survival rate is improving, many preterm babies have life-long disabilities including cerebral palsy, mental retardation, respiratory problems, and hearing and vision impairment. Preterm birth costs the U.S. \$26 billion annually. Great strides are being made through NICHD-supported research to address the complex situations faced by mothers and their babies. One of the most successful approaches for testing research questions is the NICHD research networks which allow researchers from across the country to collaborate and coordinate their work to change the way we think about pregnancy complications and change medical practice across the country. These networks deal with different aspects of pregnancy the problem of preterm birth and its consequence.

Maternal-Fetal Medicine Units Network (MFMU).—We urge continued support of the MFMU, established in 1986 to achieve a greater understanding and pursue development of effective treatments for the prevention of preterm births, low birth weight infants and medical complications during pregnancy. The MFMU Network has identified new effective therapies as well as practices that are not useful and should be abandoned. It is the only national research infrastructure capable of performing the much needed large trials that provide the evidence on which sound medical practice is based. The MFMU Network is also the ideal vehicle to collaborate with other national and international research networks in order to improve maternal and child health. Since its inception, the Network has made several exciting scientific advancements and has been able to rapidly turn laboratory and clinical research into diagnostic examinations and treatment procedures that directly benefit those affected. There remains a need for more clinical research and clinical trials to test new treatments and procedures during pregnancy as well as in labor and delivery. There is little incentive for industry trials in this space, and the MFMU Network provides an infrastructure to be able to focus on therapies and preventive strategies that have significant impact on the health of mothers and their babies. Until new options are created for identifying those at risk and developing cause specific interventions, preterm birth will remain one of the most pressing problems in obstetrics, but there are multiple other areas to look at including chronic conditions during pregnancy and innovative interventions that will improve infant and maternal mortality and morbidity.

PregSource.—We urge Congress to continue its support of NICHD's PregSource™ initiative, which recently launched. This crowd-sourcing project allows pregnant women to track their health data from gestation to early infancy and access evidence-based information about healthy pregnancies, as well as will 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.

ECHO. SMFM urges Congress to continue support for the Environmental influences in Child Health Outcomes (ECHO) initiative, which looks to understand the effects of environmental exposures of child health and development. ECHO will include pre-, peri- and postnatal outcomes, which is essential to truly understand the health and development of the population and how we can improve their health. It would also be important to expand ECHO to include cohorts that start in pregnancy given that the long term outcome of children is dependent on intrauterine development.

All of US. We also encourage Congress' continued support for the All of Us Research initiative, which is an effort to gather data from over a million people in the U.S., specific to personalized medicine. Given that women enrolled in All of Us are likely to become pregnant, it is essential to ensure that this effort includes pregnancy as well.

Zika. Continued support for the NICHD for long-term follow-up and study of women exposed to Zika and their infants who have been affected by Zika is sorely needed. We urge Congress to continue to support funding to the NICHD for research on the long-term follow-up and effects of Zika on this population, as well as for public health surveillance programs through the CDC to address Zika.

CDC.—CDC's Division of Reproductive Health (DRH) and National Center for Birth Defects and Developmental Disabilities (NCBDDD) are doing important work related to pregnant mothers.. An estimated 700 to 900 women in the U.S. died from pregnancy-related causes in 2016, and, alarmingly, the United States is the only western nation in which that number is rising. CDC support is vitally important to State-level efforts to establish maternal mortality review committees whose inquiry into maternal deaths will help us understand these poor outcomes for women and their infants and effectively plan to reverse this trend.

HRSA.—HRSA's work is critical to maternal and child health. The MCH Block Grant supports the reduction of infant mortality and improves maternal health and wellbeing by serving more than 50 million people. This program ensures that women and their children have access to quality care and provides access to comprehensive prenatal and postnatal care to women—especially low income and at-risk pregnant women. HRSA's family planning initiatives ensure access to comprehensive family planning and preventive health services to more than 4 million people—reducing unintended pregnancy rates, among other things. Finally, HRSA's support for the Alliance for Innovation in Maternal Health (AIM) is working to reduce maternal mortality through implementation of care bundles at the State and institutional level. This work is actively reducing maternal mortality in key areas including postpartum hemorrhage and hypertension, among others.

In conclusion, with Congress' support of vital HHS programs, researchers, clinicians and patients can continue to peel away the layers of complex problems of pregnancy that have such devastating consequences and truly improve the health and wellbeing of mothers, infants and children.

[This statement was submitted by Dr. Sean Blackwell, President, Society for Maternal-Fetal Medicine.]

PREPARED STATEMENT OF THE SOCIETY FOR NEUROSCIENCE

Mr. Chairman and members of the Subcommittee, I am Richard Haganir, President of the Society for Neuroscience (SfN), and it is my honor to present this testimony on behalf of the Society in strong support of at least \$39.3 billion in funding for the National Institutes of Health, a \$2.215 billion increase over fiscal year 2018 enacted figures. As a professor at, and the director of, The Solomon H. Snyder Department of Neuroscience at Johns Hopkins University, I understand the importance of Federal funding for neuroscience research. In my laboratory, we use Federal funding from NIH, including funding from Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative, to expand our knowledge about how our brain adapts and transmits information. Specifically, we are building tools to help other researchers look more deeply into the brain to determine what functions are involved in learning and memory. While this research will not result in a cure tomorrow, it has the capacity to help laboratories around the globe gain a better understanding of how the brain works and provide a foundation to launch research projects that were not possible before. Funding for NIH is critical to understand the brain and nervous system.

Thanks to the efforts of this Subcommittee, NIH has experienced significant funding increases in recent years. As the Subcommittee continues its work for fiscal year 2019, we also ask that Congress work to ensure that final fiscal year 2019 funding is approved before the end of fiscal year 2018. Reliance on continuing resolutions in place of regular appropriations has real implications for scientists working in the field as it severely restricts NIH's ability to fund science. For some, this means waiting for a final decision on NIH's funding before knowing if their highly scored grant would be supported. This delays the launch of research, hiring of researchers, and otherwise causes meritorious science to sit on the shelf. For others, it means operating a lab at 90 percent of the awarded funding until full-year appropriations are finalized—similarly impacting hiring and causing science to “stop and start”—resulting in wasted effort, data, and resources. There is no substitute for robust, sustained, and predictable funding for NIH.

As a BRAIN funded scientist, I would also like to express the Society's appreciation for your support of the BRAIN Initiative. The BRAIN Initiative is a critical piece for promoting future discoveries across neuroscience and related scientific disciplines (see an example below). By including part of this funding in 21st Century Cures—and note that it is only part of the funding that the BRAIN Initiative will require—Congress is maintaining the momentum of this endeavor. Please remember however, using those funds to supplant regular appropriations would be counter-productive and not fulfill the intent of 21st Century Cures.

The deeper our grasp of basic science, the more successful those focused on clinical and translational research will be. Neuroscientists use a wide-range of experimental and animal models that are not used elsewhere in the research pipeline. Basic research creates discoveries—sometimes unexpected—that expand our knowledge of biological processes. These discoveries reveal new targets to treat brain disorders that affect millions of people in the United States and beyond. Some recent, exciting advancements include the following:

THE IMPACTS OF NEUROSCIENCE RESEARCH

New Technologies Unlock the Brain's Mysteries

My own BRAIN Initiative supported research investigates how neurons communicate and coordinate with each other to form circuits. Neurons are constantly relaying information to each other through connections called synapses. Neuroscientists previously discovered that multiple kinds of internal cellular inputs influence the responsiveness of the receiving neuron, strengthening or weakening the connection of particular pathways. This process is essential for learning and memory and is impacted in neurological and psychiatric disorders like Alzheimer's disease, autism, and schizophrenia. And yet today, monitoring more than one pathway at a time is a challenge. Consequently, we have a limited understanding of the complexities of how synaptic changes occur and are regulated. My laboratory is developing new

tools to simultaneously evaluate multiple types of cell signaling to better understand brain activity during learning in awake, behaving animals. These tools will enable us to develop a complex, and more complete, picture of how learning and other higher brain functions are achieved. The tools developed in my laboratory will also inform how specific cell circuits involved in learning are affected in disorders mentioned above. My hope is that the tools generated will help other neuroscientists overcome some of the enormous challenges they face when studying the brain.

Cutting-Edge Research on Addiction

NIH supported research is also addressing the Nation's addiction crisis by determining how drug abuse affects the brain. Critically, more than half of new drug users are teens. A teenage brain is different than an adult's brain in many ways—it is both more malleable and vulnerable to insult. Unprecedented in scale, the NIH Adolescent Brain Cognitive Development (ABCD) study is tracking brain development and substance use of over 10,000 U.S. children from childhood through adulthood. The ABCD Research Consortium includes a data analysis center and 21 research sites across the country to conduct assessments in preadolescents prior to risk-taking experiences like drug experimentation. This data was recently released and provides researchers with a high-quality baseline to evaluate the effects of teen drug exposure. Researchers will follow teens involved in the study for 10 years and repeatedly evaluate brain structure, function, and behavior to uncover critical risk factors and the developmental consequences of drug misuse. The results will represent teens from all demographics and inform strategies to prevent drug use and addiction and guide future precision medicine-based treatments.

NIH is also assisting and supporting strategic efforts to combat opioid addiction. NIH-funded researchers are developing next generation pain relievers that target pain without eliciting euphoria, a key side effect that contributes to addiction. Most current opioid medications bind to several receptors and their interactions trigger pain relief alongside a range of negative side effects. An example of this work is a project funded by the National Institute on Drug Abuse, which revealed the structure of a receptor in the brain, providing researchers with a critical foundation for designing future non-addictive pain medications. By understanding this receptor, researchers can develop medications that selectively target specific actions in the hope that these drugs will treat pain without leading to addiction or risk of overdose, and be the precise, safe alternative to opioids that our country so desperately needs.

THE IMPACT OF NEUROSCIENCE INVESTMENT

While the research funded at the NIH is important to the future of health, it is also a key economic driver. Most of the funding provided to the NIH is dispersed to universities and research organizations across the country resulting in significant contributions to local economies. In fiscal year 2016, when Congress provided the first of its \$2 billion increases for NIH, 27,000 new jobs were created combined with an additional \$4 billion in economic activity. In 2016 alone, NIH funding spurred almost \$64.8 billion in economic activity nationwide.¹

Congress's commitment to fund basic and translational neuroscience creates the essential foundation to address diseases that strike nearly one billion people globally and more than 100 million Americans every year. Perhaps the most frightening number to consider, however, is \$800 billion. This is the current estimate of the economic impact on American families and the economy of diseases and disorders of the brain.^{2,3} This number will only grow in the years ahead, into the trillions, unless we act.

For the United States to remain a scientific leader, Congress must continue its commitment to funding basic research. If we delay or decrease funding for research, other nations in Asia and Europe, who are investing heavily, will catch up and pass us in the near future. Meanwhile, we have seen a divestment from industry in neuroscience and philanthropic support cannot fill the void. It is too expensive for charities; it is too far from the profit centers for private industry. Only Congress can take the steps necessary to ensure all Americans will see progress in the development of cures, treatments, and methods of prevention that will assure a better, healthier future.

On behalf of the Society for Neuroscience, we thank this Subcommittee for its support and we look forward to working with you in the months and years ahead.

¹ <http://www.unitedformedicalresearch.com/wp-content/uploads/2017/03/NIH-Role-in-the-Economy-fiscal-year-2016.pdf>.

² Brain Facts: A Primer on the Brain and Nervous System. Society for Neuroscience. 2012.

³ Gooch, C., Pracht, E., Borenstein, A. 2017. The burden of neurological disease in the United States: A summary report and call to action. *Annals of Neurology*, 81(4):479–484.

[This statement was submitted by Richard Haganir, PhD, President, Society for Neuroscience.]

PREPARED STATEMENT OF STATEMENT OF THE NATIONAL ASSOCIATION OF FOSTER GRANDPARENT PROGRAM DIRECTORS

Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee, thank you for the opportunity to submit this testimony in support of fiscal year 2019 funding for the Foster Grandparent Program (FGP), the oldest of the three programs known collectively as Senior Corps, which are authorized by Title II of the Domestic Volunteer Service Act (DVSA) of 1973, and as amended through the National Service Act of 1990, and the Serve America Act of 2009 authored by Senator Orrin Hatch and the late Senator Edward Kennedy. The Foster Grandparent Program is administered through the Corporation for National and Community Service (CNCS).

The Foster Grandparent Program began in 1965 with 800 volunteers in 45 institutions. Since that time, the program has grown across the country to include 25,190 Foster Grandparents serving an average of 189,000 children annually through assignments in non-profit organizations, schools, Head Start centers, and residential shelters. The National Association of Foster Grandparent Program Directors (NAFGPD) is a membership-supported professional organization representing Foster Grandparent Programs nationwide, local sponsoring agencies, and program participants.

I respectfully request that the Subcommittee provide the Corporation for National & Community Service with 115.6 million in fiscal year 2019. A funding level of \$115.6 million would allow for the volunteer stipend to be increased from its current rate of \$2.65 per hour to the authorized level of \$3.00 per hour, the first increase in 17 years.

I would like to begin by thanking the distinguished Members of the Subcommittee for your steadfast support of the Foster Grandparent Program. No matter what the circumstances, this Subcommittee has always been there to protect the integrity and mission of our program. Our participants and the children they serve across the country are the beneficiaries of your commitment to FGP, and for that we thank you. NAFGPD was disappointed to learn that the President's fiscal year 2019 proposed budget once again called for not only the elimination of the Foster Grandparent Program, but the Corporation for National and Community Service. In this great time of budget uncertainty, our programs and the communities they serve need your support now more than ever.

For more than 50 years, Foster Grandparent Programs and their network of local sponsors have made efficient use of Federal dollars to make real changes in the lives of children and seniors through high impact and measurable service assignments in communities across the country.

The Foster Grandparent Program began in 1965 by Sargent Shriver as part of President Lyndon Johnson's War on Poverty. The Foster Grandparent Program provides opportunities for low-income Americans age 55 and older to serve children and youth in their community for an average of 15–40 hours each week. Those who meet income limits (200 percent of poverty) qualify for the small, non-taxable stipend reimbursement, transportation assistance, orientation, training opportunities, and a daily meal. Preliminary results of a volunteer study currently being completed by CNCS show that 70 percent of Senior Corps volunteers who initially reported five or more symptoms of depression reported fewer symptoms at the end of the first year of service. (www.seniorcorps.gov/healthyvolunteers).

Every Foster Grandparent Program performs a 3-point National Service Criminal History Check (NSCHC) on volunteers and staff. More than just a simple background check, the NSCHC is performed by programs navigating different laws in each State to comply with requirements, keeping in mind that the safety of those we serve is paramount.

Throughout our long history, our program has received strong bipartisan support. As First Ladies, Nancy Reagan championed the work of Foster Grandparents, and Barbara Bush welcomed Foster Grandparents to the White House, and even become an honorary Foster Grandparent herself.

To further illustrate the value of an investment in the Foster Grandparent Program, here are a few testimonials from grandparents and school administrators (www.nationalservice.gov/programs/senior-corps/senior-corps-stories)

For Grandpa Jerry, the kids he mentors through the Foster Grandparent Program remind him of himself when he was young. "I understand their anger, I felt it as a kid. I understand their tears because they were my tears too."

“Expect the unexpected” was the first piece of advice Foster Grandparent, Al Hodder, received as he prepared for his first day volunteering with English language learners at Portland High School. Within minutes of entering the classroom and introducing himself to a room filled with teenage students, a girl rushed over to him to ask for help on a paper. Without having much background on the subject, Hodder dove right in, helping her research, plan and edit her paper. From that moment on he was hooked, enthusiastically anticipating each new day and challenge as a Foster Grandparent.

“When we have Granny Audrey we can do a lot more independent work, a lot more skill based, specific things that we just can’t do in large groups. It’s great to have granny here,” said kindergarten teacher Christine Rhodes.

“I see her in the hallway. She’s reviewing letters and sounds, the kids just truly love working with her. They need her,” said Cullom. When she talks, the kids listen.

And at the end of the day, it’s not about the lessons she taught them. It’s about the feeling she leaves them with, that only a grandmother can give.

“I get just as much out of it as the children because they bring so much love. And that’s everything,” Monroe said.

Foster Grandparent Programs represent the best in Federal partnerships with local communities. Federal dollars flow directly to local sponsoring agencies, which allows for local entities to determine where the greatest need is in their community. Foster Grandparent programs have forged partnerships with thousands of community organizations that value and support the Foster Grandparent’s service. FGP has served local communities for over 50 years in a high quality, efficient, and cost-effective manner, saving local communities money by helping our older volunteers stay independent and healthy and not dependent upon costly in-home or institutional care.

In closing, I would like to reiterate NAFGPD’s request that the Subcommittee provide at least \$115.6 million for FGP in the fiscal year 2019 appropriations bill. This level of funding will provide Foster Grandparent Program participants with their first stipend increase in over 17 years and will result in valuable service to children who have special or exceptional needs or who are at academic, social or financial disadvantage. I want to thank you again for the Subcommittee’s support and leadership for Foster Grandparent Programs over the years. NAFGPD believes that you and your colleagues in Congress appreciate what our senior volunteers accomplish every day in communities across the country.

[This statement was submitted by Jeanine Nemitz, President, National Association of Foster Grandparent Program Directors.]

PREPARED STATEMENT OF STATEMENT OF THE NATIONAL
ALOPECIA AREATA FOUNDATION

THE FOUNDATION’S FISCAL YEAR 2019 L–HHS APPROPRIATIONS RECOMMENDATIONS

—At least \$39.3 billion in program level funding for the National Institutes of Health (NIH).

—Proportional funding increase for NIH’s National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS); the National Institute of Allergy and Infectious Diseases (NIAID); and the National Center for Advancing Translational Science (NCATS)

Chairman Blunt, Ranking Member Murray and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the alopecia areata community as you work to craft the fiscal year 2019 L–HHS Appropriations Bill.

ABOUT ALOPECIA AREATA

Alopecia areata is a disfiguring autoimmune skin disease resulting in the loss of hair on the scalp and elsewhere on the body.

It appears on the skin, most often as one or more small, round, smooth patches of hair loss on the scalp and can progress to total scalp hair loss (alopecia totalis) or complete body hair loss (alopecia universalis).

Alopecia areata affects as many as 6.8 million in the U.S. with a cumulative lifetime incidence of 2.1 percent and there is a large unmet medical need for treatment options for both adult and children. The disease onset often occurs at an early age

and alopecia areata affects as many as 1.2 million children under the age of 12 in the U.S.

Alopecia areata is known to have a profound impact on patients' quality of life. The sudden onset, recurrent episodes, and unpredictable course of hair loss can lead to difficulties at work, at school and in relationships. Alopecia areata patients experience higher rates of depression, anxiety and suicidal ideation, especially in children and adolescents. The knowledge that medical interventions are extremely limited and of minor effectiveness further exacerbates the emotional stresses patients' experience. In recent years, scientific advancements have been made but there are currently no FDA approved treatments for this life-altering disease. The standard of care for alopecia areata is grossly inadequate. There is no universally proven therapy that induces and sustains remission and available treatment options are of limited effectiveness, especially in more extensive forms of the disease. The most commonly used off-label treatments such as intralesional corticosteroid injections and topical immunotherapies are painful, require continuous administration, and can have prohibitive irritant and allergic side effects.

Alopecia areata takes a tremendous physical, emotional, and social toll on affected individuals and patients are desperate to have treatments approved that are safe and efficacious. While re-growing hair or preventing hair loss may serve as important endpoints for treatment development, the reduction in quality of life that alopecia areata patients endure should be taken into account when establishing an appropriate benefit-risk profile for potential treatments. Alopecia areata should no longer be considered a cosmetic disorder, but a disfiguring, psychologically devastating disease of the skin that requires medical treatment.

ABOUT THE FOUNDATION

The National Alopecia Areata 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 two prestigious Research Advisory Councils. Founded in 1981, NAAF is an influential foundation representing people 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 Registry, Biobank and Clinical Trials Network 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 2016 Alopecia Areata Research Summit featuring presentations from the Food and Drug Administration (FDA), the Patient-Centered Outcomes Research Institute (PCORI) and NIAMS.

NATIONAL INSTITUTES OF HEALTH

NIH hosts a modest and growing alopecia areata research portfolio, and the Foundation works closely with NIH to advance critical activities. NIH projects, in coordination with the Foundation, have successfully identified biomarkers and developed 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 5-year grant to the researchers at Columbia to continue this work through an Alopecia Areata Center for Translational Research. To continue to build on this momentum, please provide NIH with meaningful funding increases to facilitate growth in the alopecia areata research portfolio.

PATIENT PERSPECTIVE

My name is Miranda. As a small child, my mother braided my hair before school in the morning, and once during this routine she spotted a quarter-sized patch of hair missing from the back of my head. Starting that day, my family began the route taken by so many others who have encountered the abrupt diagnosis of alopecia areata. They took me traveling across States, bringing me to grand rounds where dozens of doctors examined me for hours, cutting my scalp for biopsies, giving

me injections, ointments, and experimenting with laser treatment at the expense of my time learning in school and enjoying other activities. By the end of these trials, I was a teenager, and so distraught over my appearance and how others treated me that I became depressed and sick to the point of hospitalization. Now, after years of therapy and learning to manage wigs and make-up to hide my disease, I meet with support groups to gain confidence and try to help others avoid a similar downward spiral. If I had known that “just hair” would cause my family and I a lifetime of grief, I would have done almost anything to get it back.

[This statement was submitted by Dory Kranz, President and Chief Executive Officer, National Alopecia Areata Foundation.]

PREPARED STATEMENT OF THE STUDENT SUPPORT AND ACADEMIC ENRICHMENT

Dear Senators Shelby, Leahy, Blunt, and Murray:

The undersigned national and State organizations write to request that the Committee provide full funding for the Student Support and Academic Enrichment (SSAE) grant program, found under Title IV, Part A of the bipartisan Every Student Succeeds Act (ESSA).

The SSAE grant program, authorized at \$1.6 billion for fiscal year 2019, supports three important education areas: (1) safe and healthy students activities, such as providing comprehensive mental and behavioral health services to students and implementing gun violence prevention programs; (2) increasing student access to a well-rounded education, such as: STEM; computer science and accelerated learning courses; physical education; the arts; music; foreign languages; college and career counseling; effective school library programs; and, (3) providing students with access to technology and digital materials and educators with technology professional development opportunities.

We are grateful that Congress recognized the importance of Title IV–A and provided \$1.1 billion in fiscal year 2018 and strongly urge Congress to fully fund the SSAE program in fiscal year 2019. This will provide districts enough funds and flexibility to make meaningful investments in priority program areas determined by their needs assessments. Additionally, this funding level obviates the need for a competitive option and allows the flexible block grant to operate as Congress intended, as a formula grant that benefits all districts equitably.

On behalf of the millions of students, parents and educators that we collectively represent, we urge you to please appropriate full funding in fiscal year 2019 for the Student Support and Academic Enrichment grant program under Title IV–A of ESSA and allow States and districts to make meaningful investments in programs that are critical to student success.

Sincerely,

NATIONAL ORGANIZATIONS

| | | |
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| American Psychological Association | El Sistema USA | National Association of Elementary School Principals (NAESP) |
| American School Band Directors Association | Futures Without Violence | National Association of School Nurses |
| American School Counselor Association | Girl Scouts of the USA | Phi Mu Alpha Sinfonia Fraternity |
| Collaborative for Academic, Social, and Emotional Learning (CASEL) | International Society for Technology in Education (ISTE) | Progressive Music Quadrant |
| Committee for Children Consortium for School Networking (CoSN) | League of American Orchestras | Research QuaverMusic |
| Council of Administrators of Special Education | Learning Disabilities Association of America | School Social Work Association of America |
| Council of School Supervisors and Administrators | Little Kids Rock | SHAPE America—Society of Health and Physical Educators |
| Drum Corps International | Museum of Science, Boston | Software and Information Industry Association |
| Education Through Music, Inc. | Music for All, Inc. | The College Board |
| EducationPlus | Music Teachers National Association | Trust for America’s Health |
| | NAMM Foundation | VH1 Save The Music Foundation |
| | National Association for College Admission Counseling (NACAC) | |
| | National Association for Music Education (NAfME) | |

STATE AND LOCAL ORGANIZATIONS

- Alabama*
Alabama Music Educators Association
Anniston City Schools
Conecuh County Board of Education
Dothan City Schools
Elmore County Public Schools
Lowndes County Public School District
Midfield City Schools
Sheffield City Schools
Talladega City Schools
- California*
California Music Educators Association
Organization of American Kodály Educators
United Administrators of Oakland Schools
Western Association for College Admission Counseling
WURRLYedu
- Colorado*
Colorado Society of School Psychologists
- Connecticut*
Hartford Principals' and Supervisors' Association
Thompson Association of School Administrators
- Delaware*
Delaware Music Educators Association
- Florida*
Florida Association of School Psychologists (FASP)
Florida Music Education Association
- Georgia*
Georgia Association of School Psychologists
Georgia K12 CTO CoSN Chapter
- Hawaii*
Hawaii ACAC
Hawaii Society for Technology in Education
Hawaii Music Education Association
- Idaho*
Idaho Music Educators Association
Idaho School Psychologist Association
- Illinois*
Illinois Computing Educators (ICE-IL)
- Indiana*
Indiana Association of School Psychologists
Indiana Music Educators Association
- Iowa*
Iowa ACAC
Iowa School Psychologists Association
- Kansas*
Kansas Music Educators Association
- Kentucky*
Kentucky Assoc. for Psychology in the Schools (KAPS)
Kentucky Association for College Admission Counseling
Kentucky Music Educators Association
- Louisiana*
Louisiana School Psychological Association
- Maine*
Maine Music Educators Association
- Maryland*
Maryland Music Educators' Association
Maryland Society for Educational Technology (MSET)
Public School Administrators & Supervisors Association of Baltimore City
- Massachusetts*
Boston Association of School Administrators & Supervisor
- Michigan*
Gordon Institute for Music Learning
Michigan Association for College Admission Counseling
Michigan Association for Computer Users in Learning (MACUL)
Michigan Association for Media in Education
Michigan Association of School Psychologists
- Minnesota*
Armstrong Boulevard Brass Quintet
Minnesota Association of School Psychologists
- Minnesota Music Educators Association*
Minnesota School Psychology Association
- Mississippi*
Mississippi Music Educators Association
- Missouri*
Midwest Education Technology Community (METC)
Missouri Association for College Admission Counseling
Missouri Association of School Psychologists
Missouri Music Educators Association
- Montana*
Montana Educational Technology Association (META)
Montana Music Educators Association
- Nebraska*
Nebraska Educational Technology Association (NETA)
Nebraska Music Education Association
Nebraska School Psychologists Association
- Nevada*
Nevada Association of School Psychologists
- New Hampshire*
New Hampshire Music Educators Association
New Hampshire Society for Technology in Education (NHSTE)
- New Jersey*
New Jersey Association of School Psychologists
New Jersey Music Educators Association
- New Mexico*
New Mexico Music Educators Association
Rocky Mountain Association for College Admissions Counseling
The New Mexico Society of Technology in Education
- New York*
New York Association of School Psychologists
New York State Association for Computers and

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| Technologies in Education (NYSCATE) | Pennsylvania Music Educators Association | Utah Music Educators Association |
| New York State School Music Association | <i>Rhode Island</i> Rhode Island Music Education Association (RIMEA) | <i>Vermont</i> Vermont Association of School Psychologists |
| Yonkers Council of Administrators | The Rhode Island School Psychologists Association | Vermont Music Educators Association |
| <i>North Carolina</i> North Carolina Music Educators Association | <i>South Carolina</i> Southern Association for College Admission Counseling | <i>Virginia</i> Virginia Music Educators Association |
| North Carolina Technology in Education Society | <i>Tennessee</i> Shelby County Schools Tennessee Association of School Psychologists | Virginia Society for Technology in Education |
| <i>North Dakota</i> North Dakota Association of School Psychologists | Tennessee Educational Technology Association (TETA) | <i>Washington</i> Washington State Association of School Psychologist |
| North Dakota Music Educators Association | Tennessee Music Education Association | <i>West Virginia</i> West Virginia Music Educators Association |
| <i>Ohio</i> Ohio School Psychologists Association | <i>Texas</i> Texas Association for College Admissions Counseling | <i>Wisconsin</i> Wisconsin Association for College Admission Counseling |
| The Ohio Association for College Admission Counseling | Texas Association of School Psychologists | Wisconsin Music Educators Association |
| <i>Oklahoma</i> Oklahoma School Psychological Association | <i>Utah</i> Cache County School District | Wisconsin School Psychologists Association |
| <i>Pennsylvania</i> Association of School Psychologists of Pennsylvania | Utah Association of School Psychologists | <i>Wyoming</i> Wyoming Music Educators Association |
| Pennsylvania Association for Educational Communications and Tech (PAECT) | Utah Coalition for Educational Technology (UCET) | Wyoming School Psychologist Association |

PREPARED STATEMENT OF JOHN AND MARY ANNE STULL

Please support the Fight against LE "It destroys people and then it kills you"

Mary Anne is 4th generation primary LE. The short story is like most Primary LE . . . her young adult life was diagnosed as "poor lymph system" and treated with diuretics. Years of that took its toll to the point she had to stop and then the LE pushed into both legs and the threat of infection compelled us to seek information outside our healthcare provider.

After only one week of Internet searching it was obvious that Mary Anne has LE and that there were alternatives.

We campaigned our insurance company and pressured our local health provider to prescribe PT treatment. We live in a remote part of Washington State so after a few visits I took on the treatment because they felt she would have to remain in bandages for the remainder of her life. At this point LE has taken her youth and esteem. But we agreed not to give in and continued the treatment, acquired a full body pump and long list of support stockings and toecaps. We literally squeezed out the fluid and broke down the fiber material.

So after 3 years we thought we beat it. We were looking for real nylons and something that could make her feel good about herself.

Then it all fell apart.

Mary Anne came down with a viral infection in November of 2017 and by December her leg began to swell from 37 cm to 55 cm. We went to our healthcare provider and PT and we were told to keep bandaging and that it happens. You see Mary Anne's LE keeps her from fighting the infections. She is constantly fighting infections, oral, respiratory... Always.

By January Mary Anne was short of breath, could no longer negotiate the stairs and unable to have a night rest.

In March we were desperate and we went in to have a CT and discover Mary Anne had been in AFIB for some time and we had to rush her to the hospital.

We were lucky and well cared for. She lost 45 lbs. of fluid and yes her leg returned. BUT she is still in AFIB trying to get her blood thinners to work.

We know we are the lucky ones and feel so much pain for all the LE sufferers. I understand why doctors and administrator act the way they do about patients. They see most illness as avoidable and a result of poor health choices.

NO one gets LE because they are an alcoholic but LE can drive people to abuse alcohol. Eating disorders do not cause LE but LE can drive people to look like they are abusers.

Mary Anne didn't do anything to cause her LE but LE took her youth, her self-esteem and almost her life and now besides the stocking and all the sigma of LE she has to wear a defib vest .. No, LE can't kill .. it's like RA it just eats away until you can't fight it.

If I were to address the doctors I would say . . . your oath is to do no harm.. Recognize you have a bias.. and that bias injures others.

PREPARED STATEMENT OF TEACH FOR AMERICA

Thank you for the opportunity to submit testimony on the importance of Federal funding for evidence-based teacher training and recruitment programs at the U.S. Department of Education and the Corporation for National and Community Service in fiscal year 2019.

Teach For America (TFA) is a national non-profit that finds, develops, and supports a diverse network of leaders who expand opportunity from classrooms, schools, and every sector and field that shapes the broader systems in which schools operate.

Since 1990, TFA has placed and supported over 56,000 teachers in high-need schools throughout the country, with about two-thirds of our alumni continuing to work in education. Today, we have a corps of nearly 6,400 teachers in 51 urban and rural regions in 36 States and the District of Columbia.

With nearly 28 years of experience in recruiting and training teachers, our model is among one of the most rigorously evaluated teacher preparation and leadership development programs in the country. We rely on external researchers to analyze, validate, and identify opportunities to improve our programmatic model. A growing body of the most rigorous research demonstrates that our corps members and alumni are making a positive impact on students, and we continue to seek additional information to further strengthen our work.

We believe that the Federal Government should prioritize its support for programs with evidence of effectiveness, and applaud the Committee's commitment to results-driven initiatives.

I would like to highlight several of these programs and ask for your continued support in fiscal year 2019.

Corporation for National and Community Service (AmeriCorps): \$1.1 B/\$412 Million

Since 1994, more than 1 million individuals-including TFA corps members-have served through national service programs like AmeriCorps.

Together, these individuals have provided more than 1.4 billion hours of service to tackle the toughest problems in our communities. Unfortunately, many individuals who want to serve, particularly as educators, face significant economic barriers, including high student debt and the cost of teacher certification, which make it difficult to enter a lower-paying profession such as teaching. This is no different for TFA corps members.

Fortunately, our teachers can use the AmeriCorps Education Award to pay for college tuition or to pay down student debt. This award also enables TFA corps members to defer their undergraduate loans for the first 2 years of teaching and have the interest, which accrues during those 2 years, paid off by the Federal Government.

These awards make it possible for people from all walks of life to join TFA and many other AmeriCorps partner programs. TFA's partnership with AmeriCorps has helped put tens of thousands of quality educators in low-income urban and rural areas and developed a diverse pipeline of leadership for our country. In fact, in 2017, our incoming corps was about half people of color. In addition, one-third of corps members were the first in their family to attend college and nearly 45 percent received Pell Grants.

DEPARTMENT OF EDUCATION

Supporting Effective Educator Development (SEED): \$94 Million

TFA corps members receive 2 years of ongoing training and support to prepare them to teach in low-income, high-need schools. The SEED grant has supported this training by funding TFA's teacher-training institutes, which all corps members must complete before they enter their classrooms.

The education landscape has changed dramatically since TFA sent its first cohort of teachers into the classroom 28 years ago. SEED support has been critical to adjusting our training to meet the needs of students and to align with what States and school districts need of their teachers.

With the support of a 2013 SEED Grant, TFA launched its first regional training institutes in 2014. These new institutes allowed regions to build out their own locally driven teacher preparation in which teachers receive training and teach summer school in the same communities where they will serve. By tailoring training to the specific needs of individual communities, we were able to expand learning opportunities for local students, while also developing teachers who were familiar with and invested in their local communities. With the help of continued SEED funding in 2015 and 2017, TFA has expanded from two regional institutes in 2014 to 13 in 2018. In addition, five of our regions that serve predominantly rural communities worked together to launch the Delta Collective Summer Institute in Mississippi. Having a training experience grounded in the unique needs and assets of rural communities will continue to help foster a corps of teachers who are more engaged and invested in their rural communities and can serve students living in these communities more effectively.

The 2015 passage of the bipartisan Every Student Succeeds Act (ESSA) expanded SEED eligibility to institutions of higher education, which is why it is important that SEED funding is restored to the fiscal year 2016 level of \$94 million. Furthermore, the 2017 SEED grant competition demonstrates a potential unintended consequence of this policy change. Of the ten organizations awarded grants in 2017 80 percent were institutions of higher education. Based on this, TFA is concerned that the original Congressional intent of SEED may be undermined. As the only Federal funding available to national non-profits for improving teacher quality, SEED was created to support non-profits with a national reach to broaden the impact of research-based teacher preparation and development by bringing it to a national scale. Further, we believe that the only way we can collectively solve for the greatest educational challenges is to promote innovation from a diversity of perspectives across the education field. It is our hope that Congress and the Department of Education can ensure diversity of SEED grantees and balance awards to institutions of higher education and non-profits.

Education, Innovation and Research (EIR): \$180 Million in Fiscal Year 2019

Education Innovation and Research (EIR) grants support new methods to improve student achievement, increase high school graduation rates, and improve college enrollment and completion. EIR is unique, as it requires projects to have a promising model and/or high evidence of effectiveness in order to win. In addition, grantees must fund an independent evaluation.

Through a 2010 EIR Expansion grant, TFA was able to pilot new strategies to attract a more racially and socioeconomically diverse corps of teachers. In the first year of the grant, 34 percent of the 2011 corps identified as people of color, 30 percent came from low-income backgrounds, and 22 percent reported being the first in their family to graduate from college. In the last year of the grant, nearly half of the 2015 corps identified as people of color, 47 percent come from low-income backgrounds, a third report being the first in their family to graduate from college. In addition, by 2015, 20 percent of corps members had a background in science, technology, engineering, or math (STEM).

Through a 2017 Early Phase grant, TFA is expanding its Rural School Leadership Academy (RSLA) to serve more than 250 school leaders in rural communities over the next 5 years. The RSLA is a 1 year professional development program focused on growing the skills and mind-sets necessary for individuals to become school leaders in rural communities. The RSLA not only represents important professional development for rural teachers, this program is a key tool in our work to retain great talent in rural communities across the country.

Over the last 5 years, the U.S. ED received nearly 5,000 applications but made only 156 grants. This is a total application-success rate of only 3.1 percent. Given this demand from the education field and EIR's focus on supporting programs with evidence of effectiveness, we believe this increase in funding-which is consistent with the President's budget request-is a wise investment.

Title IIA of the Elementary and Secondary Education Act: \$2.35 Billion in Fiscal Year 2019

Title IIA is the key fund in ESSA that supports teacher and principal development. The recent enactment of ESSA provides important new opportunities to use those funds more effectively to improve teacher and principal quality, which helps students succeed.

CONCLUSION

I appreciate the challenges that the Committee faces in setting funding levels across a multitude of worthy programs, and I look forward to working with you to meet the needs of America's students and teachers.

[This statement was submitted by Elisa Villanueva Beard, CEO, Teach For America.]

PREPARED STATEMENT OF TEACH FOR AMERICA—CHICAGO-NORTHWEST INDIANA

Thank you for the opportunity to submit testimony on the importance of Federal funding for evidence-based teacher training and recruitment programs at the U.S. Department of Education and the Corporation for National and Community Service in fiscal year 2019. As the Executive Director of Teach For America-Chicago-Northwest Indiana I am pleased to share the impact that Federal funding has on our mission.

Teach For America (TFA) is a national non-profit that finds, develops, and supports a diverse network of leaders who expand opportunity from classrooms, schools, and every sector and field that shapes the broader systems in which schools operate.

Since 1990, TFA has placed and supported over 56,000 teachers in high-need schools throughout the country, with about two-thirds of our alumni continuing to work in education. Today, we have a corps of nearly 6,400 teachers in 51 urban and rural regions in 36 States and the District of Columbia. Since Teach For America (TFA) launched Chicago in 2000, our network of leaders has played a pivotal role in transforming the education landscape in Chicago and Northwest Indiana. From an original corps of 40 teachers, our region's network includes more than 3,000 members. . More than 1,000 are highly effective teachers, and more than 240 of our local members are school leaders (principals, assistant principals, and deans), leading some of the highest-performing schools serving low-income students throughout the region. Collectively, we are impacting the lives of more than 125,000 low-income students across the region.

With nearly 28 years of experience in recruiting and training teachers, our model is among one of the most rigorously evaluated teacher preparation and leadership development programs in the country. We rely on external researchers to analyze, validate, and identify opportunities to improve our programmatic model. A growing body of the most rigorous research demonstrates that our corps members and alumni are making a positive impact on students, and we continue to seek additional information to further strengthen our work.

We believe that the Federal Government should prioritize its support for programs with evidence of effectiveness, and applaud the Committee's commitment to results-driven initiatives.

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Together, these individuals have provided more than 1.4 billion hours of service to tackle the toughest problems in our communities. Unfortunately, many individuals who want to serve, particularly as educators, face significant economic barriers, including high student debt and the cost of teacher certification, which make it difficult to enter a lower-paying profession such as teaching. This is no different for TFA corps members.

Fortunately, our teachers can use the AmeriCorps Education Award to pay for college tuition or to pay down student debt. This award also enables TFA corps members to defer their undergraduate loans for the first 2 years of teaching and have the interest, which accrues during those 2 years, paid off by the Federal Government. Teach For America and AmeriCorps alum, Michael Abello, a Chicago native, started his career as a 2008 Teach For America- Chicago-Northwest Indiana corps member teaching early childhood education at John M. Smyth Elementary. During

his time in the corps, Michael was one of five Teach For America teachers across the country who earned the Sue Lehmann Excellence in Teaching Award, an award celebrating teachers that foster substantial academic and personal growth in their students through their innovative work and practices in their schools. Michael is now the Principal of Piccolo School of Excellence where he has been the school leader since 2014. Under Michael's leadership, Piccolo has become a nationally competitive school achieving the highest rating according to the district's School Quality Rating Policy, and he increased staff retention from 68 percent to 92 percent. He has two current AmeriCorps Teach For America corps members working at his school along with other alums on his leadership team and veteran teacher staff. Prior to his role at Piccolo, he was Assistant Principal at two other traditional public schools, and he also spent 2 years on Teach For America's staff coaching early childhood and lower elementary corps members.

These education awards make it possible for people from all walks of life to join TFA and many other AmeriCorps partner programs. TFA's partnership with AmeriCorps has helped put tens of thousands of quality educators in low-income urban and rural areas and developed a diverse pipeline of leadership for our country. In fact, in 2017, our incoming corps was about half people of color. In addition, one-third of corps members were the first in their family to attend college and nearly 45 percent received Pell Grants.

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With the support of a 2013 SEED Grant, TFA launched its first regional training institutes in 2014. These new institutes allowed regions to build out their own locally driven teacher preparation in which teachers receive training and teach summer school in the same communities where they will serve. By tailoring training to the specific needs of individual communities, we were able to expand learning opportunities for local students, while also developing teachers who were familiar with and invested in their local communities. With the help of continued SEED funding in 2015 and 2017, TFA has expanded from two regional institutes in 2014 to 13 in 2018. In addition, five of our regions that serve predominantly rural communities worked together to launch the Delta Collective Summer Institute in Mississippi. Having a training experience grounded in the unique needs and assets of rural communities will continue to help foster a corps of teachers who are more engaged and invested in their rural communities and can serve students living in these communities more effectively.

The 2015 passage of the bipartisan Every Student Succeeds Act (ESSA) expanded SEED eligibility to institutions of higher education, which is why it is important that SEED funding is restored to the fiscal year 2016 level of \$94 million. Furthermore, the 2017 SEED grant competition demonstrates a potential unintended consequence of this policy change. Of the ten organizations awarded grants in 2017, 80 percent were institutions of higher education. Based on this, TFA is concerned that the original Congressional intent of SEED may be undermined. As the only Federal funding available to national non-profits for improving teacher quality, SEED was created to support non-profits with a national reach to broaden the impact of research-based teacher preparation and development by bringing it to a national scale. Further, we believe that the only way we can collectively solve for the greatest educational challenges is to promote innovation from a diversity of perspectives across the education field. It is our hope that Congress and the Department of Education can ensure diversity of SEED grantees and balance awards to institutions of higher education and non-profits.

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Through a 2010 EIR Expansion grant, TFA was able to pilot new strategies to attract a more racially and socioeconomically diverse corps of teachers. In the first year of the grant, 34 percent of the 2011 corps identified as people of color, 30 percent came from low-income backgrounds, and 22 percent reported being the first in their family to graduate from college. In the last year of the grant, nearly half of the 2015 corps identified as people of color, 47 percent come from low-income backgrounds, a third report being the first in their family to graduate from college. In addition, by 2015, 20 percent of corps members had a background in science, technology, engineering, or math (STEM).

Through a 2017 Early Phase grant, TFA is expanding its Rural School Leadership Academy (RSLA) to serve more than 250 school leaders in rural communities over the next 5 years. The RSLA is a 1 year professional development program focused on growing the skills and mind-sets necessary for individuals to become school leaders in rural communities. The RSLA not only represents important professional development for rural teachers, this program is a key tool in our work to retain great talent in rural communities across the country.

Over the last 5 years, the U.S. Department of Education received nearly 5,000 applications but made only 156 grants. This is a total application-success rate of only 3.1 percent. Given this demand from the education field and EIR's focus on supporting programs with evidence of effectiveness, we believe this increase in funding—which is consistent with the President's budget request—is a wise investment.

Title IIA of the Elementary and Secondary Education Act: \$2.35 Billion in Fiscal Year 2019

Title IIA is the key fund in ESSA that supports teacher and principal development. The recent enactment of ESSA provides important new opportunities to use those funds more effectively to improve teacher and principal quality, which helps students succeed.

CONCLUSION

I appreciate the challenges that the Committee faces in setting funding levels across a multitude of worthy programs, and I look forward to working with you to meet the needs of America's students and teachers.

[This statement was submitted by Aneesh Sohoni, Executive Director, Teach For America—Chicago-Northwest Indiana.]

PREPARED STATEMENT OF TEACH FOR AMERICA—CONNECTICUT

Thank you for the opportunity to submit testimony on the importance of Federal funding for evidence-based teacher training and recruitment programs at the U.S. Department of Education and the Corporation for National and Community Service in fiscal year 2019. As the Executive Director of Teach For America-Connecticut I am pleased to share the impact that Federal funding has on our mission.

Teach For America (TFA) is a national non-profit that finds, develops, and supports a diverse network of leaders who expand opportunity from classrooms, schools, and every sector and field that shapes the broader systems in which schools operate.

Since 1990, TFA has placed and supported over 56,000 teachers in high-need schools throughout the country, with about two-thirds of our alumni continuing to work in education. Today, we have a corps of nearly 6,400 teachers in 51 urban and rural regions in 36 States and the District of Columbia. We began our work in Connecticut in 2006. Today, we have teachers in Bridgeport, Hartford, New Haven, and Stamford. Altogether, we reach more than 6,500 students growing up in low-income neighborhoods in Connecticut.

With nearly 28 years of experience in recruiting and training teachers, our model is among one of the most rigorously evaluated teacher preparation and leadership development programs in the country. We rely on external researchers to analyze, validate, and identify opportunities to improve our programmatic model. A growing body of the most rigorous research demonstrates that our corps members and alumni are making a positive impact on students, and we continue to seek additional information to further strengthen our work.

We believe that the Federal Government should prioritize its support for programs with evidence of effectiveness, and applaud the Committee's commitment to results-driven initiatives.

I would like to highlight several of these programs and ask for your continued support in fiscal year 2019.

Corporation for National and Community Service (AmeriCorps): \$1.1 B / \$412 Million

Since 1994, more than 1 million individuals—including TFA corps members—have served through national service programs like AmeriCorps.

Together, these individuals have provided more than 1.4 billion hours of service to tackle the toughest problems in our communities. Unfortunately, many individuals who want to serve, particularly as educators, face significant economic barriers, including high student debt and the cost of teacher certification, which make it difficult to enter a lower-paying profession such as teaching. This is no different for TFA corps members.

Fortunately, our teachers can use the AmeriCorps Education Award to pay for college tuition or to pay down student debt. This award also enables TFA corps members to defer their undergraduate loans for the first 2 years of teaching and have the interest, which accrues during those 2 years, paid off by the Federal Government.

These education awards make it possible for people from all walks of life to join TFA and many other AmeriCorps partner programs. TFA's partnership with AmeriCorps has helped put tens of thousands of quality educators in low-income urban and rural areas and developed a diverse pipeline of leadership for our country. In fact, in 2017, our incoming corps was about half people of color. In addition, one-third of corps members were the first in their family to attend college and nearly 45 percent received Pell Grants.

DEPARTMENT OF EDUCATION

Supporting Effective Educator Development (SEED): \$94 Million

TFA corps members receive 2 years of ongoing training and support to prepare them to teach in low-income, high-need schools. The SEED grant has supported this training by funding TFA's teacher-training institutes, which all corps members must complete before they enter their classrooms.

The education landscape has changed dramatically since TFA sent its first cohort of teachers into the classroom 28 years ago. SEED support has been critical to adjusting our training to meet the needs of students and to align with what States and school districts need of their teachers.

With the support of a 2013 SEED Grant, TFA launched its first regional training institutes in 2014. These new institutes allowed regions to build out their own locally driven teacher preparation in which teachers receive training and teach summer school in the same communities where they will serve. By tailoring training to the specific needs of individual communities, we were able to expand learning opportunities for local students, while also developing teachers who were familiar with and invested in their local communities. With the help of continued SEED funding in 2015 and 2017, TFA has expanded from two regional institutes in 2014 to 13 in 2018. In addition, five of our regions that serve predominantly rural communities worked together to launch the Delta Collective Summer Institute in Mississippi. Having a training experience grounded in the unique needs and assets of rural communities will continue to help foster a corps of teachers who are more engaged and invested in their rural communities and can serve students living in these communities more effectively.

The 2015 passage of the bipartisan Every Student Succeeds Act (ESSA) expanded SEED eligibility to institutions of higher education, which is why it is important that SEED funding is restored to the fiscal year 2016 level of \$94 million. Furthermore, the 2017 SEED grant competition demonstrates a potential unintended consequence of this policy change. Of the ten organizations awarded grants in 2017, 80 percent were institutions of higher education. Based on this, TFA is concerned that the original Congressional intent of SEED may be undermined. As the only Federal funding available to national non-profits for improving teacher quality, SEED was created to support non-profits with a national reach to broaden the impact of research-based teacher preparation and development by bringing it to a national scale. Further, we believe that the only way we can collectively solve for the greatest educational challenges is to promote innovation from a diversity of perspectives across the education field. It is our hope that Congress and the Department of Education can ensure diversity of SEED grantees and balance awards to institutions of higher education and non-profits.

Education, Innovation and Research (EIR): \$180 Million in Fiscal Year 2019

Education Innovation and Research (EIR) grants support new methods to improve student achievement, increase high school graduation rates, and improve college enrollment and completion. EIR is unique, as it requires projects to have a promising

model and/or high evidence of effectiveness in order to win. In addition, grantees must fund an independent evaluation.

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Title IIA of the Elementary and Secondary Education Act: \$2.35 Billion in Fiscal Year 2019

Title IIA is the key fund in ESSA that supports teacher and principal development. The recent enactment of ESSA provides important new opportunities to use those funds more effectively to improve teacher and principal quality, which helps students succeed.

CONCLUSION

I appreciate the challenges that the Committee faces in setting funding levels across a multitude of worthy programs, and I look forward to working with you to meet the needs of America's students and teachers.

[This statement was submitted by Nate Snow, Executive Director, Teach For America—Connecticut.]

PREPARED STATEMENT OF TEACH FOR AMERICA—MEMPHIS & TEACH FOR AMERICA—NASHVILLE

Thank you for the opportunity to submit testimony on the importance of Federal funding for evidence-based teacher training and recruitment programs at the U.S. Department of Education and the Corporation for National and Community Service in fiscal year 2019. As the Executive Directors for Teach For America-Memphis and Teach For America-Nashville we are pleased to share the impact that Federal funding has on our mission.

Teach For America (TFA) is a national non-profit that finds, develops, and supports a diverse network of leaders who expand opportunity from classrooms, schools, and every sector and field that shapes the broader systems in which schools operate.

Since 1990, TFA has placed and supported over 56,000 teachers in high-need schools throughout the country, with about two-thirds of our alumni continuing to work in education. Today, we have a corps of nearly 6,400 teachers in 51 urban and rural regions in 36 States and the District of Columbia.

In Memphis, TFA was established in 2006 and we now have more than 750 corps members and alumni working in Memphis. 72 percent of our 2016 corps members will continue to teach in Memphis for a third year, and a full 80 percent will remain in Memphis. In addition, TFA-Memphis was again named one of the top teacher prep programs in the State of Tennessee this year—TFA-Memphis and TFA-Nashville were the only teacher preparation programs to receive the top score of 4 in every category.

In Nashville, TFA was established in 2009. We are embarking on our 10th year of working in partnership with the city and school district to improve educational outcomes. We will start the 2018–2019 school year with over 1,000 leaders in the TFA network in Nashville, including over 170 corps members. Year over year, the State Board of Education rates TFA-Nashville among the top provider of new teachers in the State. This last year, TFA-Nashville was ranked the #1 overall teacher

preparation program, including providing the highest percentage of highly effective teachers at the elementary level, the middle school level, and for new Special Education teachers. We also have one of the highest rates of providing teachers in “highly demanded” classrooms such as STEM, SPED, and ELL classrooms.

With nearly 28 years of experience in recruiting and training teachers, our model is among one of the most rigorously evaluated teacher preparation and leadership development programs in the country. We rely on external researchers to analyze, validate, and identify opportunities to improve our programmatic model. A growing body of the most rigorous research demonstrates that our corps members and alumni are making a positive impact on students, and we continue to seek additional information to further strengthen our work.

We believe that the Federal Government should prioritize its support for programs with evidence of effectiveness, and applaud the Committee’s commitment to results-driven initiatives.

We would like to highlight several of these programs and ask for your continued support in fiscal year 2019.

Corporation for National and Community Service (AmeriCorps): \$1.1 B / \$412 Million

Since 1994, more than 1 million individuals—including TFA corps members—have served through national service programs like AmeriCorps.

Together, these individuals have provided more than 1.4 billion hours of service to tackle the toughest problems in our communities. Unfortunately, many individuals who want to serve, particularly as educators, face significant economic barriers, including high student debt and the cost of teacher certification, which make it difficult to enter a lower-paying profession such as teaching. This is no different for TFA corps members.

Fortunately, our teachers can use the AmeriCorps Education Award to pay for college tuition or to pay down student debt. This award also enables TFA corps members to defer their undergraduate loans for the first 2 years of teaching and have the interest, which accrues during those 2 years, paid off by the Federal Government.

In Nashville, this award has helped hundreds of our corps members become incredibly effective TFA alumni as they progress in their careers. Today, teaching and school leadership are the most common professions of our 750 alumni. In fact, TFA corps member and alumni teachers compose nearly 10 percent of the overall teacher workforce in Nashville, and our nearly 1 in 5 school leaders who predominantly serve families in poverty are TFA alumni. Our TFA alumni school leaders, in particular, are producing extraordinary academic results: Of the top 15 public middle and high schools without entrance requirements, TFA alumni lead 13 of them. Similarly, TFA alumni lead 72 percent of the top-achieving “Level 5” schools in Nashville.

In TFA-Memphis, 83 percent of alumni are working full-time in education including 219 local teachers, 22 school leaders, and 7 school system leaders. TFA-Memphis alumni lead the two schools noted locally to have 100 percent of their graduating classes accepted into 4-year programs and lead at every level of the highest performing charter network in the city. Alumni also lead the district’s strategy and innovation office, which has worked to ensure clarity between the district and its charter schools on accountability, as well as pioneer a newly piloted student-based funding formula. And alumni lead local organizations that work with students in a variety of ways to increase college attainment and are succeeding in securing college acceptance for nearly every student they work with and ensuring they stay in college once enrolled. At every level of Memphis, you can find our alumni working to create change for our students.

These education awards make it possible for people from all walks of life to join TFA and many other AmeriCorps partner programs. TFA’s partnership with AmeriCorps has helped put tens of thousands of quality educators in low-income urban and rural areas and developed a diverse pipeline of leadership for our country. In fact, in 2017, our incoming corps was about half people of color. In addition, one-third of corps members were the first in their family to attend college and nearly 45 percent received Pell Grants.

DEPARTMENT OF EDUCATION

Supporting Effective Educator Development (SEED): \$94 Million

TFA corps members receive 2 years of ongoing training and support to prepare them to teach in low-income, high-need schools. The SEED grant has supported this training by funding TFA’s teacher-training institutes, which all corps members must complete before they enter their classrooms.

The education landscape has changed dramatically since TFA sent its first cohort of teachers into the classroom 28 years ago. SEED support has been critical to adjusting our training to meet the needs of students and to align with what States and school districts need of their teachers.

With the support of a 2013 SEED Grant, TFA launched its first regional training institutes in 2014. These new institutes allowed regions to build out their own locally driven teacher preparation in which teachers receive training and teach summer school in the same communities where they will serve. By tailoring training to the specific needs of individual communities, we were able to expand learning opportunities for local students, while also developing teachers who were familiar with and invested in their local communities. With the help of continued SEED funding in 2015 and 2017, TFA has expanded from two regional institutes in 2014 to 13 in 2018. This expansion includes teacher training institutes in Memphis and Nashville.

In 2013, TFA-Memphis launched our regional teacher training institute in partnership with Achievement School District, KIPP, Memphis Business Academy, Gestalt Community Schools and University of Memphis. This summer we will bring more than 150 corps members train and teach in Memphis. In Nashville our regional institute launched in 2014 in partnership with Metro Nashville Public Schools and Lipscomb University. This year, there will be over 90 corps members attending. The Summer Academies (Nashville regional institute) has been a resounding success in Nashville, with over 375 corps members educating over 1,200 students. This has prevented summer learning loss (reversing an average loss of 2 months of reading learning to gaining approximately 2.5 months instead) and helped high school students stay on track for on-time graduation by recovering 250 credit hours over the last 2 years, for example.

In addition, five of our regions that serve predominantly rural communities worked together to launch the Delta Collective Summer Institute in Mississippi. Having a training experience grounded in the unique needs and assets of rural communities will continue to help foster a corps of teachers who are more engaged and invested in their rural communities and can serve students living in these communities more effectively.

The 2015 passage of the bipartisan Every Student Succeeds Act (ESSA) expanded SEED eligibility to institutions of higher education, which is why it is important that SEED funding is restored to the fiscal year 2016 level of \$94 million. Furthermore, the 2017 SEED grant competition demonstrates a potential unintended consequence of this policy change. Of the ten organizations awarded grants in 2017, 80 percent were institutions of higher education. Based on this, TFA is concerned that the original Congressional intent of SEED may be undermined. As the only Federal funding available to national non-profits for improving teacher quality, SEED was created to support non-profits with a national reach to broaden the impact of research-based teacher preparation and development by bringing it to a national scale. Further, we believe that the only way we can collectively solve for the greatest educational challenges is to promote innovation from a diversity of perspectives across the education field. It is our hope that Congress and the Department of Education can ensure diversity of SEED grantees and balance awards to institutions of higher education and non-profits.

Education, Innovation and Research (EIR): \$180 Million in Fiscal Year 2019

Education Innovation and Research (EIR) grants support new methods to improve student achievement, increase high school graduation rates, and improve college enrollment and completion. EIR is unique, as it requires projects to have a promising model and/or high evidence of effectiveness in order to win. In addition, grantees must fund an independent evaluation.

Through a 2010 EIR Expansion grant, TFA was able to pilot new strategies to attract a more racially and socioeconomically diverse corps of teachers. In the first year of the grant, 34 percent of the 2011 corps identified as people of color, 30 percent came from low-income backgrounds, and 22 percent reported being the first in their family to graduate from college. In the last year of the grant, nearly half of the 2015 corps identified as people of color, 47 percent come from low-income backgrounds, a third report being the first in their family to graduate from college. In addition, by 2015, 20 percent of corps members had a background in science, technology, engineering, or math (STEM).

Through a 2017 Early Phase grant, TFA is expanding its Rural School Leadership Academy (RSLA) to serve more than 250 school leaders in rural communities over the next 5 years. The RSLA is a 1 year professional development program focused on growing the skills and mind-sets necessary for individuals to become school leaders in rural communities. The RSLA not only represents important professional de-

velopment for rural teachers, this program is a key tool in our work to retain great talent in rural communities across the country.

Over the last 5 years, the U.S. Department of Education received nearly 5,000 applications but made only 156 grants. This is a total application-success rate of only 3.1 percent. Given this demand from the education field and EIR's focus on supporting programs with evidence of effectiveness, we believe this increase in funding—which is consistent with the President's budget request—is a wise investment.

Title IIA of the Elementary and Secondary Education Act: \$2.35 Billion in Fiscal Year 2019

Title IIA is the key fund in ESSA that supports teacher and principal development. The recent enactment of ESSA provides important new opportunities to use those funds more effectively to improve teacher and principal quality, which helps students succeed.

CONCLUSION

I appreciate the challenges that the Committee faces in setting funding levels across a multitude of worthy programs, and I look forward to working with you to meet the needs of America's students and teachers.

[This statement was submitted by Athena Palmer & Ben Schumacher, Executive Director(s), Teach For America—Memphis & Teach For America—Nashville.]

PREPARED STATEMENT OF TEACH FOR AMERICA—OKLAHOMA CITY

Thank you for the opportunity to submit testimony on the importance of Federal funding for evidence-based teacher training and recruitment programs at the U.S. Department of Education and the Corporation for National and Community Service in fiscal year 2019. As the Executive Director of Teach For America-Oklahoma City I am pleased to share the impact that Federal funding has on our mission.

Teach For America (TFA) is a national non-profit that finds, develops, and supports a diverse network of leaders who expand opportunity from classrooms, schools, and every sector and field that shapes the broader systems in which schools operate.

Since 1990, TFA has placed and supported over 56,000 teachers in high-need schools throughout the country, with about two-thirds of our alumni continuing to work in education. Today, we have a corps of nearly 6,400 teachers in 51 urban and rural regions in 36 States and the District of Columbia. Since launching in 2009, TFA-Oklahoma has brought over 800 corps members to teach in low-income classrooms across 80 schools throughout Tulsa and Oklahoma City, impacting over 15,000 students. These corps members work tirelessly to improve public education in Oklahoma.

We believe that the Federal Government should prioritize its support for programs with evidence of effectiveness, and applaud the Committee's commitment to results-driven initiatives.

I would like to highlight several of these programs and ask for your continued support in fiscal year 2019.

Corporation for National and Community Service (AmeriCorps): \$1.1 B/\$412 Million

Since 1994, more than 1 million individuals—including TFA corps members—have served through national service programs like AmeriCorps.

Together, these individuals have provided more than 1.4 billion hours of service to tackle the toughest problems in our communities. Unfortunately, many individuals who want to serve, particularly as educators, face significant economic barriers, including high student debt and the cost of teacher certification, which make it difficult to enter a lower-paying profession such as teaching. This is no different for TFA corps members.

Fortunately, our teachers can use the AmeriCorps Education Award to pay for college tuition or to pay down student debt. This award also enables TFA corps members to defer their undergraduate loans for the first 2 years of teaching and have the interest, which accrues during those 2 years, paid off by the Federal Government. One example of the impact this support can have on the leadership trajectory of our teachers is that of Jessica Johnson, a native Oklahoma City graduate who joined the TFA corps and taught in Philadelphia in 2008. She is now a principal with Thelma R. Parks Elementary School in OKC and oversees the learning of 340 students. She is redefining what it means for a school to be a model of community collaboration towards student growth and achievement.

These education awards make it possible for people from all walks of life to join TFA and many other AmeriCorps partner programs. TFA's partnership with

AmeriCorps has helped put tens of thousands of quality educators in low-income urban and rural areas and developed a diverse pipeline of leadership for our country. In fact, in 2017, our incoming corps was about half people of color. In addition, one-third of corps members were the first in their family to attend college and nearly 45 percent received Pell Grants.

DEPARTMENT OF EDUCATION

Supporting Effective Educator Development (SEED): \$94 Million

TFA corps members receive 2 years of ongoing training and support to prepare them to teach in low-income, high-need schools. The SEED grant has supported this training by funding TFA's teacher-training institutes, which all corps members must complete before they enter their classrooms.

The education landscape has changed dramatically since TFA sent its first cohort of teachers into the classroom 28 years ago. SEED support has been critical to adjusting our training to meet the needs of students and to align with what States and school districts need of their teachers.

With the support of a 2013 SEED Grant, TFA launched its first regional training institutes in 2014. These new institutes allowed regions to build out their own locally driven teacher preparation in which teachers receive training and teach summer school in the same communities where they will serve. By tailoring training to the specific needs of individual communities, we were able to expand learning opportunities for local students, while also developing teachers who were familiar with and invested in their local communities. With the help of continued SEED funding in 2015 and 2017, TFA has expanded from two regional institutes in 2014 to 13 in 2018. In addition, five of our regions that serve predominantly rural communities worked together to launch the Delta Collective Summer Institute in Mississippi. Having a training experience grounded in the unique needs and assets of rural communities will continue to help foster a corps of teachers who are more engaged and invested in their rural communities and can serve students living in these communities more effectively.

The 2015 passage of the bipartisan Every Student Succeeds Act (ESSA) expanded SEED eligibility to institutions of higher education, which is why it is important that SEED funding is restored to the fiscal year 2016 level of \$94 million. Furthermore, the 2017 SEED grant competition demonstrates a potential unintended consequence of this policy change. Of the ten organizations awarded grants in 2017, 80 percent were institutions of higher education. Based on this, TFA is concerned that the original Congressional intent of SEED may be undermined. As the only Federal funding available to national non-profits for improving teacher quality, SEED was created to support non-profits with a national reach to broaden the impact of research-based teacher preparation and development by bringing it to a national scale. Further, we believe that the only way we can collectively solve for the greatest educational challenges is to promote innovation from a diversity of perspectives across the education field. It is our hope that Congress and the Department of Education can ensure diversity of SEED grantees and balance awards to institutions of higher education and non-profits.

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Education Innovation and Research (EIR) grants support new methods to improve student achievement, increase high school graduation rates, and improve college enrollment and completion. EIR is unique, as it requires projects to have a promising model and/or high evidence of effectiveness in order to win. In addition, grantees must fund an independent evaluation.

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Over the last 5 years, the U.S. Department of Education received nearly 5,000 applications but made only 156 grants. This is a total application-success rate of only 3.1 percent. Given this demand from the education field and EIR's focus on supporting programs with evidence of effectiveness, we believe this increase in funding—which is consistent with the President's budget request—is a wise investment.

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CONCLUSION

I appreciate the challenges that the Committee faces in setting funding levels across a multitude of worthy programs, and I look forward to working with you to meet the needs of America's students and teachers.

[This statement was submitted by Art Serna Jr., Executive Director, Teach For America—Oklahoma City.]

PREPARED STATEMENT OF TEACH FOR AMERICA—RHODE ISLAND

Thank you for the opportunity to submit testimony on the importance of Federal funding for evidence-based teacher training and recruitment programs at the U.S. Department of Education and the Corporation for National and Community Service in fiscal year 2019. As the Executive Director of Teach For America-Rhode Island, I am pleased to share the impact that Federal funding has on our mission.

Teach For America (TFA) is a national non-profit that finds, develops, and supports a diverse network of leaders who expand opportunity from classrooms, schools, and every sector and field that shapes the broader systems in which schools operate.

Since 1990, TFA has placed and supported over 56,000 teachers in high-need schools throughout the country, with about two-thirds of our alumni continuing to work in education. Today, we have a corps of nearly 6,400 teachers in 51 urban and rural regions in 36 States and the District of Columbia. Since 2010, TFA-Rhode Island has been working to draw diverse leaders committed to educational equity in the State. As a result, we have 53 corps members currently in the classroom and more than 230 alumni living and working in the State—89 percent directly in education or a field that impacts education.

With nearly 28 years of experience in recruiting and training teachers, TFA's model is among one of the most rigorously evaluated teacher preparation and leadership development programs in the country. We rely on external researchers to analyze, validate, and identify opportunities to improve our programmatic model. A growing body of the most rigorous research demonstrates that our corps members and alumni are making a positive impact on students, and we continue to seek additional information to further strengthen our work.

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The 2015 passage of the bipartisan Every Student Succeeds Act (ESSA) expanded SEED eligibility to institutions of higher education, which is why it is important that SEED funding is restored to the fiscal year 2016 level of \$94 million. Furthermore, the 2017 SEED grant competition demonstrates a potential unintended consequence of this policy change. Of the ten organizations awarded grants in 2017, 80 percent were institutions of higher education. Based on this, TFA is concerned that the original Congressional intent of SEED may be undermined. As the only Federal funding available to national non-profits for improving teacher quality, SEED was created to support non-profits with a national reach to broaden the impact of research-based teacher preparation and development by bringing it to a national scale. Further, we believe that the only way we can collectively solve for the greatest educational challenges is to promote innovation from a diversity of perspectives across the education field. It is our hope that Congress and the Department of Education can ensure diversity of SEED grantees and balance awards to institutions of higher education and non-profits.

Education, Innovation and Research (EIR): \$180 Million in Fiscal Year 2019

Education Innovation and Research (EIR) grants support new methods to improve student achievement, increase high school graduation rates, and improve college enrollment and completion. EIR is unique, as it requires projects to have a promising model and/or high evidence of effectiveness in order to win. In addition, grantees must fund an independent evaluation.

Through a 2010 EIR Expansion grant, TFA was able to pilot new strategies to attract a more racially and socioeconomically diverse corps of teachers. In the first year of the grant, 34 percent of the 2011 corps identified as people of color, 30 percent came from low-income backgrounds, and 22 percent reported being the first in their family to graduate from college. In the last year of the grant, nearly half of the 2015 corps identified as people of color, 47 percent come from low-income backgrounds, a third report being the first in their family to graduate from college. In addition, by 2015, 20 percent of corps members had a background in science, technology, engineering, or math (STEM).

Through a 2017 Early Phase grant, TFA is expanding its Rural School Leadership Academy (RSLA) to serve more than 250 school leaders in rural communities over the next 5 years. The RSLA is a 1 year professional development program focused on growing the skills and mind-sets necessary for individuals to become school lead-

ers in rural communities. The RSLA not only represents important professional development for rural teachers, this program is a key tool in our work to retain great talent in rural communities across the country.

Over the last 5 years, the U.S. Department of Education received nearly 5,000 applications but made only 156 grants. This is a total application-success rate of only 3.1 percent. Given this demand from the education field and EIR's focus on supporting programs with evidence of effectiveness, we believe this increase in funding—which is consistent with the President's budget request—is a wise investment.

Title IIA of the Elementary and Secondary Education Act: \$2.35 Billion in Fiscal Year 2019

Title IIA is the key fund in ESSA that supports teacher and principal development. The recent enactment of ESSA provides important new opportunities to use those funds more effectively to improve teacher and principal quality, which helps students succeed.

CONCLUSION

I appreciate the challenges that the Committee faces in setting funding levels across a multitude of worthy programs, and I look forward to working with you to meet the needs of America's students and teachers.

[This statement was submitted by Kristine Frech, Executive Director, Teach For America—Rhode Island.]

PREPARED STATEMENT OF TEACH FOR AMERICA—SOUTH CAROLINA

Thank you for the opportunity to submit testimony on the importance of Federal funding for evidence-based teacher training and recruitment programs at the U.S. Department of Education and the Corporation for National and Community Service in fiscal year 2019. As the Executive Director of Teach For America-South Carolina I am pleased to share the impact that Federal funding has on our mission.

Teach For America (TFA) is a national non-profit that finds, develops, and supports a diverse network of leaders who expand opportunity from classrooms, schools, and every sector and field that shapes the broader systems in which schools operate.

Since 1990, TFA has placed and supported over 56,000 teachers in high-need schools throughout the country, with about two-thirds of our alumni continuing to work in education. Today, we have a corps of nearly 6,400 teachers in 51 urban and rural regions in 36 States and the District of Columbia. Teach For America launched our efforts in South Carolina in 2011 with 30 teachers, and we have worked diligently to support highly qualified teachers throughout our State over the last 7 years. This year, Teach For America—South Carolina provided more than 90 teachers to partner districts throughout the Pee Dee, Orangeburg, and Lowcountry regions of the State. Ninety percent of our teachers are leading classrooms in rural communities. Our partner districts average a “poverty index,” a composite measure developed by the South Carolina Education Oversight Committee of students eligible for Medicaid and/or free or reduced price lunch, of 79.5 percent, and go as high as 89 percent. In the short term, our Corps Members will lead their students to make dramatic academic gains, putting them on the path toward future success. In the long-term, our alumni will continue to lead classrooms, work in district and school administration, in policy, and throughout a variety of sectors within our State. Our alumni base is growing. Currently, we have nearly 300 alumni living throughout South Carolina impacting our education system from all sectors. In 2016, 81 percent of our alumni were working in jobs in the education field, and 44 percent were continuing on as K–12 classroom teachers.

With nearly 28 years of experience in recruiting and training teachers, our model is among one of the most rigorously evaluated teacher preparation and leadership development programs in the country. We rely on external researchers to analyze, validate, and identify opportunities to improve our programmatic model. A growing body of the most rigorous research demonstrates that our corps members and alumni are making a positive impact on students, and we continue to seek additional information to further strengthen our work.

We believe that the Federal Government should prioritize its support for programs with evidence of effectiveness, and applaud the Committee's commitment to results-driven initiatives.

I would like to highlight several of these programs and ask for your continued support in fiscal year 2019.

Corporation for National and Community Service (AmeriCorps): \$1.1 B / \$412 Million

Since 1994, more than 1 million individuals—including TFA corps members—have served through national service programs like AmeriCorps.

Together, these individuals have provided more than 1.4 billion hours of service to tackle the toughest problems in our communities. Unfortunately, many individuals who want to serve, particularly as educators, face significant economic barriers, including high student debt and the cost of teacher certification, which make it difficult to enter a lower-paying profession such as teaching. This is no different for TFA corps members.

Fortunately, our teachers can use the AmeriCorps Education Award to pay for college tuition or to pay down student debt. This award also enables TFA corps members to defer their undergraduate loans for the first 2 years of teaching and have the interest, which accrues during those 2 years, paid off by the Federal Government. Brandon Johnson is one of our Teach For America—South Carolina alumnus who was able to dedicate himself to his passion for educational equity because of the support he received through Teach For America.

A native of North Augusta, SC, Brandon graduated from the University of South Carolina in 2014 and afterward joined Teach For America—South Carolina. He fostered the growth of more than 300 middle school students as a Corps Member in Marion County for 3 years. After the corps, he earned his master's degree from Coastal Carolina University and currently serves as an Assistant Principal in Spartanburg School District 7. Most recently, he completed our competitive Rural School Leadership Academy Fellowship, which provided him specialized training and development to one day lead his own school. Mr. Johnson, like so many of our Teach For America alumni, draws inspiration from a deep belief that all students in South Carolina deserve the opportunity to attain an excellent education.

These education awards make it possible for people from all walks of life to join TFA and many other AmeriCorps partner programs. TFA's partnership with AmeriCorps has helped put tens of thousands of quality educators in low-income urban and rural areas and developed a diverse pipeline of leadership for our country. In fact, in 2017, our incoming corps was about half people of color. In addition, one-third of corps members were the first in their family to attend college and nearly 45 percent received Pell Grants.

DEPARTMENT OF EDUCATION

Supporting Effective Educator Development (SEED): \$94 Million

TFA corps members receive 2 years of ongoing training and support to prepare them to teach in low-income, high-need schools. The SEED grant has supported this training by funding TFA's teacher-training institutes, which all corps members must complete before they enter their classrooms.

The education landscape has changed dramatically since TFA sent its first cohort of teachers into the classroom 28 years ago. SEED support has been critical to adjusting our training to meet the needs of students and to align with what States and school districts need of their teachers.

With the support of a 2013 SEED Grant, TFA launched its first regional training institutes in 2014. These new institutes allowed regions to build out their own locally driven teacher preparation in which teachers receive training and teach summer school in the same communities where they will serve. By tailoring training to the specific needs of individual communities, we were able to expand learning opportunities for local students, while also developing teachers who were familiar with and invested in their local communities. With the help of continued SEED funding in 2015 and 2017, TFA has expanded from two regional institutes in 2014 to 13 in 2018. In addition, five of our regions that serve predominantly rural communities worked together to launch the Delta Collective Summer Institute in Mississippi. Having a training experience grounded in the unique needs and assets of rural communities will continue to help foster a corps of teachers who are more engaged and invested in their rural communities and can serve students living in these communities more effectively.

The 2015 passage of the bipartisan Every Student Succeeds Act (ESSA) expanded SEED eligibility to institutions of higher education, which is why it is important that SEED funding is restored to the fiscal year 2016 level of \$94 million. Furthermore, the 2017 SEED grant competition demonstrates a potential unintended consequence of this policy change. Of the ten organizations awarded grants in 2017, 80 percent were institutions of higher education. Based on this, TFA is concerned that the original Congressional intent of SEED may be undermined. As the only Federal funding available to national non-profits for improving teacher quality, SEED was created to support non-profits with a national reach to broaden the impact of re-

search-based teacher preparation and development by bringing it to a national scale. Further, we believe that the only way we can collectively solve for the greatest educational challenges is to promote innovation from a diversity of perspectives across the education field. It is our hope that Congress and the Department of Education can ensure diversity of SEED grantees and balance awards to institutions of higher education and non-profits.

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CONCLUSION

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[This statement was submitted by Troy D. Evans, Executive Director, Teach For America—South Carolina.]

PREPARED STATEMENT OF TERRI POORE, POLICY DIRECTOR 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 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 \$49.4 million to \$150 million. We are grateful to the committee for the \$5 million increase for RPE in the fiscal year 2018 Omnibus Appropriations Act bringing funding to \$49.4 million. 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.

A 2017 survey by NAESV revealed that almost 40 percent of programs had a waiting list of a month or more for prevention programming. According to a 2018 survey by the National Sexual Violence Resource Center, the average percent of coverage of RPE-funded programs was 39 percent of the State. Nearly half of the States responding reported RPE funding coverage in their State at 20 percent or less with rural areas especially lacking in access to prevention.

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:

- 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.
- Connecticut's Women & Families Center* developed a multi-session curriculum addressing issues of violence and injury targeting middle school youth.
- 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.
- 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.
- 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 healthcare, 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.

According to the National Intimate Partner and Sexual Violence Survey (CDC, 2011):

- Nearly 1 in 5 women have been the victim of rape or attempted rape.
- Most female victims of completed rape (79.6 percent) experienced their first rape before the age of 25; 42.2 percent experienced their first completed rape before the age of 18 years.
- More than one-quarter of male victims of completed rape (27.8 percent) experienced their first rape when they were 10 years of age or younger.

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 percent 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."

Funding History: In the 2013 reauthorization of Violence Against Women Act, Congress cut authorization for RPE from \$80 to \$50 million. In fiscal year 2017, the program was funded at \$44.4 million, a \$5 million increase from fiscal year 2016. In fiscal year 2018, RPE was funded in the omnibus at \$49.4 million.

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 TOURETTE ASSOCIATION OF AMERICA

Dear Chairman Blunt, Ranking Member Murray and Members of the Subcommittee:

The Tourette Association of America (TAA) would like to take this opportunity to thank the members of the Subcommittee for the opportunity to submit written testimony and for considering our request for funding for fiscal year 2019. 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 Tourette Syndrome (TS) and Tic Disorder community. We respectfully request that you continue funding the \$2 million appropriation for the program in fiscal year 2019 Labor, Health and Human Services (LHHS), Education and Related Agencies Appropriations. The program on TS 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 TS. With your support at the previously enacted level of \$2 million, CDC can ensure critically necessary progress continues in the areas of public education, research and diagnosis for TS and Tic Disorders.

The TAA is the premier national non-profit organization working to make life better for all people affected by TS and Tic Disorders. We have served in this capacity for 46 years. Tics are involuntary, repetitive movements and vocalizations. They are the defining feature of a group of childhood-onset, neurodevelopmental conditions known collectively as Tic Disorders and individually as Tourette Syndrome, Chronic Tic Disorder (Motor or Vocal Type), and Provisional Tic Disorder. People with TS and Tic Disorders often have substantial healthcare costs across their lifespan for healthcare visits, special educational services, medication, and psychological and behavioral counseling.

The CDC Tourette Syndrome Website (<https://www.cdc.gov/ncbddd/tourette/data.html>) on data and statistics states that data suggests roughly 50 percent of children and teens with TS are not diagnosed. Based on current research, it is our estimate that the combined total of all school-aged children with TS or another related Tic Disorder is approximately 1-in-100. Some studies include children with undiagnosed TS and children with diagnosed TS with estimates that 1 out of every 162 children (0.6 percent) have TS. However, these numbers do not include children with Chronic or Provisional Tic Disorders. Diagnosis is often complicated. Among children diagnosed with TS, 86 percent have been diagnosed with at least one additional mental, behavioral, or developmental condition according to the CDC website. These co-occurring conditions include Attention Deficit-Hyperactivity Disorder (ADHD), Obsessive Compulsive Disorder (OCD), Autism, Oppositional Defiance Dis-

order, anxiety, depression, learning difficulties among others. Primary care, family physicians and pediatricians will often diagnose the co-occurring condition(s) and not the TS or Tic Disorder due to a lack of education around TS and Tic Disorders in medical school. 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 to a pediatric neurologist for assessment.

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 TS had other mental, behavioral, or emotional disorders or learning and language disorders. 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 TS, Tic Disorders and associated co-morbidities, educators can refer students for assessment by their physician or a pediatric neurologist 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 for the child.

TS and Tic Disorders are greatly misunderstood and often suffer from misinformation and stigma. For example, Coprolalia is an extreme and rare case of Tourette often sensationalized by the media. It is the involuntary utterance of obscene and socially unacceptable words and phrases. It is relatively rare in individuals with TS (only 10 percent of those diagnosed have this symptom), 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 TS and Tic Disorders to ensure a better understanding which can lead to better diagnosis and earlier treatment.

Delayed diagnosis or the lack of diagnosis can increase healthcare costs with additional doctor visits and assessments, increase education costs and delay important treatment and therapy for the patient. For example, 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 teaches people with TS a set of specific skills they can use to manage their tic urges or behaviors without having to use voluntary suppression. According to a study published in the *Journal of the American Medical Association* in 2010, "Behavior therapy for children with Tourette disorder: a randomized controlled trial", there were significant reductions in tic severity and improved ability to function in 52.5 percent of children who underwent CBIT therapy in the study. 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.

The CDC TS program strives to learn more about TS, who it affects, how symptoms appear and change, if tics are an early indicator for the co-occurring conditions, the impact of TS across the lifespan of patients and identifying factors that relate to better or worse outcomes. This information is critical to improving treatments, therapies and better understanding the relationship of the co-occurring conditions. Consequently, increasing a better understanding and awareness among the general public, government officials, doctors and educators is extremely important for the many individuals, diagnosed and undiagnosed, who live with TS and Tic Disorders.

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 2019 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 TRUST FOR AMERICA'S HEALTH

Thank you Chairman Alexander and Ranking Member Murray, and other members of the subcommittee for providing this opportunity to provide a written statement in support of fiscal year 2019 appropriations for the Department of Health and Human Services. I'm John Auerbach, President and CEO of Trust for America's Health (TFAH), a nonprofit, nonpartisan organization dedicated to saving lives by working to make prevention of illness and injury a national priority. I joined this dedicated organization after working in public health for 30 years—as a city health commissioner, a State public health commissioner and as the associate director of the Centers for Disease Control and Prevention (CDC).

Nothing reflects the values of a country more than the health of its residents. And sadly, Americans are not as healthy as they could or should be—in large part because we routinely underfund our Nation's public health system, far too often at the expense of paying for treatment and care in the healthcare system. The country needs a long-term commitment to rebuilding the Nation's public health capabilities—not just to filling some of the more dangerous gaps, but also to ensuring that each community will be prepared, responsive, and resilient when the unexpected occurs.

Thank you for providing the CDC funding in fiscal year 2018 for a much-needed laboratory and the expansion of its work to address the opioid epidemic, as well as other vitally important efforts. However, much of CDC's important work remains dangerously underfunded, which means our Nation is vulnerable to serious health threats. We share the CDC Coalition's recommendation that Congress provide CDC with \$8.445 billion in fiscal year 2019, which would put us on a path toward the goal of providing CDC with a 22 percent increase in funding by fiscal year 2022.

Approximately seventy-five percent of the CDC's annual budget flows to your home districts and communities in the form of grants and contracts to State, territorial, Tribal, and local public health departments and community organizations, to conduct critical public health and prevention activities upon which every American relies. This includes funding to protect us from infectious disease (such as the annual flu and the threat of outbreaks such as Ebola and Zika), delivering immunizations to prevent childhood diseases and ensuring preparedness for events such as the many natural disasters we faced in 2017.

In fact, 2017 was one of the worst years on record for natural disasters, and our Nation's public health and healthcare systems were on the front lines—staffing shelters, minimizing disaster related injuries, infections and trauma and ensuring that the elderly and other vulnerable populations were not overlooked. The Public Health Emergency Preparedness (PHEP) Cooperative Agreement Program is the only Federal program that supports the work of State and local health departments to prepare for and respond to emergencies. This core emergency preparedness funding has been cut by about 29 percent since the program was established in fiscal year 2002. TFAH recommends \$824 million for the Public Health Emergency Preparedness Cooperative Agreement Program to address gaps in State and local preparedness.

In addition, the Hospital Preparedness Program (HPP), administered by the Assistant Secretary for Preparedness and Response (ASPR), is the only Federal or State funding most States and cities receive to support health system preparedness for disasters. The program has seen its funding cut nearly in half since fiscal year 2003. TFAH recommends \$474 million for the Hospital Preparedness Program in fiscal year 2019.

A sustained investment in public health and prevention is also essential to reduce high rates of disease and improve health in the United States. Twelve percent of CDC's budget comes from the Prevention and Public Health Fund, with about \$625 million annually directed to State and local efforts to ensure access to vaccines, avoid healthcare-associated infections, reduce tobacco use among teenagers, and prevent diabetes, heart disease and cancer. We urge you to oppose further cuts to the Prevention Fund.

Chronic diseases are responsible for roughly 80 percent of healthcare spending in the United States and the causes are often associated with the social, economic, and environmental conditions in our cities, towns and counties. For example, poverty is strongly associated with poorer health. In addition, people may adopt unhealthy behaviors that directly lead to injury, illness and preventable deaths.

As a result, these diseases cannot be adequately addressed by simply investing in the healthcare system to assist after people become ill. CDC's National Center for Chronic Disease Prevention and Health Promotion funds public and private partners to reduce the rates of death and disability by promoting healthy behaviors and creating safer conditions in people's homes, workplaces, neighborhoods and schools. CDC also funds communities to develop culturally tailored approaches to combat

health disparities through the Racial and Ethnic Approaches to Community Health (REACH) program. TFAH recommends \$63.3 million for the Division of Nutrition, Physical Activity, and Obesity at CDC's National Center for Chronic Disease Prevention and Health Promotion, and \$57.9 million for the REACH program.

One of the great contributions of the public health system is its ability to provide useful information about whose health is at risk or impaired and why. This allows us to invest and carefully target our interventions and better understand what works to safeguard the public. Supporting research and acting on the knowledge it generates helps create safe, healthy environments that are free of environmental toxins and other hazards. Without the right data, including those collected by the National Environmental Public Health Tracking Network, researchers and policy-makers struggle to answer basic questions about life-threatening health conditions. TFAH recommends funding the Tracking Network at \$40 million as a down payment toward fully funding the Tracking Network within the next 5 years.

Finally, as you know, opioid misuse is a public health epidemic that has touched nearly all of our communities. Drug-related deaths have tripled since 2000. In 2016, 142,000 Americans died from overlapping epidemics of alcohol- and drug-induced fatalities and suicide—an average of one every four minutes. That's more than the number of Americans who died in all U.S. wars since 1950 combined. Many of these deaths are related to inappropriate prescribing practices and the misuse of such prescription drugs. But they also stem from circumstance when people self-medicate in response to despair caused by trauma and other adverse conditions they've experienced in their lives. The response to the epidemic certainly needs to include drug treatment, overdose reversal and appropriate prescribing. But it also needs to include educational and skill-building programs for children and adults; early screening, support and referral systems in our schools and communities and attention paid to the conditions that create the stress and despair. With proper support, the public health sector can identify and offer the proven interventions and effective policies to reduce many of these factors.

TFAH recommends \$625.4 million for CDC's National Center for Injury Prevention and Control to expand its opioid overdose prevention effort to all 50 States and the District of Columbia. We also encourage you to provide at least \$248.2 million for the Center for Substance Abuse Prevention at the Substance Abuse and Mental Health Services Administration, and \$1.9 billion for the Substance Abuse Prevention and Treatment Block Grant (SABG), which provides critical prevention funding for the States. SABG alone accounts for approximately 32 percent of spending by State substance abuse agencies, yet until fiscal year 2016 the SABG had been level funded for several years despite the increased burden of substance misuse.

In closing, let me thank you again for your support of public health in 2018 and in the past. Such support is vital to ensuring that the Nation has a functioning public health infrastructure and the American people are protected from avoidable threats. But I respectfully encourage you to do more to restore the cuts of the past and to build on the progress and track record of CDC and the public health system at the State, local, territorial and Tribal levels. It is only when we have strong and robust public health and preventive efforts in every community that we will demonstrate that we are indeed a Nation that prioritizes the health of its people.

[This statement was submitted by John Auerbach, President and CEO, Trust for America's Health.]

PREPARED STATEMENT OF THE U.S. HEREDITARY ANGIOEDEMA ASSOCIATION

SUMMARY OF FISCAL YEAR 2019 RECOMMENDATIONS

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- Provide the National Institutes of Health (NIH) with at least a \$2 billion increase in discretionary funding for fiscal year 2019 to bring overall funding up to a minimum of \$39.1 billion annually. Continue to support advancement of the NIH hereditary angioedema research portfolio as well as encourage activities focused on rare disease research.
 - Provide the Centers for Disease Control and Prevention (CDC) with a meaningful funding increase to facilitate surveillance, education, and awareness activities.
 - Encourage the Centers for Medicare and Medicaid Services (CMS) to prevent discrimination in health coverage by ensuring rare disease patients do not face arbitrary access restrictions that steer individuals and families into tax-payer funded healthcare.
-

Chairman Blunt and Ranking Member Murray, thank you for the opportunity to present the views of the U.S. Hereditary Angioedema Association (HAEA) on funding for NIH and CDC during consideration of fiscal year 2019 L-HHS appropriations. The HAEA is a patient-driven organization comprised of affected individuals and their families. In this regard, we would primarily like to recognize this Subcommittee for its leadership and commitment to providing medical research and public health programs with notable funding increases for fiscal year 2018. This investment will have a tangible positive impact for patients by significantly improving scientific inquiry and public health activities.

The HAEA is a non-profit patient advocacy organization dedicated to serving the estimated 6,000 HAE sufferers in the U.S. We provide a support network and a wide range of personalized services for patients and their families. We are also committed to advancing clinical research designed to improve the lives of HAE patients and ultimately find a cure.

Hereditary angioedema (HAE) is a painful, disfiguring, debilitating, and potentially fatal genetic disease that occurs in about 1 in 30,000 people. Symptoms include episodes of swelling in various body parts including the hands, feet, face and airway. Patients often have bouts of excruciating abdominal pain, nausea and vomiting that is caused by swelling in the intestinal wall. The majority of HAE patients experience their first attack during childhood or adolescence. Approximately one-third of undiagnosed HAE patients are subject to unnecessary exploratory abdominal surgery. About 50 percent of patients with HAE will experience laryngeal edema at some point in their life. This swelling is exceedingly dangerous because it can lead to death by asphyxiation. The historical mortality rate due to laryngeal swelling is 30 percent.

RESEARCH THROUGH THE NATIONAL INSTITUTES OF HEALTH

There was a time not long ago that HAE was a debilitating, and often life-ending, chronic disease. In addition to the serious health impacts, affected individuals suffered with trauma, anxiety, and PTSD stemming from torturous attacks (and the uncertainty of when the next attack might occur). Due to advancements in medical research, HAE patients now have access to life-altering and life-sustaining medications. Managing the disease properly now allows many the freedom to work productively, live independently, and thrive.

While we are appreciative of the scientific progress, there is much more that needs to be done. There is no cure of HAE, and treatment is highly individualized. Little is known about the underlying science of this disease and successful treatment often involves personalized care and a customized therapeutic regimen prepared by a leading physician expert (as well as trial and error).

NIH has a modest, but meaningful HAE research portfolio. Recent annual investments will facilitate growth in this portfolio and have led to important new scientific projects. The ongoing research at NIH (and complimentary research through the Department of Defense Peer-Reviewed Medical Research Program) will lead to a time when HAE patients can move beyond their disease. A notable funding increase for fiscal year 2018 and sustained increase for fiscal year 2019 will only accelerate this process and lower health costs by improving care for HAE patients.

CDC PUBLIC AWARENESS AND EDUCATION TO PREVENT HAE DEATHS

HAE patients often suffer for many years, and may be subject to unnecessary medical procedures and surgery prior to receiving an accurate diagnosis. Raising awareness about HAE among healthcare providers and the general public will help reduce delays in diagnosis and limit the amount of time that patients must spend without treatment for a condition that could, at any moment, end their lives.

Once diagnosed, patients are able to piece together a family history of mysterious deaths and episodes of swelling that previously had no name. In some families, this condition has come to be accepted as something that must simply be endured. Increased public awareness is crucial so that these patients understand that HAE often requires emergency treatment, and disabling attacks no longer need to be passively accepted. While HAE cannot yet be cured, the use of available treatments can significantly improve quality of life. Physician education and public awareness is needed to prevent unnecessary suffering and ensure an early and accurate diagnosis.

PROPER HEALTH COVERAGE AND ACCESS

One of the most serious health issues impacting the HAE community is the ongoing and increasing denial/restriction of payment assistance, particularly charitable assistance. In both fiscal year 2016 and fiscal year 2017, this Subcommittee asked

CMS to provide a justification for why rare disease patients would have the ability to receive charitable assistance restricted, and encouraged the elimination of arbitrary barriers to protect individuals that rely on life-sustaining medication, including the HAE community. To our knowledge, no action has been taken and no explanation was ever provided. Without charitable assistance, many HAE patients have no other options to access treatments. This restrictive situation continues to increment each year and adversely impacts families affected by HAE. Please, once again, encourage CMS to positively resolve this issue for rare disease patients or otherwise provide substantive feedback.

MARY GAIL RUNYAN'S STORY

My name is Mary Gail Runyan. I am a Hereditary Angioedema (HAE) patient/caregiver. HAE is a very rare, severe, and potentially life-threatening genetic condition that occurs in about 1 in 10,000 to 1 in 50,000 people. HAE symptoms include painful and disabling episodes of edema (swelling) in all body parts including the abdomen. Throat swelling can close the airway and cause death by asphyxiation.

I have lost a grandfather and two uncles due to asphyxiation caused by Hereditary Angioedema. At the time of their deaths the much-needed preventative and acute treatment for HAE was not available. This certainly isn't the case now. Our HAE community is so fortunate to have many different options available.

I have personally experienced several laryngeal attacks before the availability of FDA approved treatments for HAE. These life-threatening attacks made me realize how precious life truly is and how quickly life can be taken away. A treatment plan for those of us who have HAE is critical.

Because of advances in science and research in HAE, I no longer live in fear of the "what ifs" of HAE. I no longer spend countless hours in the ER waiting to be treated for an attack or hospitalization. I am no longer secluded in my home for days not wanting to be seen because of disfiguring facial swelling caused by HAE.

I am pleased to announce that I can now prevent my attacks by self-infusing at home, and I am living my life to the fullest! Nevertheless, so much remains to be done! On behalf of my family and the HAE community, I encourage the Committee to fund education, awareness and research initiatives for Hereditary Angioedema.

[This statement was submitted by Anthony Castaldo, President, U.S. Hereditary Angioedema Association.]

PREPARED STATEMENT OF THE UNITED TRIBES TECHNICAL COLLEGE

United Tribes Technical College (UTTC) has for 49 years, and with the most basic of funding, provided postsecondary career and technical education and family services to some of the most impoverished high risk Indian students from throughout the Nation. Despite such challenges we have consistently had excellent retention and placement rates and are fully accredited by the Higher Learning Commission. We are proud of our role in helping to break generational poverty and in helping to build a strong Indian Country middle class by training the next generation of law enforcement officers, educators, medical providers, and administrators; however, there is a long way to go and we need to expand our efforts. We are governed by the five tribes located wholly or in part in North Dakota. We are not part of the North Dakota University System and do not have a tax base or State-appropriated funds on which to rely. The funding requests of the UTTC Board for fiscal year 2019 are:

- \$10 million for base funding authorized under Section 117 of the Carl Perkins Act for the Tribally Controlled Postsecondary Career and Technical Institutions program. This is \$500,000 above the fiscal year 2018 enacted level. These funds are awarded competitively and distributed via formula. We would like a change to the formula that is not so reliant on Indian Student Count in order to avoid dramatic swings in annual awards.
- \$35 million in discretionary funds as requested by the American Indian Higher Education Consortium for Title III-A (Section 316) of the Higher Education Act, \$3.5 million above the fiscal year 2016 level.
- Sufficient funding for the Pell Grant program to provide the maximum grant. For fiscal year 2018, the Pell Grant program was funded at a level sufficient to, when combined with mandatory funding, provided the maximum Pell Grant award of \$6,095.

Tribally Controlled Career and Technical Institutions. UTTC appreciates the \$1.2 million increase for Section 117 Perkins in fiscal year 2018. We all realize the urgent need to better prepare a workforce to meet industry and other emerging needs.

We are part of that undertaking, but need more resources to come closer to our potential.

Acquisition of additional base funding is critical. We struggle to maintain course offerings and services to adequately provide educational services at the same level as our State counterparts. Perkins funds are central to the viability of our core post-secondary education programs. Very little of the other funds we receive may be used for core career and technical educational programs; they are competitive, often one-time targeted supplemental funds. Our Perkins funding provides a base level of support while allowing the college to compete for desperately needed discretionary funds.

We highlight several recent updates of our curricula to meet job market needs. First, at the certificate level, UTTC recognized the need for more certified welders and heavy equipment operators in relation to the oil boom and expanded these programs in response to the workforce need. UTTC is now the only welding test site in a multi-State region approved by the American Welding Society, and while the North Dakota Bakken oil boom has diminished, these professions remain in demand. We are now able to train students for good paying in-demand employment with a focus on career rather than just a job. We are also partnering with Lake Region State College of the North Dakota University System to enhance our Justice programs through the sharing of faculty and resources. This is in part in response to the unintended consequences of the oil boom in North Dakota such as increases in crimes and substance abuse (opioid, methamphetamine, and heroin) and the resulting social ills such as human trafficking and domestic violence.

Funding for United Tribes Technical College is a good investment. We have:

- Higher Learning Commission Accreditation through 2021. A campus site visit held in April 2017 indicated we have a firm foundation for furthering efforts as a data driven institution. We offer 1 diploma, 4 certificates, 14 Associate degrees, and 4 Bachelor degree programs of study (Criminal Justice; Elementary Education; Business Administration; Environmental Science and Research). Business Management, Criminal Justice, and General Studies are fully available and offered online. UTTC continues to be the only TCU in the country approved by the Higher Learning Commission to offer full programs online.
- Services including a Child Development Center, family literacy program, wellness center, area transportation, K-7 BIE-funded elementary school, tutoring, counseling, family and single student housing, and campus security.
- A projected return on Federal investment of 20-1 (2005 study).
- From 2016-2017, UTTC had a fall to fall retention rate of 38.4 percent and a 2017 fall semester persistence rate of 49 percent. Of the 68 graduates in 2017, 45 students were employed, for a placement rate of 66 percent. Additionally, 14 of those graduates continued their education.
- Students from 51 tribes were represented at UTTC during the 2016 -2017 academic year.
- Our students are very low income, and 69.6 percent of our undergraduate students receive Pell Grants in 2016-2017.
- An unduplicated count of 557 undergraduate degree-seeking students and 4 non-degree seeking students; 1,382 continuing education students; and 28 dual credit enrollment high school students for a total of 1,571 of all students for 2016-2017.
- A critical role in the regional economy. A North Dakota State University study reports that the five tribal colleges in North Dakota made a direct and secondary economic contribution to the State of \$192,911,000 in 2016 and UTTC had a \$59.6 million dollar direct and secondary economic impact on the Bismarck/Mandan communities for the same period.

Title III-A (Section 316) Strengthening Institutions.—The Title III-A Strengthening Institutions funding is very important for all the tribal colleges and we support the American Indian Higher Education Consortium's request of \$35 million for discretionary funding, \$3.5 million above fiscal year 2018. This is in addition to the \$30 million in (Part F) mandatory funding. While these are not operational funds, they are critical for developmental activities and provide an opportunity for a modest amount of construction funding. Funds are distributed via a formula with up to 30 percent of funds authorized to be set-aside for competitive funding for facility construction and maintenance. We share with the other tribal colleges serious issues of inadequate physical infrastructure.

We are in need of additional student family housing as our waiting list averages 49 student families over the course of the year. Students who do not receive campus housing rent in Bismarck with average monthly rent ranging from a one bedroom at \$800/month to \$1,250 for a three bedroom apartment. Approximately 50 percent

of students are housed in the 100-year-old buildings of what was previously Fort Abraham Lincoln and the other 50 percent of students residing in homes donated by the Federal Government in 1973. These buildings require major rehabilitation.

Title III funds provide much needed support to strengthen academic offerings and infrastructure. Specifically, Title III has been instrumental in the College's efforts to provide Baccalaureate programs, online Associate programs, and increase the technology infrastructure necessary to support student learning and campus management functions. Professional development activities have been supported by Title III resulting in enhanced intellectual and technical capacity of faculty and staff.

Additional activities carried out with support of Title III funding have been associated with increasing the College's Institutional Resources capabilities in order to strengthen relationships with alumni and forming relationships with organizations and individuals who may become supporters of the College. With the current Title III award, the College is anticipating expanding academic offerings through the development of a Master's level program. The support of Title III will be critical for attaining accreditation approval, program development, and acquiring highly qualified faculty.

Pell Grants.—We support the fiscal year 2018 Appropriations providing a maximum Pell Grant award of \$6,095 (reflecting the combined discretionary and mandatory funding) that that Congress last year reinstated the year-found Pell Grant, thus allowing students the opportunity to earn a third semester of Pell Grant funding during an academic year. As noted above, 70 percent of our undergraduate students receive Pell Grants. This resource makes all the difference in whether many of our students can attend college.

Thank you for your consideration of the concerns of United Tribes Technical College.

[This statement was submitted by Leander R. McDonald, PhD, President, United Tribes Technical College.]

PREPARED STATEMENT OF VOICE FOR ADOPTION

Voice for Adoption (VFA) offers the following testimony requesting increased funds for the following five programs under the supervision of the Administration for Children and Families (ACF): Child Welfare Services (CWS), Promoting Safe and Stable Families, the Adoption and Kinship Incentives Fund, and the Adoption Opportunities Act.

In February, Congress passed the Family First Prevention Services Act (PL 115–123). The legislation has potential to expand services that can prevent the placement of children into foster care. It challenges States to reduce the number of children and youth in congregate placements. It will be a challenge to States to build the capacity and access to services (mental health, substance use, and in-home services) and to build the infrastructure of services and providers.

The challenge is against a backdrop of ever increasing foster care numbers driven by the opioid epidemic in parts of the country. Since 2012 the number of children in foster care has increased by 10 percent to 437,000 in 2016. VFA believes it is critical for Congress to fully fund six programs to both build capacity to effectively implement the Family First Act and help address the crisis many communities are facing as foster care placement demands explode.

The Family First Act provides funding for services to prevent the placement of children in foster care but does not fund services to prevent child abuse and neglect. Child welfare strategy must significantly increase funding for child abuse prevention.

VFA calls on Congress to fully fund Child Welfare Services from \$269 million to \$325 million and Promoting Safe and Stable Families from \$99 million in discretionary funding to \$200 million; increase funding to the Adoption Opportunities Act to \$60 million; fully fund the Adoption and Kinship Incentives Fund at \$75 million.

Impact of Opioids on Child Abuse and Neglect and Foster Care

Earlier this year HHS through the Secretary of Planning and Evaluation conducted an analysis of child welfare data and supplemented that work with field level research. Some of the key findings included:

- A 10 percent increase in overdose death rates correspond to a 4.4 percent increase in the foster care entry rate and a 10 percent increase in the hospitalization rate due to drug use corresponds to a 3.3 percent increase in the foster care entry rate.
- While in past drug epidemics family and communities could fill some of the gaps, today agencies report that family members across generations may be ex-

- periencing substance use problems forcing greater reliance on State custody and non-relative care.
- Parents using substances have multiple problems including domestic violence, mental illness, trauma history, and addressing substance abuse alone is unlikely to be effective.
- Substance use assessment is haphazard and there is a lack of “family-friendly” treatment that includes family therapy, child care, parenting classes and developmental services.
- There is a shortage of foster homes and this is exacerbated by the need to keep children longer in care which keeps existing homes full and unable to accept new placements.

FAMILY FIRST ACT

In fiscal year 2020, Families First will allow States to draw funds for children and families at risk of foster care. States taking the optional services will be limited to evidence-based services for families that need intervention, post-adoption, and reunification services. States must engage in and coordinate public-private agencies experienced with providing child and family community-based services, including mental health, substance use, and public health providers. There is a limited supply of foster homes and family-based aftercare support that can provide for post-discharge services for children leaving institutional care. Child welfare agencies need to find and support more family-based foster care homes. These four funds can help States develop evidence-based services that will meet the laws “well-supported,” “supported,” and “promising” standards and can assist the coordination of community based behavioral health and human services.

Child Welfare Services (CWS), Title IV-B part 1

We ask for \$325 million for Child Welfare Services, the full authorization and above the current total of \$269 million. Starting in fiscal year 2020, the Families First Act will allow States to draw funds for children and families at risk of foster care. CWS is flexible enough to allow States to test out and develop these services and provide the research required to meet these evidence standards.

Promoting Safe and Stable Families (PSSF), Title IV-B part 2

We also asking for full funding of \$200 million for Promoting Safe and Stable Families. Currently this appropriations is set at \$99 million despite being authorized at \$200 million. These funds supplement \$345 million in mandatory funds divided between services, the courts, substance use treatment grants and workforce development. Appropriations to \$200 million could be used for the four key services under PSSF: family reunification, adoption support, family preservation and family support. There are limited services for reunification services for children who return to their families and the same is true of post adoption services. These will all be eligible services under Family First but there are few models now eligible for funding.

The Adoption Opportunities Act

The Adoption Opportunities program is the Nation’s oldest adoption program created to develop adoption promotion, post adoption services and strategies. It has funded grants to reduce barriers to adoption, reduce disproportionality, and more recently to promote adoptions of older youth in foster care and develop post-adoption services. It is funded at \$39 million. We ask for funding at \$60 million to develop evidence-based models for post adoption services to families.

The Adoption and Kinship Incentive Fund

We ask for a continued funding level of \$75 million for the adoption incentive fund. The fund was created in the Adoption and Safe Families Act (ASFA). In 2014 it became the Adoption and Legal Guardianship Incentive Payments Program. We thank the Appropriations Committee for partially addressing a recent shortfall in this incentive fund with the 2018 appropriations of \$75 million. In recent years HHS has been not been able to fully award States because of a reduced appropriation. As a result, HHS has made up the previous year’s shortfall with the following year’s appropriations. The \$75 million for fiscal year 2018 was a significant step in addressing the shortfall of 2017. In the beginning years Congress would recognize this and provide an extra amount of appropriation. Your 2018 appropriation reestablished this practice. When HHS issues the latest awards for fiscal year 2018, this September, there will have \$25 million remaining. That will likely fall short to fully fund the incentives. And we again ask for an appropriation of \$75 million to fully fund 2018 awards and have enough in place for fiscal year 2019.

These funds are reinvested by States into adoption services. These funds can be used by States to build both the evidence-based adoption services include post-adoption counseling and services that can prevent and reduce adoption disruption. VFA thanks you for this consideration and stands ready to respond to your questions and concerns.

[This statement was submitted by Schylar Baber, Executive Director, Voice for Adoption.]

PREPARED STATEMENT OF THE WASHINGTON STATE LONG-TERM CARE OMBUDSMAN PROGRAMS

Chairman Blunt and Ranking Member Murray, I am pleased to present this testimony on behalf of the nearly 72,000 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 vulnerable citizens that it serves, and for the \$1 million increase for the program in the Consolidated Appropriations Act, 2018. I submit this statement and the funding recommendations for the fiscal year 2018 for SLTCOPs administered through the Administration for Community Living, in the Department of Health and Human Services to include:

- \$5 million under the Elder Justice Act
- An additional \$19.98 million for assisted living ombudsman services under Title VII and,
- \$17.78 million under Title VII of the Older Americans Act.

Long-term care ombudsmen help older adults and people living with disabilities have a good quality of life, receive quality care, and be treated with dignity. LTC Ombudsmen are paid professionals who recruit, train and oversee teams of local volunteers who want to give back to their communities. The advocacy we provide is the first line of protection for thousands of elders living in licensed long-term care facilities. Last year, volunteers in Washington donated approximately 39,000 hours of their time and skill to resolve complaints made to the program with a success rate of nearly 92 percent resolved. We save the State resources, by resolving complaints at the lowest level keeping them out of the expensive regulatory and legal systems. However, like our sister program's across the Nation, we are not able to keep up with consumer needs and growing costs which is of concern giving the aging of the baby boomer generation in the U.S.

In Washington and other States, the number of Assisted Living Facility residents has grown tremendously. By the end of 2018, Washington will have 2,000 additional assisted living facility beds but no expansion in ombudsman services. The growing number of long-term care residents makes it financially and resources to provide the cost saving advocacy services provided by LTC Ombudsman Programs.

To alleviate the effects of diminished budgets and expanding long-term care populations, we respectfully request the following funding to support all SLTCOPs.

First, we request \$5,000,000 to support the work of SLTCOPs under the Elder Justice Act (EJC). This appropriation would allow States to hire and train staff and recruit more volunteers to prevent abuse, neglect, and exploitation of residents and investigate complaints. However, the funds have been authorized since 2010, to date no EJC funds have been appropriated for SLTCOPs. Second, we request \$19,980,000 to support SLTCOP work with residents of assisted living, board and care, and similar community-based long-term care settings. While the mandate to serve residents in assisted living facilities was added to our mission Act, there have been no appropriations for this function. Assisted living and similar businesses have boomed, but SLTCOP funding has not increased to meet the demand and respond to the industry boom.

Washington State has demonstrated leadership by reducing costs in their Medicaid system, while improving consumer choice in community based long-term. Assisted living has proven to be a viable option for those who qualify for more costly nursing home care, but wish to exercise their choice to live in assisted living. Assisted living residents have complex medical needs, very much like the nursing home residents of 20 years ago. Growth in the number of assisted living facilities, in conjunction with complex needs of consumers and diminished funding, threatens our Nation's Long-Term Care Ombudsman Programs. These challenges to State Programs hinder our ability to meet program requirements to provide regular and timely access to all residents wanting long-term care ombudsman services. Current funding levels preclude SLTCOPs from quickly responding to complaints and monitoring facilities. Without our eyes and ears in these buildings, residents are at risk of abuse, neglect, and serious financial exploitation, and any number of violations to

their rights. Our third request is for \$17.784 million, which is level funding for the core program under Title VII of the Older Americans Act.

In addition to improving the quality of life and care for millions of vulnerable long-term care residents, our work saves Medicare and Medicaid funds by avoiding unnecessary costs associated with poor quality care, unnecessary hospitalizations and expensive procedures and treatments. Furthermore, nationally in 2016, nearly 7,331 volunteers served in the SLTCOP. For every one staff ombudsman, six volunteer ombudsmen serve residents. Ombudsman staff and volunteers investigated 199,493 complaints made by 129,559 individuals. Ombudsmen were able to resolve or partially resolve 74 percent—or an ombudsman resolved three out of every four complaints investigated.

In 2017, Washington State had 3,577 long-term care facilities with approximately 70,000 residents. Our state program includes myself, and two other full time staff, which has not changed much since 1989. Thankfully, we have great partnerships with other not-for-profits to operate local ombudsman programs, extending our reach into the most isolated of nursing home residents in our rural communities. These partners include seven Area Agency on Aging entities and three Community Action Programs and in total, we employ 17.12 full-time staff. Two national studies about the effectiveness about the LTC Ombudsman Program (the Institute of Medicine, and the Bader Report) have recommended that best practice be to employ one full-time paid staff ombudsman for every 2,000 long-term care residents or licensed beds. Washington State falls short of that goal at having only 49 percent of the needed paid staff.

Although we have a great team of paid and volunteer ombudsmen, our program is still not able to cover every facility in our State. Nearly half of the licensed facilities in our State never receive routine visits by an ombudsman, which is the hallmark activity of the Program and vital to building trusting and effective working relationships. We are so busy responding to complaints and phone calls that we are not able to conduct regular outreach, build presence in all facilities, and make our services known to isolated residents and their family members. We are overwhelmed with complaints about unwanted and unlawful discharges, also known as, “resident dumping” by residents, their loved ones and by hospitals, which involves expensive legal issues, interactions with multiple health and long-term care community systems, state entities and the courts.

Currently, Federal Older Americans Act funding comprises about a third of the total funding required to maintain the Washington Long-Term Care Ombudsman Program, at its current level, with the majority of funding coming from our State General Funds. We understand that this subcommittee faces a strained financial situation, but a continued commitment to SLTCOPs protects the health and safety of millions of older adults living in nursing homes and assisted living facilities. I believe their protection should remain a high priority.

Demand for our services is growing. The number of complex and very troubling cases that long-term care ombudsmen investigate has been steadily increasing. In addition, there continues to be a disturbing increase in the frequency and severity of citations for egregious regulatory violations by long-term care providers that put residents in immediate jeopardy of harm, which, unfortunately, is true for nursing homes in my State. Ombudsmen are needed now more than ever in nursing homes, assisted living, and similar care facilities where we are required to serve.

The people who operate long-term care facilities have recognized the value and benefit of having ombudsmen assist with staff training and consultation. In order to improve advocacy and services available to residents, our office and NASOP respectfully request the aforementioned funding levels. We also appreciate that the testimony of the Elder Justice Coalition also calls for these increases.

Thank you for your ongoing support.

[This statement was submitted by Patricia L. Hunter, Member, National Association of State Long-Term Care Ombudsman Programs.]

PREPARED STATEMENT OF WORLD VISION US

Mr. Chairman, Ranking Member Murray, and members of the Subcommittee, I am submitting this testimony for your consideration on behalf of World Vision, one of the largest faith-based organizations working in humanitarian relief and development. Specifically, I ask that the Subcommittee seek to fund the Department of Labor’s Bureau for International Labor Affairs (ILAB) at \$91.125 million, including \$58.825 million for the child labor grants program, \$7.5 million for the worker rights program, and \$6.04 million for program evaluation.

World Vision US has more than one million private donors in every State and Congressional district, partners with over 16,000 churches in the United States, and works with a wide variety of corporations and foundations. We are motivated by our Christian faith to serve every child in need and their family; those of any faith, or none. We partner with faith leaders throughout the world, equipping them to meet the needs of their communities.

We are part of a global World Vision Partnership, which implements programming to help children, families and communities through international relief, development, and advocacy assistance. Although private donors support the foundation of our work, the U.S. Government is an invaluable partner as we work to achieve our broad goals for children. We leverage this partnership to reach vulnerable children and families in nearly 100 countries around the world, ensuring that the precious resources of the American taxpayer are prudently used to promote and protect the well-being of children and communities abroad.

We also use this partnership with the U.S. Government to leverage private funding. We've successfully used grant funded programs to spur private fundraising from both corporations and individuals and to leverage and integrate resources in a way that ensures taxpayer dollars go further. Through World Vision's work around the world, we see the impact that violence and exploitation can have on children and their families. 73 million children are in hazardous child labor which prevents them from attending school and is harmful to their physical, mental, and social development. Boys and girls around the world work in agriculture, mining, quarrying, fishing, factories, domestic work, and commercial sexual exploitation. 4.3 million children are in forced labor, including in situations of trafficking. The work of Department of Labor's Bureau of International Labor Affairs and its partners protect children from exploitation and violence, allowing them the opportunity to fulfill their full potential and contribute positively to their communities and countries. This work also supports the U.S. Government's Action Plan for Children in Adversity (APCA), which is a whole-of-government framework for providing protective family care and an environment for children that is free from deprivation, exploitation, and danger. ILAB's anti-child and forced labor work encourages global economic growth and addresses exploitative business practices that undercut American workers and companies.

Our global economy feels the impact of violence against and exploitation of children. The economic costs of child labor amount to 2.4–6.6 percent of the world's gross national income annually. The global income lost by children out of school and instead engaged in hazardous work amounts to \$176 billion annually. Child labor impacts the economies of U.S. Government trading partners and the investments the U.S. Government makes in other areas of development and trade. Child labor depresses wages and earning potential of future workers, keeping economic growth and achievement of development objectives stagnant. The cost to children, communities, and the global economy is too great for the U.S. Government to step back from its leadership role in ending child labor and forced labor.

Since 1995, the Department of Labor through the Bureau for International Labor Affairs' Office of Child Labor, Forced Labor, and Trafficking has worked with partners to directly impact the lives of nearly two million children vulnerable to exploitative labor, combat forced labor, and address worker rights in countries with which the United States has trade agreements or preference programs. To address child labor, ILAB programs take a holistic approach, including community and government involvement to increase access to education for children and support livelihood opportunities for families to meet basic needs and reduce reliance on child labor. ILAB has been a leader in the global fight to end child labor. Since 2000, child labor has been reduced by half globally, in no small part due to the efforts of the U.S. through ILAB.

World Vision is one of many ILAB partners working to address hazardous child labor through education interventions, strengthening family livelihoods, increasing accountability of employers towards child labor standards, and sustainably building the capacity our local and national governments of countries which the U.S. has trading relationships with. For example, in Ethiopia, World Vision is working to address exploitative child labor by helping youth ages 14–17 develop marketable skills to secure appropriate work and serve as community leaders. The project aims to reach 12,000 Ethiopian male and female youth, both in school and out of school, and their 7,500 households. In the Philippines, World Vision, through funding from the Bureau for International Labor Affairs, implemented the ABK3 Livelihoods, Education, Advocacy, and Protection to Reduce Child labor in Sugarcane Areas (ABK3 LEAP) project from 2011 to 2015. The project reduced child labor in target communities by 86 percent while providing education opportunities and necessary resources for families to keep children out of hazardous forms of work.

In the Philippines, the perceived (or real) lack of quality education, difficulty staying caught up with class work, and economic drivers contributed to child labor and school dropout. To address these challenges World Vision worked with 12,310 students in over 250 schools to help struggling learners revive their interest and improve their participation in school through the Catch-Up program. Catch-Up complemented learning in the classroom and was notably important during the start of the sugarcane harvest season when students are more likely to work in the field after school with some eventually dropping out of school. The Catch-Up program trained peer teachers (Little Teachers) to support students who were struggling in their studies and boosted students' confidence in their skills while promoting engagement with learning material in the classroom. As a result, junior high school enrollment increased by 36 percent between 2012 and 2015. In the 2014–2015 school year, school attendance increased and the number of students dropping out decreased to nearly zero. The number of children who did not repeat a year level in school increased by 10 percent in 2015. This innovative and effective outreach to struggling students significantly contributed to the success of the project in reducing child labor and increasing school enrollment.

While we acknowledge the constraints and challenges of our current fiscal climate, ILAB's grant program supports economic growth for our trade partners and ensures our trade partners are effectively implementing labor standards. ILAB combines understanding the problem of child labor and forced labor through research with targeted, effective action to measurably reduce child labor and forced labor. Past proposals to end ILAB's programming to combat exploitative child labor would functionally end all U.S. programming to reduce international child labor and would directly impact the roughly 150,000 children annually who benefit from ILAB funding. ILAB's grant program not only benefits the children and families we serve, but creates the opportunity for American workers and companies to compete more effectively in the global economy.

As an organization that has worked with ILAB we can attest to the rigor of their programs and the critical support that their staff provide. ILAB is among the most rigorous donors that we work with, requiring a level of evaluation to ensure effectiveness that is not found in many other donors. They are setting a high standard for the effective and targeted use of U.S. taxpayer dollars. After more than 20 years addressing child labor and forced labor, ILAB's work is an asset to the U.S. Government and provides leadership in international arenas. Presently, eight U.S. offices within the Department of State, USAID, and the Department of Labor fund programs that focus or include a component on ending violence against children globally. Almost 50 percent of spending in fiscal year 2015 to end violence against children came from ILAB. As the subcommittee considers funding levels for fiscal year 2019, we hope you will take into consideration the impact of ILAB programs and the value they provide in building a better world for children and for American workers and companies.

The number of children in child labor is declining but progress has slowed significantly—child labor only declined by 9.7 percent from 2012–2016 compared to 22 percent during the 4 years prior. If progress continues at the current pace, 121 million children will still be engaged in child labor in 2025. It will take an extra push in the coming years not only to renew the rate at which we fight child labor, but also to reach the most vulnerable children, in the hardest to reach places. I ask that the Subcommittee seek to fund the Department of Labor's Bureau for International Labor Affairs at \$91.125 million for the Bureau of International Labor Affairs, including \$58.825 million for the child labor grants program, \$7.5 million for the worker rights program, and \$6.04 million for program evaluation.

Thank you for the opportunity to provide written testimony and for considering this request.

[This statement was submitted by Robert Zachritz, Vice President, Advocacy and Government Relations, World Vision US.]

PREPARED STATEMENT OF THE ZIKA COALITION

Zika Coalition: Fiscal Year 2019 Federal Funding Priorities

| Program | Fiscal Year 2019 Request |
|--|--------------------------|
| National Institutes of Health (total) | \$39,300,000,000 |
| National Institute of Child Health and Development | \$1,531,000,000 |
| National Institute of Allergy and Infectious Disease | \$5,550,000,000 |

Zika Coalition: Fiscal Year 2019 Federal Funding Priorities—Continued

| Program | Fiscal Year 2019 Request |
|--|--------------------------|
| Zika in Infants and Pregnancy (ZIP) Study (NICHD/NIAID) | \$5,000,000 |
| Center for Disease Control and Prevention | |
| National Center for Birth Defects and Developmental Disabilities | \$150,600,000 |
| Zika Response Activities | \$10,000,000 |
| National Center for Emerging and Zoonotic Infectious Diseases | \$615,000,000 |
| Public Health Emergency Preparedness Cooperative Agreement | \$824,000,000 |
| Health Resources and Services Administration | |
| Title V Maternal and Child Health Block Grant | \$660,000,000 |

On behalf of the Zika Coalition, a group of organizations representing patients, healthcare providers, persons with intellectual and developmental disabilities, public health, and businesses, we urge you to include ample funding to combat the Zika virus in the fiscal year 2019 appropriations bills. Zika virus remains a significant public health concern, particularly in areas impacted by hurricanes and flooding in 2017.

Even with the number of reported infections dropping, Zika continues to be a threat. Public health entities must educate their communities on the danger of the virus and how to avoid it, while State, local and tribal governments must implement and continue robust vector control programs. At the same time, impacted children and their families continue to need significant medical and educational interventions and other supports. In order to address these complex needs, we request that the following programs be funded at the levels specified below in the fiscal year 2019 Labor, Health and Human Services, Education, and Related Agencies (Labor-HHS) Appropriations Bill.

- National Institutes of Health (NIH)—\$39.3 billion, with \$5.55 billion for the National Institute of Allergy and Infectious Diseases (NIAID) and \$1.53 billion for the Eunice K. Shriver National Institute of Child Health and Human Development (NICHD)

Thanks to previous Federal investment, NIH is making tremendous progress in the prevention, diagnosis and treatment of the Zika virus. NIAID continues its work on a vaccine and other preventive measures, while NICHD is investigating how Zika virus affects reproductive health and pregnancy. However, this work is at a critical juncture and may not be able to continue without sustained funding.

Within NIH, we specifically request \$5 million in continued funding for the Zika in Pregnancy (ZIP) Study, which is conducted as a partnership between NICHD and NIAID. With previous Federal funding, this multi-country study has enrolled over 5,000 pregnant women and their children. Sustained funding will allow for continued surveillance of enrolled families to determine the long-term impacts of Zika on child development.

- Centers for Disease Control and Prevention’s (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD)—\$150.6 million

NCBDDD is the lead Federal agency carrying out critical surveillance, research, education and prevention activities concerning birth defects and developmental disabilities. As such, it has played a critical role in developing our knowledge about the virus and its impacts. Since the outbreak of Zika, the Center has built rapid response birth defects surveillance systems in 50 jurisdictions, coordinated efforts to educate families and providers about preventing Zika infection and caring for impacted families, and supported public health research.

We are pleased that the President’s Budget requested an additional \$10 million to carry out Zika-related surveillance and continue the Zika pregnancy registry. We ask that these funds be preserved as this work is critical in understanding the long-term impacts of the virus.

- CDC’s National Center for Emerging and Zoonotic Infectious Diseases (NCEZID)—\$615 million

NCEZID houses the CDC’s program charged with detecting and responding to infectious disease outbreaks, including Zika. The Center has been critical in the fight against the Zika virus by supporting local surveillance and vector control programs and providing guidance on laboratory testing for Zika. Within NCEZID, the Epidemiology and Laboratory Capacity (ELC) cooperative agreement is central to ensuring State, local, tribal and territorial governments have

the necessary public health workforce, disease detection systems, laboratory capacity and health information dissemination abilities to combat the Zika threat. In order to sustain this important work, we ask that NCEZID be funded at \$615 million, with \$46 million designated for vector control.

—CDC’s Public Health Emergency Preparedness Cooperative Agreement (PHEP)—\$824 million

PHEP supports State, local, tribal and territorial public health departments’ ability to respond to public health crises, including Zika. Increased funds help communities maintain systems to identify and investigate a Zika outbreak, coordinate response with both government and non-government entities, and purchase and distribute Zika Prevention Kits that include insect repellent, window screens and other supplies. The services provided through PHEP are especially important in areas hit by natural disasters such as hurricanes and/or flooding. The Zika Coalition requests \$824 million for these important response efforts.

—HRSA’s Title V Maternal & Child Health Services Block Grant—\$660 million

The Title V Maternal & Child Health Services Block Grant (Title V) is distributed to 59 States and jurisdictions to address the health needs of mothers, infants and children, including children with special healthcare needs and their families. Title V programs have supported the response to Zika by disseminating public health information and prevention tools and supplies to providers and the public; providing technical expertise to support pregnancy registries and conduct ongoing birth defects surveillance; and handling newborn screening follow-up and connecting affected families with appropriate community resources. The Coalition is grateful for the increase in funding in fiscal year 2018; however, the President’s budget request would consolidate several other programs into the Block Grant program, stretching limited resources even further, and making it even more necessary to maintain funding in fiscal year 2019. We urge you to increase funding for Title V in fiscal year 2019.

The Zika Coalition stands ready to work with you throughout the appropriations process to ensure that our country’s resources to fight the Zika virus and mitigate its impacts are adequately funded. For more information, please contact Cynthia Pellegrini, Senior Vice President for Public Policy and Government Affairs, March of Dimes, at cpellegrini@marchofidmes.org.

ZIKA COALITION MEMBERS

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| AABB | Association of Reproductive Health Professionals |
| American Association for Clinical Chemistry | Association of Schools and Programs of Public Health |
| American Association for Pediatric Ophthalmology and Strabismus | Association of State and Territorial Health Officials |
| American Association of Colleges of Pharmacy | Association of University Centers on Disabilities |
| American Association on Health and Disability | Association of Women’s Health, Obstetric and Neonatal Nurses |
| American Clinical Laboratory Association | Avery’s Angels Gastroschisis Foundation |
| American College of Nurse-Midwives | Big Cities Health Coalition |
| American College of Preventive Medicine | Children’s Environmental Health Network |
| American Congress of Obstetricians and Gynecologists* | Commissioned Officers Association of the U.S. Public Health Service, Inc. (COA) |
| American Medical Association | Community Action Partnership |
| American Public Health Association* | Cooley’s Anemia Foundation |
| American Sexual Health Association | Council of State and Territorial Epidemiologists |
| American Society for Reproductive Medicine | Easterseals* |
| American Society of Tropical Medicine and Hygiene | Endocrine Society |
| Association for Professionals in Infection Control and Epidemiology | Epilepsy Foundation of New Jersey |
| Association of American Veterinary Medical Colleges | Every Child By Two |
| Association of Maternal & Child Health Programs* | Family Voices |
| Association of Public Health Laboratories* | GBS CIDP Foundation International |
| | Genetic Alliance |
| | Grifols |
| | Healthcare Ready |
| | Infectious Diseases Society of America* |
| | Johnson & Johnson |

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| March of Dimes* | Pregistry |
| National Association of County and City Health Officials* | Public Health Institute |
| National Association of Pediatric Nurse Practitioners | Research!America |
| National Birth Defects Prevention Network | RESOLVE: The National Infertility Association |
| National Coalition of STD Directors | Society for Maternal-Fetal Medicine |
| National Environmental Health Association* | Society for Women's Health Research |
| National Foundation for Infectious Diseases | Spina Bifida Association |
| National Hispanic Medical Association | Teratology Society |
| National Indian Health Board | The American Society for Clinical Pathology |
| National Mosquito Control Association | The Arc* |
| National Organization for Rare Disorders (NORD)* | The National Campaign to Prevent Teen and Unplanned Pregnancy |
| Newborn Foundation | The Society for Healthcare Epidemiology of America |
| Novavax | Trisomy 18 Foundation |
| OraSure Technologies | Trust for America's Health* |
| Organization of Teratology Information Specialists | University of South Florida Birth Defects Surveillance Program |
| | *designates Steering Committee Member |

[This statement was submitted by Cynthia Pellegrini, Senior Vice President, Public Policy and Government Affairs, March of Dimes.]