

**DEPARTMENT OF LABOR, HEALTH AND
HUMAN SERVICES, AND EDUCATION, AND
RELATED AGENCIES APPROPRIATIONS FOR
FISCAL YEAR 2018**

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 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 level funding of \$445 million for fiscal year 2020, \$55 million in fiscal year 2018 for the replacement of the public broadcasting interconnection system, and \$30 million for Ready To Learn at the Department of Education.

As we mark the 50th anniversary of the 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 enriches 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 is indispensable to sustaining the essential public service mission of America's public media stations defined by community-based accountability and universal service. CPB serves as the steward of the Federal appropriation, ensuring that 95 cents of every dollar we receive 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. The appropriation is vital seed money—especially for stations serving small towns and rural America, as well as those serving underserved populations where the appropriation can represent as much as 80 or even 100 percent of their budget.

Education is the heart of our mission. Public media reaches 68 percent of all children age two to eight, providing educational content and services that are proven to prepare them for school, especially those 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. More than 25 years ago, Congress recognized the reach and potential of public media to help disadvantaged children become better prepared to enter school. In 2015, Congress reaffirmed its support of Ready To Learn, furthering public media stations' and producers' work in coordinating and connecting STEM and literacy learning experiences for children across multiple platforms and outlets.

Our work does not end with early education. Through CPB's "American Graduate" initiative, public media focuses on addressing the crisis of one million young people failing to graduate from high school every year. Since 2011, more than 120 public media stations in 49 States have worked with 1,700 partners to raise awareness, attract mentors for young people, and create local solutions for long-term success. I am pleased to report that in 2015, the high school graduation rate rose to 83 percent for the first time in our Nation's history. As these new graduates continue their education through career, technical, or university instruction, public media will provide them with high quality content and resources to support their efforts.

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 and 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, locally owned and operated, also act as conveners, providing a multiplier effect in terms of content connected to engagement on issues of importance both locally and nationally.

Our 50-year old but evergreen mission directs us to tell America's constantly evolving story utilizing diverse voices and talents, to fund high quality educational, informational and inspirational content, to fund lifelong learning for our youngest and oldest citizens, and to invest in trusted journalism, locally, nationally and internationally. CPB fulfills its diversity mission, in part, by providing funding for the Independent Television Service, the five Minority Consortia entities in television, several public radio consortia, and numerous minority public radio stations. Moreover, CPB makes direct investments in the development of diverse primetime and children's broadcast programs as well as innovative digital content.

In this disruptive and fragmented media environment, public media's commitment to serving as a trusted source of information—providing in-depth factual coverage, 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. 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, the foundation upon which a well-functioning democracy depends.

Public media's mission is to deliver value to the American people in the form of content that gives them the information they need to understand our changing world, to raise their families, teach their children, improve their communities, spark intellectual curiosity and enhance daily life. Over the past 3 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 "Military Medicine: Beyond the Battlefield," which tells the personal stories of physicians, military personnel, wounded warriors and their families in terms of how medical advances are changing lives; as well as StoryCorps' Military Voices initiative and the annual Memorial Day and Fourth of July concerts broadcast and streamed by PBS to millions.

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.

SPECTRUM AUCTION

The vast majority of public television stations did not participate in the spectrum auction and will not receive auction proceeds, neither will CPB nor will PBS. By law, all spectrum auction proceeds will go to the nonprofit entity or State or local governmental body that holds the license for that station. License-holders can use the revenue in any manner it chooses—even for purposes outside of public broadcasting. For those stations that participated, this one time only influx of monies may allow the recipients to strengthen their financial foundation, enhance their local educational mission, and increase their service to their communities. But for all other stations and public media writ large, the continued Federal investment is essential to sustaining this valued service for all Americans.

Public television as well as some public radio stations will also bear the costs of the spectrum repacking process, and it is not certain that the \$1.75 billion that Con-

gress has set aside to cover the costs of the repack will be sufficient. Further, the spectrum auction process does not provide any financial assistance to public television stations for translators needed to change channels in the repack. This places an undue financial burden on those stations since they will assume the extra expense as they seek to ensure universal access.

INTERCONNECTION INFRASTRUCTURE

Interconnection is the backbone of the public media system. It delivers content from public media producers to public television and radio stations in communities throughout the country. Without it, there is no nationwide public media service. Congress, recognizing the need, has always funded public media's interconnection system; providing a separate appropriation for interconnection since fiscal year 1991. As we near the expiration of public television and radio's interconnection systems, CPB has helped PBS and NPR to develop a plan for the most cost effective and efficient delivery system possible.

CONCLUSION

CPB's fiscal year 2020 request of \$445 million and fiscal year 2018 requests of \$55 million and \$30 million for interconnection and Ready To Learn, respectively, balance the fiscal reality facing our Nation with our statutory mandate to provide a valuable and trusted service to all Americans. With your support, CPB will continue to serve as a trusted steward of the Federal appropriation; by investing these precious taxpayer dollars in ways that strengthen the health of our democratic system and 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: We are pleased to present the following information to support the Railroad Retirement Board's (RRB) fiscal year 2018 budget request of \$111,225,000 for our retirement, unemployment and other programs.

The RRB administers comprehensive retirement/survivor and unemployment/sickness insurance benefit programs for railroad workers and their families under the Railroad Retirement (RRA) and Railroad Unemployment Insurance (RUIA) Acts. The RRB also has administrative responsibilities under the Social Security Act for certain benefit payments and Medicare coverage for railroad workers.

During fiscal year 2016, the RRB paid \$12.5 billion, net of recoveries and offsetting collections, in retirement/survivor benefits to about 553,000 beneficiaries. This included benefits paid on behalf of the Social Security Administration amounting to \$1.5 billion to about 111,000 beneficiaries. The RRB also paid \$132.3 million in unemployment-sickness benefits net of recoveries and offsetting collections. About 17,000 railroad workers received unemployment insurance benefits, and approximately 17,000 received sickness benefits.

PROPOSED FUNDING FOR AGENCY ADMINISTRATION

The RRB faces major challenges in its mission to pay benefits and serve as responsible stewards for our Customer's Trust funds and agency resources. Those areas of challenge include agency staffing and information technology. The President's proposed budget would provide \$111,225,000 for agency operations. At this level, no funding is included toward a multi-year plan to re-engineer legacy mainframe applications while funding 798 full-time equivalents (FTEs). The remainder of this testimony will focus on these areas with a few additional topics in conclusion.

AGENCY STAFFING

The RRB's dedicated and experienced workforce is the foundation for our tradition of excellence in customer service and satisfaction. About seventy-percent of our administrative expense is for labor. Based on trend analysis of full-time equivalent (FTE) reporting of attritions and accessions from 2010 through 2017, the RRB has attrited half of its agency. Like many Federal agencies, the RRB also has a number

of employees at or near retirement age. About 50 percent of our employees have 20 or more years of service, and nearly 29 percent of our current workforce will be eligible for retirement by fiscal year 2018. The FTE level the RRB can fund for the fiscal year 2018 President's Budget is 798 and it will be difficult to get to this FTE level and sustain vital beneficiary services. The RRB recognizes the ongoing need and responsibility to manage our human capital resources effectively through focused workforce planning and talent management efforts combined with identifying information technology improvements and initiatives to better support a leaner agency, while achieving the agency's mission.

INFORMATION TECHNOLOGY IMPROVEMENTS

The President and the Office of Management and Budget (OMB) have challenged agencies to be effective and efficient. The RRB has chosen to be progressive in implementing initiatives and improvements. In fiscal year 2016, about \$1.9 million in IT funding was targeted toward system modernization to re-engineer mainframe applications. Fiscal year 2017 continuing resolution and the enacted Consolidated Appropriations Act, 2017 funding provided for very limited IT investments. As a result, in the current year the RRB may be taking on risk in support of the agency's critical need to migrate over 14 million lines of COBOL code that support more than 4,200 custom programs included in 200 major application systems. We awarded a contract in fiscal year 2015 to implement the code conversion, subject to funds availability. We assumed risk in our fiscal year 2016 Operating Plan to leverage funds of about \$1.9 million towards the code conversion project contract to mitigate the cybersecurity risks of operating legacy systems, enhance data analytics capabilities towards stronger program integrity measures, and create FTE savings that can be accrued from changes in business processes. In addition, a large number of the agency's technology employees are at or nearing retirement age, so the skills required to enhance and maintain legacy benefit systems, especially developers with COBOL skills, will be hard to find. Given that technology advances rapidly, it is essential that we have the ability to modernize business applications.

Fiscal year 2018 funding for the code conversion project, if received, will re-engineer critical legacy mainframe applications to sustain agency operations and enable a RRB workforce equipped with modern tools and technologies to do their jobs in the most efficient and effective manner. Each year that enacted funding does not equal the agency's request for system modernization; the contract work will stop, which jeopardizes the success of the project.

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 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, 2016, was approximately \$25.1 billion, an increase of almost \$0.6 billion from the previous year. Through March 1, 2017, the Trust had transferred approximately \$20.1 billion to the Railroad Retirement Board 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 2016. 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 2016. The report indicated that even as maximum daily benefit rates are projected to rise approximately 36 percent (from \$72 to \$98) from 2015 to 2026, 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 2018 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 2018, 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 the Office of Audit (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 2018, 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 Act of 2010 Oversight.

OA must also accomplish the following mandated activities with its own staff: Audit of the RRB's financial statements pursuant to the requirements of the Ac-

countability of Tax Dollars Act of 2002; evaluation of information security pursuant to the Federal Information Security Management Act (FISMA); audit of the RRB's compliance with the Improper Payments Elimination and Recovery Act of 2010; review of IG Requirements for Government Charge Card Abuse and Prevention Act of 2012; identification of Performance and Management Challenges for fiscal year 2017; and semi-annual reporting in accordance with the Inspector General Act of 1978, as amended.

During fiscal year 2018, OA will complete the audit of the RRB's fiscal year 2017 financial statements and begin its audit of the agency's fiscal year 2018 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. In addition to performing the annual evaluation of information security, OA also conducts audits of individual computer application systems which are required to support the annual FISMA evaluation. Our 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 2016, nearly 50 percent of direct audit time was spent completing mandated audits, and this percentage will be notably higher in fiscal year 2017 as audit work related to the Data Act must be completed and there is continued expansion of FISMA reporting requirements. These are in addition to the significant resource investment in completing our mandated assignments. 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. Additional resources will make it possible for OA to provide additional oversight to these 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

The 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, administrative sanctions, civil penalties, and the recovery of program benefit funds for any program administered by the RRB.

OI initiates cases based on information from a variety of sources. The RRB conducts computer matching of employment and earnings information reported to State governments and the Social Security Administration with RRB benefits paid data. Fraud referrals are made to OI if a match is found. OI also receives allegations of fraud through the OIG Hotline, contacts with State, local and Federal agencies, and information developed through audits conducted by the OIG's Office of Audit.

Fraud referrals from the RRB have reduced over the last several fiscal years. The Inspector General Empowerment Act (IGEA) of 2016 strengthened an OIG's ability to identify fraudulent or improper government payments through data analytics. The OIG will continue their commitment to proactively designing 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 2016

Civil Judgments	Indictments/Informations	Convictions	Recoveries/Receivables
15	32	36	¹ \$25,700,000

¹This 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, which were included in the disposition resulting from the investigation.

OI anticipates an ongoing caseload of about 225 investigations in fiscal year 2018. During fiscal year 2016, OI opened 186 new cases and closed 246. As of April 1, 2017, OI had cases open in 42 States, the District of Columbia, and Canada with estimated fraud losses of over \$595 million. Disability and 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 Offices of Inspector General and Federal law enforcement agencies that have responsibility for healthcare fraud matters. Medicare fraud investigations currently represent approximately 23 percent of OI's total caseload and more than \$354 million in fraud losses. 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 continue to investigate fraud violations of railroad employees collecting unemployment or sickness insurance benefits while working and receiving wages from an employer. Unemployment fraud cases currently constitute 17 percent of the total caseload of our investigators.

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 also use 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 2018, 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 through OIG systemic implication reports 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 all fraud matters to the OIG.

CONCLUSION

In fiscal year 2018, 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 families. The OIG will also aggressively pursue all 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 AD HOC GROUP FOR MEDICAL RESEARCH

The Ad Hoc Group for Medical Research is a coalition of more than 300 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 \$2 billion increase provided in the final fiscal year 2016 spending bill, and by the Subcommittee's tireless efforts to continue this budget trajectory with another \$2 billion increase for NIH in fiscal year 2017.

The Ad Hoc Group is extremely concerned by the Administration's fiscal year 2018 budget proposal to reverse these investments in the NIH with a \$7.2 billion (21 percent) cut, which the Administration estimates would lead to approximately 2,000 fewer research grants compared to fiscal year 2016. Additionally, we urge you to reject problematic policy proposals in the Administration's budget that would disrupt critical research efforts and the support needed to discover tomorrow's cures. In addition to setting back medical progress, the budget proposal would undermine local and regional economies that benefit from the Nation's investment in research; United for Medical Research recently estimated that the president's proposal would lead to loss of 90,000 jobs and \$15 billion in reduced economic activity.

In a recent One Voice Against Cancer (OVAC) poll, more than two-thirds of voters said they oppose significant NIH funding cuts included in the president's fiscal year 2018 budget. Additionally, 90 percent of voters believe Federal funding for medical research is "very" or "extremely" important. Finally, 75 percent of those surveyed indicated they want Congress to significantly increase Federal funding for the NIH.

In fiscal year 2018, more than 300 organizations from the Ad Hoc Group recommend an increase of at least \$2 billion above fiscal year 2017 for NIH, in addition to funds included in the 21st Century Cures Act for targeted initiatives. This funding level would enable real growth over biomedical inflation as an important step to ensuring stability in the nation's research capacity over the long term. Moreover, our recommendation would help advance the scientific momentum envisioned by the 21st Century Cures Act—enacted with broad bipartisan support—in which the Innovation Account supplements the agency's base budget. Securing a reliable, robust budget trajectory for NIH will be 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.

Science and innovation are essential if we are to continue to meet current and emerging health challenges, improve our Nation's physical and fiscal health, and sustain our leadership in medical research. In order 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 predictable increases in the NIH budget.

NIH: A Public-Private 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 57,000 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 partnered with a pharmaceutical company to produce a naloxone nasal spray, the first easy-to-use, non-injectable version of a life-saving treatment for opioid or heroin overdoses. NIH-supported researchers collaborated with the pharmaceutical industry to develop 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.
 - Thanks to an unprecedented collaborative effort between NIH and industry, 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

Despite recent increases, over the past decade, NIH has lost nearly 20 percent of its budget after inflation, significantly impacting the Nation's ability to sustain the scientific momentum that has contributed so greatly to our Nation's health and our economic vitality. 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 predictable 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 the past decade is on the next generation of scientists, who has seen training funds slashed and the possibility of sustaining a career in research diminished. Of particular concern is the challenge of 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, but that capacity simply cannot weather repeated blows such as persistent below-inflation funding levels and sequestration cuts, which jeopardize our competitive edge in an increasingly innovation-based global marketplace. Other countries have significantly increased their investment in biomedical science. This shift in funding is creating an innovation deficit in the U.S. and raises the concern 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, a coalition of scientific advocates, institutions and industries, in 2015, NIH-funded research supported an estimated 350,000 jobs all across the United States and generated more than \$60 billion in new economic activity.

The Ad Hoc Group's members recognize the tremendous challenges facing our Nation's economy and acknowledge the difficult decisions that must be made to restore our country's fiscal health. Nevertheless, we believe strongly that NIH is an essential part of the solution to the Nation's economic restoration. 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 2018, the Ad Hoc Group for Medical Research recommends that NIH receive at least a \$2 billion increase over fiscal year 2017, in addition to funds included in 21st Century Cures for targeted initiatives, as the next step toward a multi-year increase in our Nation's investment in medical research.

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

Dear Chairman Blunt and Members of the Subcommittee:

AIDS Alliance for Women, Infants, Children, Youth & Families 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 2018 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 2018.

Ryan White Part D Background and History

Over concerns with the increase in the number of pediatric AIDS cases, 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 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 2012, Part D provided funding to 114 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 28 percent of women living with HIV infection are served by the Ryan White program. 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. The Affordable Care Act (ACA), along with the continuation of the Ryan White Program will dramatically improve health access and outcomes for many more women, infants, children, and youth living with HIV disease.

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-cen-

tered 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 meeting the goals of the National HIV/AIDS Strategy on behalf women and youth.

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 2018 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. If we believe that one day we will realize an “AIDS-free generation,” then surely we know how essential it is to maintain the Ryan White Program and all of its Parts.

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 AIDS DRUG ASSISTANCE PROGRAMS COALITION

The ADAP Coalition is a national partnership of HIV local, regional, and national organizations and pharmaceutical companies, who advocate together on behalf of AIDS Drug Assistance Programs (ADAPs). On behalf of The ADAP Coalition, we urge your support for increased funding for ADAPs in the fiscal year 2018 Labor-Health-Education Appropriations bill and request a minimum increase of \$43 million (\$943.3 million total) for ADAPs. We thank you for your consideration of the critical funding needs for ADAPs.

The Health Resources and Services Administration (HRSA) administers the \$2.3 billion Ryan White Program that provides health and support services to more than 500,000 people living with HIV (PLWH). Ryan White Part B includes ADAPs, which provide medications to low-income individuals with HIV who have limited or no coverage from private insurance, Medicare and/or Medicaid. Some ADAPs also provide insurance continuation and wrap-around services. All States, DC, Puerto Rico, the U.S. Virgin Islands, Guam, American Samoa, the Federated States of Micronesia, the Northern Mariana Islands, Republic of Palau and Republic of the Marshall Islands receive ADAP funding.

The HIV Care Continuum begins with diagnosing HIV infections, ensuring they are diagnosed early and linked to high quality care to achieve maximum health outcomes, which includes an undetectable viral load. HIV treatment is a crucial aspect of prevention, as research indicates that people who are on antiretroviral therapy and durably virally suppressed do not transmit the virus sexually. In 2014, 82 percent of Ryan White Program clients had reached viral suppression. This figure far exceeds the national PLWH viral suppression rate of 30 percent. This demonstrates the unique success of the Ryan White Program in accelerating health outcomes for disproportionately impacted populations. Among the services necessary to improve health outcomes are linkage to, and retention in, care, as well as access to medications that suppress viral loads and thereby reduce transmission which leads to fewer new HIV infections. Access to medication through ADAP is crucial to preventing new infections and improving health outcomes.

As you contemplate the fiscal year 2018 Labor-Health-Education Appropriations bill, we ask that you consider this critical funding needs. We thank the Chairman, Ranking Member and members of the Subcommittee, for their thoughtful consideration of our recommendations. Our response to the HIV epidemic in the United

States defines us as a society, as public health agencies, and as individuals living in this country. There is no time to waste in our nation's fight against this epidemic.

[This statement was submitted by Emily McCloskey, Associate Director, Policy & Legislative Affairs, National Alliance of State and Territorial AIDS Directors.]

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/AIDS and hepatitis programs in the fiscal year 2018 Labor, Health and Human Services, Education, and Related Agencies appropriation measure. We thank you for your past support, and trust you will do your best to adequately fund these programs in the future to provide for and protect the health of Americans.

CDC VIRAL HEPATITIS PREVENTION

The CDC estimates that there are 55,000 new hepatitis infections every year, with nearly a threefold increase in new infections between 2010 and 2015 fueled mainly by increases in opioid use. There are an estimated 1.4 million people in the United States living with hepatitis B (HBV) and 3.9 million living with hepatitis C (HCV), yet more than half of them are unaware of their infection. Left untreated, viral hepatitis can cause liver damage, cirrhosis, and liver cancer, one of the fastest growing cancers. Viral hepatitis causes nearly 20,000 deaths each year, which is more than the 60 other notifiable infectious diseases combined.

While new cases and deaths due to viral hepatitis have been on the rise, several recent reports have outlined how viral hepatitis can be eliminated as a public health threat. The CDC's Division of Viral Hepatitis (DVH), the National Academies, the Department of Health and Human Services, and the World Health Organization have all released reports and strategies that identify obstacles to elimination and ways to overcome them. One common theme across each of the reports is that elimination is not possible without a serious commitment to increased resources.

Despite the large increase in the number of cases and the necessary resources to eliminate the disease, the CDC's DVH funding is only \$34 million, and is nowhere near the estimated \$308 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. This lack of funding impedes CDC's ability to properly raise public awareness, educate, screen, and treat viral hepatitis. For HCV, treatment leads to a cure in almost all cases. Unfortunately, the President's fiscal year 2018 Budget maintains funding near the \$34 million level.

Only with increased funding can we provide an adequate level of education, screening, treatment, and the surveillance needed to reduce new infections and eventually eliminate viral hepatitis in the U.S.

HIV/AIDS

A record 1.2 million people in the U.S. are living with HIV, and there are an estimated 37,600 new infections each year. The epidemic disproportionately affects racial and ethnic minority groups. In 2015, African Americans accounted for 45 percent of HIV diagnoses, though they comprise only 12 percent of the U.S. population. HIV greatly affects low income people; over 90 percent of Ryan White Program clients have a household income of less than 250 percent of the Federal Poverty Level.

The U.S. has played a leading role in fighting HIV, both domestically and abroad. The vast majority of the discretionary programs supporting domestic HIV efforts are funded through this Subcommittee. We are keenly aware of current budget constraints and competing interests for limited dollars, but programs that prevent and treat HIV are inherently in the Federal interest as they protect the public health against a highly infectious virus. If left unaddressed, insufficient funding for these programs will undoubtedly lead to increased infections, more deaths, and higher health costs.

With the advent of antiretroviral medicines, HIV has turned from a near certain death sentence to a treatable chronic disease for those with access to consistent and affordable healthcare and medications. HIV treatment not only saves the lives of people with HIV, but also reduces HIV transmission. Therefore, HIV treatment is also HIV prevention. In order to realize these benefits, people with HIV must be diagnosed through testing, and linked to and retained in care and treatment. Diagnosing, treating, and achieving viral suppression for all individuals living with HIV

are all necessary to achieve the goals of our National HIV/AIDS Strategy and one day reaching an AIDS-free generation. Federal investments in prevention, care and treatment, and research have allowed us to make great advancements in combatting HIV, and we must continue to support these programs.

THE RYAN WHITE HIV/AIDS PROGRAM

The Ryan White HIV/AIDS Program, acting at the payer of last resort, provides medications, medical care, and essential coverage completion services to approximately 533,000 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. According to the CDC, only 36 percent of people living with HIV in the U.S. have been prescribed antiretroviral treatment and 30 percent are virally suppressed. With continued funding, we can improve these numbers and health outcomes.

The AIDS Drug Assistance Program (ADAP) provides States with funds to pay for medications for about 226,000 people. An increased amount of ADAP funding now is being used to help low-income enrollees afford insurance premiums, deductibles, and high cost-sharing of their medications. We urge you to ensure that ADAP and the rest of the Ryan White Program receive adequate funding to keep up with growing demands. With increased demand for medications comes a corresponding increase in the medical care and support services provided by all other parts of the program.

With the Affordable Care Act (ACA), there are expanded opportunities for healthcare coverage for some Ryan White clients. This has led to some cost shifting, but is not a substitute for the Ryan White Program. Over eighty percent of all clients already have some sort of coverage; over half through Medicaid and Medicare. Public and private insurance programs do not provide the comprehensive array of services required to meet the needs of individuals living with HIV, which include case management, mental health and substance use services, adult dental services, and transportation, legal, and nutritional services. Since some States have not expanded Medicaid, these benefits differ from State to State. As a result, for many individuals living with HIV, the Ryan White Program is their only source of care and treatment. This approach of coordinated, comprehensive, and culturally competent care leads to better health outcomes resulting in over 83 percent of Ryan White Program clients achieving viral suppression, an increase of over 23 percent since 2010.

In the President's fiscal year 2018 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 HIV patients, including those who are co-infected with Hepatitis C. We urge your Subcommittee to reject these proposed cuts, as they could prevent Ryan White patients from receiving the complete and competent care needed to reach viral suppression.

Additionally, Ryan White Part C was cut by \$4 million in the fiscal year 2017 Omnibus Appropriations bill, therefore, we urge the Subcommittee to restore funding for this important program in fiscal year 2018.

With a changing and uncertain healthcare landscape, continued 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.

CDC HIV PREVENTION

We have made significant progress in the fight against HIV in the U.S. over the last 30 years. The CDC recently reported that between 2008 and 2014, the number of new HIV infections declined by 18 percent. The prevention of 33,200 cases over these 6 years has resulted in an estimated cost savings for medical care of \$14.9 billion. This provides solid evidence that HIV prevention efforts are working. While there are fewer new infections among heterosexuals, people who inject drugs, and women, other communities continue to experience increases, including gay, bisexual, and other men who have sex with men (MSM), particularly young black and Latino MSM. Geographically, the South has been particularly impacted, accounting for 50 percent of estimated infections but only 37 percent of the U.S. population.

With more people living with HIV than ever before, there are greater chances of HIV transmission. The CDC and its grantees have been doing their best with limited resources to keep the number of infections stable, but that is not good enough. They are focusing resources on those populations and communities most impacted, and investing in those programs that will prevent the most infections. With more

than 156,000 people living with HIV in the U.S. unaware of their infection, the CDC is also focused on increased HIV testing programs. By testing patients early, they can be connected to care, which ultimately leads to better health outcomes for the patient and the prevention of transmission to others.

There is no single way to prevent HIV, but jurisdictions use a combination of effective evidence-based approaches including testing, linkage to care, condoms, syringe service programs, and one of the newest tools: pre-exposure prophylaxis (PrEP). PrEP is a FDA approved drug that keeps HIV negative people from becoming infected. The CDC estimates that more than one in five new HIV infections are among young people between the age of 13 and 24; most of whom are young gay men. We must do a better job of educating all youth about HIV. Increasing funding to the HIV Division of Adolescent and School Health (DASH) will help achieve this goal.

We were extremely disappointed that the President has proposed a \$149 million, or 19 percent cut to HIV prevention programs at the CDC. A cut of this size would reverse the progress we have made in preventing new cases of HIV. The CDC's work is especially important as the country continues to battle the opioid crisis. Now is not the time to reverse course, and we urge the Subcommittee to recognize the importance of CDC's HIV prevention work and opposing the cuts proposed by the President.

We support continued Federal funding for programs associated with syringe services in jurisdictions that are experiencing or are at risk for significant increases in HIV or hepatitis infections due to injection drug use. We are pleased the President's budget maintains the current appropriations language that allows access to syringe services in jurisdictions that meet this criteria, and we urge the Committee to continue it in fiscal year 2018.

HIV/AIDS RESEARCH AT THE NATIONAL INSTITUTES OF HEALTH

The NIH has supported innovative basic science for better drug therapies, behavioral and biomedical prevention interventions, and has saved the lives of millions around the world. However, continued research is necessary to learn more about the disease and to develop new treatments and prevention tools. The NIH is currently studying new innovative delivery methods for PrEP, as well as an effective AIDS vaccine.

The President has proposed a nearly \$7.2 billion cut to the NIH, including \$550 million to AIDS research. Funding for the NIH has enjoyed bipartisan support over in previous budget cycles, and we hope the Subcommittee will reject the President's proposal. If enacted, progress towards new medical breakthroughs in the treatment, prevention and ultimate cure of HIV/AIDS would be set-back.

MINORITY AIDS INITIATIVE

As racial and ethnic minorities in the U.S. are disproportionately impacted by HIV/AIDS, it is critical that the Subcommittee reject the President's proposal to completely eliminate the HHS Secretary's Minority AIDS Fund, as well as his proposed reductions to 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.

We thank you for your continued support. While we have made great progress, we are far from achieving an AIDS-free generation and eradicating viral hepatitis. We have the tools, but we need continued leadership and the necessary resources—not severe budget cuts. Thank you.

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

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While new cases and deaths due to viral hepatitis have been on the rise, several recent reports have outlined how viral hepatitis can be eliminated as a public health threat. The CDC's Division of Viral Hepatitis (DVH), the National Academies, the Department of Health and Human Services, and the World Health Organization have all released reports and strategies that identify obstacles to elimination and ways to overcome them. One common theme across each of the reports is that elimination is not possible without a serious commitment to increased resources.

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

The NIH has supported innovative basic science for better drug therapies, behavioral and biomedical prevention interventions, and has saved the lives of millions around the world. However, continued research is necessary to learn more about the disease and to develop new treatments and prevention tools. The NIH is currently studying new innovative delivery methods for PrEP, as well as an effective AIDS vaccine.

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Minority AIDS Initiative (MAI)

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We thank you for your continued support. While we have made great progress, we are far from achieving an AIDS-free generation and eradicating viral hepatitis. We have the tools, but we need continued leadership and the necessary resources—not severe budget cuts. Thank you.

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

PREPARED STATEMENT OF THE ALLIANCE FOR AGING RESEARCH

Chairman Blunt, Ranking Member Murray and members of the subcommittee, the nonprofit Alliance for Aging Research advocates for policies that accelerate the pace of scientific discoveries and their application to improve the experience of aging and health. The Alliance supports increased funding of basic, translational, clinical and other evidence-based research made possible by the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC) and the Agency for Healthcare Research and Quality (AHRQ). We appreciate the opportunity to submit testimony on the fiscal year 2018 Labor, Health and Human Services, Education and Related Agencies appropriations process for these agencies.

NATIONAL INSTITUTES OF HEALTH

The NIH is the nation's medical research agency, supporting research that turns insights into healthcare interventions to improve health and save lives. The Institutes and Centers that make up the NIH are responsible for leading advances in the fight against health threats people face as they age including Alzheimer's disease (AD), cardiovascular disease, and infectious disease.

The National Institute of Aging (NIA) leads scientific efforts within the NIH to understand the nature of aging and to extend the healthy years of life. The NIA spearheads Federal research efforts on AD receiving roughly 70 percent of the NIH's AD funding. As many as 5 million Americans age 65 and older are living with the disease, with 13.2 million anticipated by 2050. To address this problem, the NIA has a comprehensive research agenda to understand AD, spanning from basic neuroscience through translational research and clinical applications. The NIA supports treatment trials and public-private partnerships aimed at slowing the disease and alleviating its symptoms. Promising projects such as the Anti-Amyloid Treatment in Asymptomatic Alzheimer's Study and the Accelerating Medicines Partnership for Alzheimer's disease are collaborations led by the NIA to characterize biomarkers and identify targets for earlier intervention in AD. In addition to work on AD, the NIA supports robust Biology of Aging, Behavioral and Social Research, and Geri-

atrics and Clinical Gerontology programs. Each of these critical programs is producing valuable knowledge and developing interventions for the leading causes of late-life disability and disease.

The National Heart, Lung, and Blood Institute (NHLBI) is responsible for NIH research, training, and education programs to promote the prevention and treatment of cardiovascular, pulmonary and endocrine diseases. NHLBI's work on cardiac issues is particularly important because as people age, they are at greater risk of developing disease such as atrial fibrillation (AFib) and heart valve disease (HVD). If not detected early and treated properly, AFib and HVD lead to adverse outcomes like stroke, heart failure, cardiac arrest and death. The NHLBI completed a year-long strategic visioning process in 2016 resulting in the identification of research priorities that will lead to a better understanding of human biology, reduce disease, advance translational research and develop workforce resources. One strategic priority is intended to help healthcare providers better identify older people with AFib who are candidates for stroke prevention treatment. The NHLBI is also considering the reinstatement of a Working Group on Valvular Heart Disease that would define and recommend promising avenues of research to reduce HVD morbidity and mortality.

The National Institute of Allergy and Infectious Diseases (NIAID) conducts and supports basic and applied research at the NIH to better understand, treat, and prevent infectious disease. Antimicrobial resistance is a persistent public challenge with a significant impact on the older adult population. Older adults more likely to develop resistant infections due to their compromised immune systems, frequent healthcare visits and transitions across settings of care, and the overuse of antibiotics in their care. The biological processes behind and human response to nearly 300 infectious agents are under investigation through NIAID-funded research. Findings from this research are vital to the creation of vaccines, drugs, and diagnostic tools to better diagnose, prevent, and treat infectious diseases.

Considering the range of promising scientific opportunities at the NIH and the potential of this research to reduce human suffering and economic burden of many age-associated diseases, the Alliance for Aging Research supports the Ad Hoc Group for Medical Research's overall ask in fiscal year 2018 for at least \$2 billion in appropriations above fiscal year 2017 levels for the NIH. This \$2 billion request is in addition to funds included in the 21st Century Cures Act for targeted initiatives. We request a minimum increase of \$400 million for NIH research into Alzheimer's disease and other forms of dementia in fiscal year 2018 and \$500 million for aging research across the NIH. These increases will ensure that the NIH and NIA have the resources they need to address dementia and many other age-related chronic diseases. The Alliance supports \$3.3 billion in funding for NHLBI and \$4.9 billion for NIAID in fiscal year 2018 to sustain current activities and further investments to fight against heart disease and antimicrobial-resistant infections in older adults. Report language was included in the fiscal year 2017 appropriations process directing the U.S. Secretary of Health and Human Services to establish an Interagency Geroscience Research Coordinating Committee (IGRCC) comprised of representatives from the NIH and other designated agencies. We further urge the subcommittee to provide \$6 million in fiscal year 2018 for the IGRCC to administer the activities and fund aging research priorities.

CENTERS FOR DISEASE CONTROL AND PREVENTION

The CDC supports communities and individuals in combatting chronic, acute, and preventable diseases that can be harmful and expensive. CDC is the premiere government agency providing surveillance capabilities to monitor the rise in antimicrobial-resistant infections that occur in healthcare settings across the U.S. The Advanced Molecular Detection Initiative provides CDC with epidemiologic and laboratory expertise to rapidly determine where emerging infections come from, whether they are resistant to antibiotics and how they are moving through the population. The CDC Antibiotic Resistance Solutions Initiative allows States to implement proven interventions that reduce the emergence and spread of antimicrobial-resistant infections and improve antibiotic use. In order to provide timely information on healthcare-associated, resistant infections, the CDC maintains the National Healthcare Safety Network (NHSN), the most widely used tracking system for infections.

CDC not only monitors and provides responses to acquired infections, but it also maintains the nation's immunization infrastructure and delivery system. CDC's Section 317 Immunization Program funding provides vaccines to financially vulnerable adults without health insurance as well as to children and adolescence through the Vaccines for Children program. The 317 Program makes critical investments in the

Immunization Information Systems (IIS) which informs providers and supports clinical decisionmaking about a patient's immunization status. At the population level the IIS provides data to guide public health strategies to improve vaccination rates.

In the area of chronic disease treatment and prevention, the CDC's Division for Heart Disease and Stroke Prevention (DHDSP) supports heart disease and stroke prevention and control activities within State and local public health departments and it conducts surveillance and research to target high-burden populations and guide public health strategies. As the lead for the Million Hearts Campaign, CDC has spent more than 5 years building partnerships to prevent heart attacks and strokes through evidence-based interventions to control blood pressure, manage cholesterol and improve physical activity.

The Alliance for Aging Research supports \$200 million in fiscal year 2018 appropriations for the CDC Antibiotic Resistance Solutions Initiative. This level of funding would allow CDC to expand healthcare-associated infections and antimicrobial resistance prevention efforts from 25 States to all 50 States. We believe that at least \$30 million in fiscal year 2018 should also be devoted to the Advanced Molecular Detection Initiative to maintain CDC's ability to effectively guide public health action, in the event of emerging resistant infections. The Alliance for Aging Research also requests at least \$21 million in fiscal year 2018 funding for the CDC National Healthcare Safety Network. This would enable infection data reporting to more than 20,000 healthcare facilities across the continuum of care, including acute-care hospitals, dialysis facilities, nursing homes and ambulatory surgical centers. The Alliance for Aging Research urges the subcommittee to provide \$650 million for the CDC's Section 317 Immunization Program in fiscal year 2018 to maintain a robust immunization infrastructure to protect the population against common but costly vaccine-preventable conditions. The Prevention and Public Health Fund is another source of funding for immunizing vulnerable populations. With this fund in jeopardy, the section 317 program becomes even more critical.

To further CDC's efforts to reduce the burden of heart disease and stroke, we support \$175 million for the CDC's Division for Heart Disease and Stroke Prevention in fiscal year 2018 and \$5 million for the CDC Million Hearts 2022 campaign.

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

The AHRQ is the Federal agency whose sole purpose is to improve the healthcare system. It does this by funding research focused on achieving the best possible care for patients, maximizing efficiency, reducing waste, and identifying incentives to optimize care. A major priority of AHRQ is targeting the poor outcomes and high costs people with multiple chronic conditions experience because of often fragmented, inefficient, and ineffective care. AHRQ devotes funding to provide clinicians with evidence-based tools to develop integrated care plans that comprehensively reflect patients' health conditions, values, preferences, and relevant life circumstances.

Additional AHRQ programs identify the risks and hazards that lead to medical errors; prevent patient injury associated with the delivery of care; promote antibiotic stewardship; improve substance abuse treatment; increase healthcare accessibility and value; and accelerate the dissemination of patient-centered outcomes research. The Alliance for Aging Research supports the Friends of AHRQ's ask of \$ 364 million in fiscal year 2018 budget authority appropriations for AHRQ. At least \$12 million of this funding should be devoted to AHRQ's efforts to combat antibiotic-resistant bacteria through research on stewardship in long-term care and ambulatory care settings.

Thank you for the opportunity to provide our views to the subcommittee on the importance of NIH, CDC and AHRQ in meeting the growing health concerns of older Americans. The Alliance for Aging Research looks forward to working with you and we will gladly provide additional information on the programs described in our testimony upon request.

[This statement was submitted by Cynthia A. Bens, Vice President of Public Policy, Alliance for Aging Research.]

PREPARED STATEMENT OF THE ALLIANCE FOR BIOSECURITY AND BIOTECHNOLOGY INNOVATION ORGANIZATION

The Alliance for Biosecurity (referred to hereafter as "the Alliance") and the Biotechnology Innovation Organization (BIO) are grateful for the opportunity to share our members' perspectives on the need for adequate funding of programs within the Department of Health and Human Services (HHS) to develop and procure medical countermeasures (MCMs) to bolster our national health security against natural and

deliberate biotreatments. The Alliance and BIO request that Congress appropriate funds to support the designated programs within HHS at the following levels for fiscal year 2018: (1) The BioShield Special Reserve Fund (SRF) at \$560 million; (2) Pandemic Influenza at \$207 million; (3) Emerging Infectious Diseases (EID) at \$200 million; (4) The Biomedical Advanced Research and Development Authority (BARDA) at \$512 million; and (5) The Strategic National Stockpile (SNS) at \$575 million.

The Alliance is a collaborative partnership between pharmaceutical and biotechnology companies, laboratories, and academics who work in the public interest to improve prevention and treatment of severe diseases, particularly those that present national security challenges. BIO is the world's largest trade association representing biotechnology companies, academic institutions, State biotechnology centers and related organizations across the United States and in more than 30 other nations. Members of the Alliance and BIO are committed to investing in, developing, and delivering innovative vaccines, therapeutics, and diagnostics that are transforming our response to chemical, biological, radiological, nuclear (CBRN) attacks, such as Anthrax and Smallpox; infectious diseases, such as Ebola and Zika; and pandemics, such as Influenza. Together, we are promoting stronger, more effective partnerships among government, private industry, and other stakeholders in order to ensure these critically needed MCMs are available for quick and effective response to biosecurity threats, regardless of origin.

Bioterrorism and emerging infectious diseases present an extraordinary and potentially grave threat to public health and national security. At least 14 material biosecurity threats have been identified by Department of Homeland Security (DHS). Recent terrorist attacks and our adversaries' expressed intent to use biological and chemical weapons increase the risk that such weapons will be used against the United States. Concurrently, we face serious threats from naturally occurring pandemics and infectious diseases, such as pandemic influenza, Ebola, and Zika. Ensuring our Nation's readiness and preparedness to respond to these public health threats requires a strong and sustained commitment to funding the development and stockpile of MCMs so that they are available in the event of an emergency.

Project BioShield Special Reserve Fund (SRF).—In fiscal year 2018, we are asking for \$560 million in no-year funds for the SRF. In 2013, Congress passed the Pandemic and All-Hazards Preparedness Reauthorization Act (PAHPRA, Public Law 113–5), which authorized \$2.8 billion in funding for the SRF over a 5 year period to purchase MCMs. Since 2013, only \$1.53 billion of this has been appropriated. This funding shortfall has negatively impacted our MCM development and procurement activities, leaving the U.S. vulnerable to CBRN threats.

Established by Congress in 2004 by the Project BioShield Act (Public Law 108–276), the SRF was originally funded at \$5.6 billion for 10 years to support companies' development and supply of products to address CBRN agents. This advance appropriation gave BARDA predictable and reliable funding to procure products, which inspired private investment and produced critical MCMs to address the highest priority threats (e.g., smallpox, anthrax, radiological). Nine products were developed, procured, and stockpiled in the first 7 years of Project BioShield. This kind of robust and reliable funding is one of the most important signs to industry and private investors that the government is serious about MCM development. It must be made clear to the private sector that government is committed to supporting and partnering with companies, willing to invest 10 to 15 years and hundreds of millions or billions of dollars in MCM development, by ensuring a secure and reliable market exists for their products.

Biomedical Advanced Research and Development Authority (BARDA).—In fiscal year 2018, we are asking for the BARDA program to be funded with no-year funds at \$512 million. BARDA is responsible for managing the Project BioShield SRF and working with biopharmaceutical companies on the advanced development of MCMs to meet the government's identified requirements. This work has been instrumental in creating the more than 160 products that are now in the advanced development pipeline. If the government fails to adequately support advanced development, we risk squandering the resources invested in the earlier stages of research and, therefore, being underprepared for the biosecurity threats we are likely to face in the future.

Pandemic Influenza.—In fiscal year 2018, we are asking for \$207 million in appropriations to fund the research and development, acquisition and stockpiling of pandemic flu vaccines. This request is consistent with what the Public Health Emergency Medical Countermeasure Enterprise (PHEMCE) Multiyear Budget (Fiscal Years 2015–2019) has outlined as needed to maintain a robust R&D pipeline, to procure products and replenish our national stockpile, and to sustain the capabilities that we have invested in over the past decade.

Pandemic influenza preparedness has been woefully underfunded by Congress since the expiry of emergency supplemental funding, which has led to significant budget shortfalls. Pandemic flu threats are ever-changing; capable of spreading rapidly and causing mass devastation including significant human loss. In 2009, 18,000 people died from the H1N1 (“Swine Flu”) pandemic. Today, H7N9 (“Bird Flu”) is continuing to evolve into new strains and is spreading across China. The U.S. Government does not have sufficient vaccines stockpiled to protect first responders in the event of a pandemic. Furthermore, many of the vaccines in the stockpile are set to expire over the next few years. Investments in pandemic influenza preparedness must be increased to ensure adequate protection and response.

Emerging Infectious Disease (EID).—In fiscal year 2018, we are asking Congress for \$200 million in no-year funding to support EID development and procurement activities within BARDA. EIDs are a constantly evolving threat to our national health security. The recent emergence of Zika exposed the need for reliable government funding and programs for the development of vaccines, therapeutics, and diagnostics to enable swift and effective response. As people across the globe become more interconnected infectious diseases will continue to pose an increased risk to Americans. Infectious diseases like Zika, Ebola, SARS and MERS do not respect borders. EID preparedness requires stable funding to support the continued development of MCMs. Establishing and funding a separate line-item for EID will reduce reliance on piecemeal funding and supplementals; ultimately taking a more fiscally responsible approach to EID response. In addition, it would allow the BARDA Director to assess the EID landscape and build and sustain a robust research & development pipeline of MCM candidates for EIDs to be stockpiled for deployment in an infectious disease emergency.

Strategic National Stockpile (SNS).—In fiscal year 2018, we are asking for \$575 million in no-year funds for the SNS. The SNS provides large quantities of essential medical supplies to States and communities during an emergency, to be deployed within 12 hours of the Federal decision to respond. Once a product is licensed or approved by the FDA, responsibility for future procurements rests with the SNS. It is truly a reflection of the success of the public-private partnership and government investment if new products are approved by FDA and placed in the SNS where they are ready to be deployed to the American public in response to a crisis. Greater funding is needed to maintain, replenish, and add additional products to the SNS. The SNS is woefully underfunded and not resourced sufficiently to procure newly FDA-approved products while maintain existing items at the required levels necessary to protect our citizens.

AFB and BIO appreciate the opportunity to share our perspectives’ with the committee and we urge members to consider the great imperative for robust funding of these programs. We stand ready to work with the Administration and Congress in our shared mission to identify, create, and obtain MCMs to protect citizens against bioterrorist attacks and potentially destabilizing emerging infectious diseases.

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 comment on the fiscal year 2018 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. Our mission is to eliminate Alzheimer’s and other dementias through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. 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. Through our funded projects and partnerships, we have been part of every major Alzheimer’s research advancement over the past 30 years. Likewise, the Association works to enhance care and provide support for all those affected by Alzheimer’s and reaches millions of people affected by Alzheimer’s and their caregivers. The Alzheimer’s Impact Movement (AIM) is the Association’s sister organization, 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 Centers for Disease Control and Prevention, deaths from Alzheimer's disease increased 55 percent between 1999 and 2014. 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 16 million Americans will have Alzheimer's by 2050 and costs will exceed \$1.1 trillion (not adjusted for inflation), creating an enormous strain on the healthcare system, families and Federal and State budgets.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 2017 Alzheimer's Disease Facts and Figures report, in 2017, America will spend an estimated \$259 billion in direct costs for those with Alzheimer's, including \$175 billion in costs to Medicare and Medicaid. Average per person Medicare costs for those with Alzheimer's and other dementias are three times higher than those without these conditions. Average per senior Medicaid spending is 23 times higher.²

A primary reason for these costs is that Alzheimer's makes treating other diseases more expensive, as most individuals with Alzheimer's have one or more comorbidities that complicate the management of the condition(s) and increase costs. For example, a senior with diabetes and Alzheimer's costs Medicare 81 percent more than a senior who only has diabetes. Nearly 30 percent of people with Alzheimer's or other dementias who have Medicare also have Medicaid coverage, compared with 11 percent of individuals without Alzheimer's or other dementias. Alzheimer's is also extremely prevalent in nursing homes, where 64 percent of Medicare residents live with the disease.

With Alzheimer's, it is not just those with the disease who suffer—it is also their caregivers and families. In 2016, 15.9 million family members and friends provided unpaid care valued at over \$230 billion. Caring for a person with Alzheimer's takes longer, lasts longer, is more personal and intrusive, and takes a heavy toll on the health of the caregivers themselves. Nearly 60 percent of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high, with nearly 40 percent reporting symptoms of depression. Caregiving may also have a negative impact on health, employment, income and family finances. Due to the physical and emotional toll of caregiving on their own health, Alzheimer's and dementia caregivers had \$10.9 billion in additional health costs in 2016.³

CHANGING THE TRAJECTORY OF ALZHEIMER'S

Until recently, there was no Federal Government 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. In addition, the National Plan must outline priority actions to reduce the financial impact of Alzheimer's on Federal programs and on families; improve health outcomes for all Americans living with Alzheimer's; and improve the prevention, diagnosis, treatment, care, institutional-, home-, and community-based Alzheimer's programs for individuals with Alzheimer's and their caregivers. Through its annual review process, NAPA has enabled, for the first time,

¹2017 Alzheimer's Disease Facts and Figures: http://www.alz.org/facts/downloads/facts_figures_2017.pdf.

²Ibid.

³Ibid.

Congress and the American people to assess whether the nation is meeting the challenges of this disease for families, communities and the economy.

As mandated by NAPA, the Secretary of Health and Human Services, in collaboration with the Advisory Council on Alzheimer's Research, Care and Services, released the first-ever National Plan in May of 2012 and has released annual updates, the most recent of which was released in August 2016. The Advisory Council, composed of both Federal members and expert non-Federal members, is an integral part of the planning process as it advises the Secretary in developing and evaluating the annual National Plan, makes recommendations to the Secretary and Congress, and assists in coordinating the work of Federal agencies involved in Alzheimer's research, care and services.

In keeping with the National Plan, NIH convened research summits in 2012 and 2015, which resulted in the development and updating of research milestones and timelines for meeting the National Plan's primary research goal of effectively treating and preventing Alzheimer's by 2025. Having a plan with measurable outcomes is important. But unless there are resources to implement the plan and the will to abide by it, we cannot hope to make adequate progress.

If we are going to succeed in the fight against Alzheimer's, Congress must continue to provide the resources the scientists need. 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 milestones established by the National Plan. This provides Congress with an account of the resources that NIH believes are needed to reach the critical goal of the National Plan: to effectively treat and prevent Alzheimer's by 2025. The latest professional judgment budget, released in August 2016, calls for an additional \$414 million for Alzheimer's research funding at NIH in fiscal year 2018.

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.⁴

Consistent with the Alzheimer's Professional Judgment Budget issued by the NIH for fiscal year 2018, the Alzheimer's Association and AIM urge Congress to listen to the scientists at the NIH by supporting an additional \$414 million for research activities and priorities included in the National Plan required under Public Law 111-375.

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 \$400 million increase for Alzheimer's research activities at NIH in fiscal year 2017. 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 \$414 million for Alzheimer's research activities at NIH in fiscal year 2018. This request is consistent with the request of NIH scientists through the fiscal year 2018 Alzheimer's Professional Judgment Budget.

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

PREPARED STATEMENT OF THE ALZHEIMER'S FOUNDATION OF AMERICA

Dear Chairmen Cochran and Blunt and Ranking Members Leahy and Murray:

On behalf of the Alzheimer's Foundation of America (AFA), a national nonprofit organization that unites more than 2,600 member organizations nationwide with the goal of providing optimal care and services to individuals confronting dementia, and

⁴ Changing the Trajectory of Alzheimer's Disease: How a Treatment by 2025 Saves Lives and Dollars: http://www.alz.org/documents_custom/trajectory.pdf.

to their caregivers and families, I am making the following appropriations request for programs impacting Alzheimer's disease caregiving services and research in the fiscal year 2018 budget.

AFA wants to commend your leadership in approving a historic increase in funding for Alzheimer's disease research at the National Institutes of Health (NIH) in fiscal year 2017. The \$400 million in additional resources to the National Institute on Aging (NIA), the leading Federal research institute at NIH devoted to finding a cure for Alzheimer's disease, will help ensure promising research gets funded and that we move ever closer to the goal of finding a cure or disease-modifying treatment by 2025 as articulated in the National Plan to Address Alzheimer's Disease.

To this end, AFA hopes Congressional appropriators will continue to build upon this progress and make combatting Alzheimer's disease a national priority.

National Institutes of Health (NIH):

To ensure continuing progress in the fight against Alzheimer's disease, AFA urges the Subcommittee to provide a total of \$2 billion for Alzheimer's disease research at NIH/NIA in fiscal year 2018. Leading Alzheimer's disease scientists state that \$2 billion in annual research funding is needed to keep us on track to achieve the 2025 goal. With the 2025 deadline looming, we can no longer wait. We need to ensure there is proper investment in promising research today that will get us to a cure tomorrow.

AFA also urges the Subcommittee to include \$36.2 billion in total funding for NIH in fiscal year 2018, including funds provided through the 21st Century Cures Act, as recommended by the Ad Hoc Group for Medical Research. This \$2 billion increase to the NIH base would enable real growth over biomedical inflation as an important step to ensuring stabilizing the Nation's research capacity over the long term.

Administration on Community Living (ACL) Programs:

AFA would like to highlight the following programs within the ACL that are critical to individuals living with dementia and their caregivers. As incidences of Alzheimer's disease increase, the importance of these programs to family caregivers is vital in meeting the challenges of caring for a loved one living with dementia.

—*National Family Caregiver Support Program (NFCSP)*: NFCSP provides grants to States and territories, based on their share of the population aged 70 and over, to fund a range of supportive services that assist family and informal caregivers in caring for their loved ones at home for as long as possible, thus providing a more person-friendly and cost-effective approach than institutional care. Last year's appropriation of \$150 million cannot possibly keep up with the need for care as our population ages. AFA urges that \$161 million be appropriated in fiscal year 2018 to support this important program.

—*Lifespan Respite Care Program (LRCP)*: AFA urges the Committee to commit \$9 million, a \$6 million increase to LRCP, in fiscal year 2018. LRCP provides competitive grants to State agencies working with Aging and Disability Resource Centers and non-profit State respite coalitions and organizations to make quality respite care available and accessible to family caregivers regardless of age or disability.

—*The Alzheimer's Disease Supportive Services Program (ADSSP)*: provides competitive grants to States to expand dementia-capable home and community-based long-term services and supports. It was funded at \$5 million in fiscal year 2017. AFA is calling for an increase of \$2.5 million to bring the ADSSP up to \$7.5 million in fiscal year 2018.

—*Alzheimer's Disease Initiative (ADI)*: AFA supports a budget request of \$16.5 million in fiscal year 2018—a \$5.5 million increase for this program—that provides grants for services such as supporting caregivers in the community, improving healthcare provider training, and raising public awareness. Research shows that education, counseling and other support for family caregivers can delay institutionalization of loved ones and improve a caregiver's own physical and mental well-being—thus reducing costs to families and government. In addition, AFA supports an appropriation of \$6.7 million, a \$2.7 million increase, for the Alzheimer's Disease Communications Campaign.

—*Falls Prevention*: AFA urges that the Subcommittee double the funding, to \$10 million in fiscal year 2018, for fall prevention activities. Increased funding will allow for expansion of this evidence-based program that prevents falls and the billions in annual healthcare costs associated with them.

Sequestration

An automatic, across-the-board cut to non-defense discretionary (NDD) spending will put all Federal programs designed to advance clinical research and provide services and supports for persons living with dementia and their family caregivers,

at jeopardy. Without action to stop sequestration in fiscal year 2018, NDD programs are projected to decline to 3.1 percent of GDP—equal to the lowest level in more than 50 years. Under these constraints, major investment in the fight against Alzheimer’s disease could be severely compromised, even if there is political will to increase funding.

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

Respectfully,

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

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF FAMILY PHYSICIANS

On behalf of the American Academy of Family Physicians (AAFP), representing 129,000 family physicians and medical students, I recommend the following appropriations for programs which are important to family physicians and our patients. I also write to urge the Committee to avoid the devastating impact of the Trump Administration’s fiscal year 2018 budget request which would harm the health of America on both an individual and community-wide basis. The AAFP is deeply concerned that draconian cuts will damage healthcare services, safety and research.

The AAFP urges that the Committee:

- Restore the discretionary budget authority for the Health Resources and Services Administration (HRSA) to the fiscal year 2010 level of \$7.48 billion;
- Provide \$364 million in budget authority for the Agency for Healthcare Research and Quality (AHRQ);
- Allocate \$4 billion to the Centers for Medicare & Medicaid Services (CMS) for program management;
- Provide \$7.8 billion to the Centers for Disease Control and Prevention (CDC);
- Appropriate \$4 billion for the Substance Abuse & Mental Health Services Administration (SAMHSA); and
- Continue the U.S. Department of Education’s Public Service Loan Forgiveness (PSLF) program.

Founded in 1947, the AAFP’s mission is to improve the health of patients, families, and communities by serving the needs of members with professionalism and creativity. We believe that wise Federal investment is important to that effort, particularly in a time of intense budgetary constraints. Within HRSA, we will highlight several programs which are priorities for the AAFP:

HRSA—Title VII, § 747 Primary Care Training & Enhancement

The Administration’s proposal to eliminate the Primary Care Training & Enhancement (PCTE) program authorized by Title VII, of the Public Health Service Act of 1963 is short-sighted and unwise. PCTE, administered by HRSA, supports the education and training of family physicians. The PCTE strengthens medical education for physicians to improve the quantity, quality, distribution, and diversity of the primary care workforce.

An Annals of Family Medicine [<http://www.annfammed.org/content/13/2/107.full>] study projects that the changing needs of the U.S. population will require an additional 33,000 practicing primary care physicians by 2035. Another study in that journal noted that [<http://www.annfammed.org/content/10/2/163>] meeting the increased demand for primary care physicians requires the expansion of the PCTE program, so we urge the Committee to increase the appropriation by \$20 million to \$59 million in fiscal year 2018.

HRSA—National Health Service Corps

Since 1972, the National Health Service Corps (NHSC) has offered financial assistance to recruit and retain healthcare providers to meet the workforce needs of communities across the nation designated as health professional shortage areas (HPSAs). Congress, as part of the bipartisan Medicare Access and CHIP Reauthorization Act of 2015 (MACRA), provided a trust fund for the NHSC which expires at the end of fiscal year 2017. The Administration’s budget proposed that the NHSC receive mandatory funding in fiscal year 2018 at the MACRA-authorized level of \$310 million. The AAFP is committed to supporting the objectives of the NHSC in assisting communities in need of family physicians, and we ask that the Committee support a program level, either appropriated or mandatory funding, of at least \$380 million for the NHSC in fiscal year 2018 to allow for an increased NHSC field

strength to meet the need of Americans in the many HPSAs with no NHSC placements.

HRSA—Teaching Health Centers Graduate Medical Education

Another HRSA program extended under a MACRA trust fund is the innovative Teaching Health Center Graduate Medical Education (THCGME) program which supports primary care medical and dental residencies in community-based settings across the country. The THCGME program addresses the overall shortage of primary care physicians and has been shown to produce graduates more likely to practice in safety net clinics. [<http://www.graham-center.org/rgc/publications-reports/publications/one-pagers/thc-graduates-safety-net-2015.html>] The Administration's budget proposes to extend the MACRA authorized mandatory funding for the THCGME program through fiscal year 2019 for an additional investment of \$120 million. Unfortunately, that level will not cover the cost as outlined in the New England Journal of Medicine in The Cost of Residency Training in Teaching Health Centers [<http://www.nejm.org/doi/pdf/10.1056/NEJMp1607866>] on August 18, 2016. The AAFP recommends that the THCGME program be funded at \$142.5 million in fiscal year 2018.

HRSA—Office of Rural Health Policy

The recent CDC study [<https://www.cdc.gov/media/releases/2017/p0112-rural-death-risk.html>] finding that Americans living in rural areas are more likely to die from five leading causes than their urban counterparts demands a sustained investment in the Office of Rural Health Policy. Recognizing that 46 million Americans—15 percent of the U.S. population—live in rural areas, the AAFP supports efforts to ensure that the U.S. eliminates disparities to access to quality care for all populations. We object to the Administration's proposal to eliminate funding for Rural Hospital Flexibility grants and State Offices of Rural Health. We ask that the Committee provide at least \$150 million for HRSA's Office of Rural Health Policy.

HRSA—Title X

The AAFP supports the Title X Federal grant program dedicated to providing women and men with comprehensive family planning and related preventive health services and appreciate that the Administration's budget request proposed sustained funding for this important activity. The AAFP strongly recommends at least \$286.5 million in fiscal year 2018 funding to support Title X clinics which offer necessary screening for sexually transmissible infections, cancer screenings, HIV testing, and contraceptive care.

Agency for Healthcare Research and Quality?

The Agency for Healthcare Research and Quality (AHRQ) is the sole Federal agency charged with producing evidence to support clinical decisionmaking, reduce healthcare costs, advance patient safety, decrease medical errors, and improve healthcare quality and access. AHRQ provides critical evidence reviews needed to answer questions on the common acute, chronic, and comorbid conditions that family physicians treat daily in their practices. The Administration proposed to consolidate AHRQ into the National Institutes of Health (NIH) and cut its appropriation to \$272 million in fiscal year 2018. The AAFP does not object to the consolidation per se, but we must respectfully insist that AHRQ's vital role in supporting and communicating primary care research be continued throughout the transition and acknowledged in the name of the new Institute. Since 1998, AHRQ has convened the U.S. Preventive Services Task Force, an independent, volunteer panel of national experts from the fields of primary care and preventive medicine which makes evidence-based recommendations about clinical services after a rigorous examination of peer-reviewed data. This important work must continue. The AAFP urges the Committee to provide no less than \$364 million in budget authority in fiscal year 2018 for AHRQ or its successor Institute to continue research vital to primary care.

Centers for Medicare & Medicaid Services

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 (CHIP) and regulates private insurance coverage in the Marketplaces. The AAFP recognizes the urgent need for CMS to have adequate resources to manage these critical programs, especially at a time when the agency is implementing MACRA. The AAFP is disappointed by the Administration's request for \$3.6 billion for program management in fiscal year 2018 and recommends that the Committee provides CMS with \$4 billion for program management to allow the agency to effectively and efficiently manage the complex implementation of MACRA.

Centers for Disease Control and Prevention

Family physicians are dedicated to treating the whole person and 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 were dismayed at the Administration's budget request to reduce funding of the Chronic Disease Prevention and Health Promotion by \$222.3 million to \$952 million and create a new America's Health Block Grant. We ask that the Committee provide \$1.1 billion for this important public health work.

The CDC also plays a pivotal role in increasing the rates of adult immunization for recommended vaccines to achieve Healthy People 2020 targets. Vaccines have proven to be a 20th century public health success by reducing the incidence of infectious disease and nearly eliminating many deadly threats, such as polio, measles, and mumps. 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 317 immunization program, which works to provide surveillance, prevention, and outbreak support and regret that the Administration proposed cutting to \$700.8 million this important Center. We ask that the Committee include \$784 million for immunization and respiratory diseases in fiscal year 2018.

Substance Abuse & Mental Health Services Administration

The AAFP is committed to addressing opioid misuse at both the national and local levels and supports SAMHSA's mission to reduce the impact of substance abuse and mental illness on America's communities. Family physicians are 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). The AAFP urges the Committee to provide \$10 million to support PDMPs as authorized by the Comprehensive Addiction and Recovery Act of 2016's §109, the National All Schedules Prescription Electronic Reporting Reauthorization.

U.S. Department of Education—Public Service Loan Forgiveness

The AAFP urges the Committee to reject the Administration's proposal to eliminate the Public Service Loan Forgiveness program, which was set to begin providing loan relief in October 2017. The student debt incurred by pursuing medical training (including leading up to, during and following medical school) serves as a barrier to choosing family medicine, and the AAFP supports efforts that reduce debt burden. Many family physicians have taken qualifying employment with the expectation that after 10 years in repayment they would be granted relief. This program should not be eliminated just as borrowers are becoming eligible.

In conclusion, the AAFP recognizes the intense budgetary pressure on the Committee, but we believe that these key investments will make our country stronger by supporting our primary care workforce and public health system. We look forward to working with the Committee as the fiscal year 2018 appropriations process gets underway.

[This statement was submitted by John Meigs, Jr., MD, FAAF, 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 2018 and beyond. AAP urges all Members of Congress to put children first when considering short and long-term Federal spending decisions, and to resist attempts to cut important child health programs in order to achieve savings for other endeavors.

As pediatricians, we not only diagnose and treat our patients, we also promote preventive interventions to improve overall health. Likewise, as policymakers, you have an integral role in ensuring the health of future generations through adequate and sustained funding of vital Federal programs. As such, we urge you to pass

strong policies that invest in children in the earliest days of life. We implore you to take meaningful strides to address chronic poverty and its impacts on the health and well-being of American families.

AAP supports robust funding of the Department of Health and Human Services (HHS) and its individual agencies which all combine to support important programs that ensure the health and safety of children. Federal funding through these agencies supports critical programs that address pressing public health challenges, and, therefore, the AAP urges the Committee to support robust funding for Reducing Underage Drinking Through Screening and Brief Intervention, Pediatric Mental Health Care Access Grants, Screening for Maternal Depression, Emergency Medical Services for Children, the National Center for Birth Defects and Developmental Disabilities, Lead Poisoning Prevention, the Agency for Toxic Substances and Disease Registry, and Global Health Programs at the Centers for Disease Control and Prevention.

Reducing Underage Drinking Through Screening and Brief Intervention

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 the risks of alcohol consumption. Alcohol use among adolescents is associated with violence, decreased academic performance, the use of other drugs, 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. Consequently, pediatric healthcare providers nationwide must have access to the training necessary to increase utilization of SBIRT. This program was authorized within the Sober Truth on Preventing (STOP) Underage Drinking Reauthorization Act, which was included as Sec. 9016 of the 21st Century Cures Act (PL 114–255). This provision provides grants to train pediatric healthcare providers in using screening and brief intervention to reduce underage drinking.

FISCAL YEAR 2018 REQUEST: \$3 MILLION;
FISCAL YEAR 2017 LEVEL: N/A

Pediatric Mental Health Care Access Grants

AAP supports the fully authorized level for the Pediatric Mental Health Care Access Grants established in Public Law 115–255, the 21st Century Cures Act. This grant program supports the development of statewide or regional pediatric mental healthcare telehealth access programs and supports the improvement of existing statewide or regional pediatric mental healthcare telehealth access programs. Research shows pervasive shortages of child and adolescent mental/behavioral health specialists throughout the U.S. To reduce this severe access barrier, 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 health into primary care settings simply makes sense. It is a setting where families regularly obtain care for their children and where identification, initial assessment, and treatment of medical and mental and behavioral health conditions occur.

FISCAL YEAR 2018 REQUEST: \$9 MILLION;
FISCAL YEAR 2017 LEVEL: N/A

Screening for Maternal Depression

AAP supports the authorized amount for the Screening and Treatment for Maternal Depression grant program from Public Law 115–255, the 21st Century Cures Act. The 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. Every year, more than 400,000 infants are born to mothers who are depressed, making perinatal depression the most underdiagnosed obstetric complication in America. Postpartum depression leads to increased costs of medical care, inappropriate medical care, child abuse and neglect, discontinuation of breastfeeding, family dysfunction, and adversely affects early brain development in children. Maternal depression can have an adverse impact on the infant, so we must address maternal depression in a timely, proactive manner in order to ensure the well-being of the mother and the healthy development of the infant.

FISCAL YEAR 2018 REQUEST: \$5 MILLION;
FISCAL YEAR 2017 LEVEL: N/A

Emergency Medical Services for Children (HRSA)

Established by Congress in 1984 and last reauthorized in 2015, the Emergency Medical Services for Children (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 the entire spectrum of emergency services is provided to children and adolescents no matter where they live, attend school, or travel. Gaps in providing quality care to children in emergencies continue to persist throughout the country. The EMSC program helps to address these gaps by promoting the quality of care provided in the pre-hospital and hospital setting, reducing pediatric mortalities due to serious injury, and supporting rigorous multi-site clinical trials through the Pediatric Emergency Care Applied Research Network (PECARN).

FISCAL YEAR 2018 REQUEST: \$20.213 MILLION;
FISCAL YEAR 2017 LEVEL: \$20.162 MILLION

National Center for Birth Defects and Developmental Disabilities (CDC)

The National Center for Birth Defects and Developmental Disabilities (NCBDDD) is 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 has proven to be an asset to children and their families and supports extramural research in every State. The Center has also played a crucial role in the country's response to the Zika virus, and increased funding is needed to ensure that NCBDDD can continue their important work while adequately continuing to fight Zika.

FISCAL YEAR 2017 REQUEST: \$152.610 MILLION;
FISCAL YEAR 2017 LEVEL: \$135.610 MILLION

Lead Poisoning Prevention Program (CDC)

There is no safe level of lead exposure, and lead damage can be permanent and irreversible, leading to increased likelihood for behavior problems, attention deficit and reading disabilities, and failure to graduate high school, in addition to experiencing a host of other impairments to their developing cardiovascular, immune, and endocrine systems. Today, over 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 as one of many forms of adversity, with lifelong health effects. Prevention efforts like those at CDC are critical to addressing this problem.

FISCAL YEAR 2018 REQUEST: \$35 MILLION;
FISCAL YEAR 2017 LEVEL: \$17 MILLION

Agency for Toxic Substances and Disease Registry (ATSDR)

The Agency for Toxic Substances and Disease Registry (ATSDR) responds to requests from environmental agencies, health agencies, policy makers and community members across the country, protecting an estimate of more than 250,000 people from exposures to harmful levels of trichloroethylene (TCE), asbestos, lead, vinyl chloride, or other substances in the environment. ATSDR provides funds to 25 State health departments and supports environmental health professionals in 10 regional offices and field offices in Alaska and Montana. This level request would maintain ATSDR's scientific and programmatic capabilities to safeguard human health. The request includes some resources to fund Pediatric Environmental Health Specialty Units (PEHSUs), run by both the AAP and the American College of Medical Toxicology.

FISCAL YEAR 2018 REQUEST: \$74.691 MILLION;
 FISCAL YEAR 2017 LEVEL: \$74.691 MILLION

Global Immunization—Polio Eradication, Measles (CDC)

The U.S. Government has played a leading role in expanding access to immunizations around the world. Since 1988, a coordinated global immunization campaign has reduced the number of polio cases by more than 99 percent, saving more than 13 million children from paralysis and bringing the disease close to eradication. August 11, 2015 marked the first year in history without a single case of wild poliovirus on the entire African continent. Investments in polio have also trained health workers and strengthened the surveillance systems, laboratory networks and biocontainment capabilities that helped to arrest the spread of Ebola in countries such as Nigeria and Uganda. Global mortality attributed to measles, one of the top five diseases killing children, declined by 79 percent between 2000 and 2014 thanks to expanded immunization, saving an estimated 17.1 million lives. Despite this progress, the world is failing to meet most of its immunization goals, due in large part to weak healthcare systems and challenges presented by migration, rapid urbanization, conflict and natural disasters. The U.S. Government has a timely opportunity to foster interagency coordination for efficiency and impact and reprioritize global immunization targets, as outlined in the Global Vaccine Action Plan, through its updates of the U.S. National Vaccine Plan and the Centers for Disease Control and Prevention's (CDC's) Global Immunization Strategic Framework. The CDC should also maintain its support for country-level polio transition plans that are led by national governments and involve a broad range of stakeholders, which will be critical to ensuring continued benefits from past investments in their routine immunization systems.

POLIO ERADICATION: FISCAL YEAR 2018 REQUEST: \$174 MILLION;
 FISCAL YEAR 2017 LEVEL: \$174 MILLION

MEASLES: FISCAL YEAR 2018 REQUEST: \$50 MILLION;
 FISCAL YEAR 2017 LEVEL: \$50 MILLION

On behalf of the 75 million American children and their families that we serve and treat, the Nation's pediatricians hope that Congress will respond to mounting evidence that child health has life-long impacts and prioritize children while determining fiscal year 2018 Federal spending levels. Federal support for children's health programs will yield high returns for the American economy. Investing in children is not only the right thing to do for the long-term physical, mental, and emotional health of the population, but is imperative for the Nation's long-term fiscal health as well.

We fully recognize the Nation's fiscal challenges and respect that difficult budgetary decisions must be made; however, we do not support funding decisions made at the expense of the health and welfare of children and families. Spending on child health has been sharply reduced since the budget caps of the Budget Control Act of 2011 were imposed on discretionary spending, and the impacts of this divestment in children are being felt across the Nation. The AAP urges Congress to eliminate the budget caps and return to a budgeting and appropriations process that can be responsive to the Nation's needs. Should the caps continue, the AAP urges Congress to maintain the parity principle between defense and non-defense discretionary spending and to ensure that child health programs are not used to pay for increases in defense spending. Focusing on the long-term needs of children and adolescents will ensure that the United States can compete in the modern, highly-educated global marketplace. Strong and sustained financial investments in children's healthcare, research, and prevention programs will help keep our children healthy and pay extraordinary dividends for years to come.

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 2018 and beyond. If we may be of further assistance please contact the AAP Department of Federal Affairs at 202-347-8600 or pjohnson@aap.org. Thank you for your consideration.

[This statement was submitted by Fernando Stein, 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 on behalf of our members and the Nation's larger museum community. My name is Laura L. Lott and I serve as President and CEO of the American Alliance of Museums. I respectfully request that the Subcommittee make a renewed investment in museums in fiscal year 2018. I urge you to fully fund the Office of Museum Services (OMS) at the Institute of Museum and Library Services (IMLS) at its most recent authorized level of \$38.6 million.

Before explaining this request, I want to express my gratitude for the \$372,000 increase to the Office of Museum Services enacted in the Consolidated Appropriations Act, 2017, Public Law 115–31. Even this miniscule increase will help a few more museums enrich their communities and preserve our many heritages. We were even more grateful for the larger increase recommended by this Subcommittee's initial fiscal year 2017 draft legislation. That it chose to make these investments despite a very limited 302(b) allocation speaks volumes about the Subcommittee's commitment to our Nation's cultural institutions. The American Alliance of Museums is deeply troubled by the Trump Administration's proposal to eliminate this essential program, and we look forward to working with you—our bipartisan allies—to defeat that proposal. While the Subcommittee will once again have to make very difficult decisions this year, I contend that this program is critical to protecting our Nation's cultural treasures and provides a tremendous economic benefit.

The Alliance is proud to represent the full range of our Nation's 33,000 museums—including aquariums, art museums, botanic gardens, children's museums, culturally specific museums, historic sites, history museums, maritime museums, military museums, natural history museums, planetariums, presidential libraries, science and technology centers, and zoos, among others—along with the professional staff and volunteers who work for and with museums.

Museums are economic engines and job creators. We are proud to report that U.S. museums employ 400,000 people and directly contribute \$21 billion to their local economies every year. Museums and other nonprofit arts institutions form a national cultural infrastructure that annually generates \$22 billion in local, State, and Federal tax revenues, far more than it receives from government sources.

This subcommittee in particular may also be interested in the ways museums are providing educational programming and the results of this investment:

- Museums spend more than \$2 billion each year on education activities; the typical museum devotes three-quarters 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, mathematics and science in third grade than children who did not. This benefit is also seen in the subgroup of children who are most at risk for deficits and delays in achievement.
- According to a recent study by researchers at the University of Arkansas, 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, adapting their programs in math, science, art, literacy, language arts, history, civics and government, economics and financial literacy, geography and social studies.
- 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 roughly 60 percent in the past decade—museums are often quite literally the classroom.

IMLS is the primary Federal agency that supports the museum field, and OMS awards grants in every State to help museums digitize, enhance and preserve their collections; provide teacher professional development; and create innovative, cross-cultural and multi-disciplinary programs and exhibits for schools and the public. It is currently due for reauthorization, and has been regularly reauthorized in the past with broad bipartisan support. The most recent reauthorization (Public Law 111–340) cleared Congress unanimously in 2010, authorizing \$38.6 million annually for the IMLS Office of Museum Services to meet the growing demand for museum programs and services. The fiscal year 2017 appropriation of \$31.7 million still falls well below its recent high of \$35.2 million in fiscal year 2010.

We applaud the 37 bipartisan Senators who recently wrote to you in support of fiscal year 2018 OMS funding, including Senators Gillibrand and Sullivan as well as every Democratic member of the Subcommittee other than the Ranking Member.

We also understand that at least two other Senators included support for the Office of Museum Services in their own letters.

Here are a few examples, just from 2016, of how IMLS Office of Museum Services funding is supporting museums' work in your communities:

Workforce Development Partnerships—Springfield Art Museum (Springfield, MO) was awarded \$14,670 to create and evaluate the Art@Work program in collaboration with the Missouri Job Center and Springfield Public Schools. Classroom activities, followed by field trips to the museum, the job center, and other sites, will lead students through exercises designed to cultivate communication and organizational skills, as well as skills related to conflict resolution and teamwork. This innovative partnership will result in the development of workforce skills in elementary schools and the identification of strategies for partnerships between art museums and workforce preparation organizations.

Increasing Access to High-Quality Early Education—Children's Museum of Tacoma (Tacoma, WA) was awarded \$141,012 to address young children's need for better access to high-quality early learning experiences and to better prepare parents and caregivers to support early learning. This project will underscore the museum's position as a community anchor, increasing its capacity to engage and serve Pierce County families by bringing this school readiness program to scale across the county. The museum will deepen programmatic partnerships with Pierce County Library and other community partners to develop a partnership model for joint program delivery at more than a dozen locations in the area.

Collections Care and Safety Improvement—Nashville Zoo (Nashville, TN) was awarded \$148,050 to purchase and install medical treatment and healthcare equipment for its large animals. The current lack of space, equipment, and technology impacts the existing collection as well as the potential to add new animals and species. These needed upgrades will benefit the animals, care providers who will operate in a safer and more effective environment, the Middle Tennessee community, and the veterinary field through a state-of-the-art teaching environment. Nashville Zoo will measure long-term results of the grant by tracking animals treated, routine healthcare provided and health outcomes.

Early Science Learning—ECHO (Burlington, VT) was awarded \$148,559 to address the need for an improved early science learning program for youth across the State of Vermont. According to a 2014 statewide assessment, less than half of Vermont's students are proficient in science. ECHO—an aquarium and science center—will partner with three local early learning providers to build school science readiness by connecting young children and preschool educators to high-quality science training materials and learning experiences. Project staff will work with educators from partner preschools to strengthen classroom curricula, implement professional development workshops, and provide partner preschools the opportunity to attend classes and family science festivals at ECHO.

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 additional giving by private foundations and individual donors. Two-thirds of Museums for America grantees report that their grant positioned the museum to receive additional private funding.

Due to the large number of grant applications and the limited funds available, many highly-rated grant proposals go unfunded each year. In 2016, the Office of Museum Services received 755 applications requesting \$115.5 million, but was only able to meet 27 percent of this need. These figures do not take into account the fact that many museums may not even apply for grants due to the unlikelihood of being funded.

Again, I know the Subcommittee faces difficult decisions and the museum community is grateful for your previous support. I hope you will consider this modest request in the context of the essential role that museums play in communities nationwide, as well as their immense economic and educational impact. If I can provide any additional information about museums in your community, I would be delighted to do so. Thank you once again for the opportunity to submit this testimony today.

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

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION FOR DENTAL RESEARCH AND
THE FRIENDS OF NATIONAL INSTITUTE OF DENTAL AND CRANIOFACIAL RESEARCH

On behalf of the American Association for Dental Research (AADR) and the Friends of National Institute of Dental and Craniofacial Research (FNIDCR), I am pleased to submit testimony describing our fiscal year 2018 requests, which include at least a \$2 billion increase over the fiscal year 2017 level for the National Institutes of Health (NIH) and \$452 million for the National Institute of Dental and Craniofacial Research (NIDCR). We are grateful that Congress approved the 21st Century Cures Act which created the NIH Innovation Account. It is critical the funding afforded via this account is used to supplement and not supplant core NIH funding. We strongly urge Congress to honor the long standing tradition of allocating resources to the entire biomedical research enterprise at NIH including all the institutes and centers. Importantly, a discovery in one area of research may be applied to another. Maintaining flexibility, honoring the scientific peer review process and supporting all research is critical to our endeavor to bring cures to all Americans.

We are extremely concerned that macro budget issues-including but not limited to-sequestration, the southern border wall and a movement to increase defense spending at the expense of non-defense discretionary spending will make any future increase in funding for NIH and NIDCR extremely challenging. Therefore, Congress must build on the momentum generated in the fiscal year 2017 omnibus appropriations bill and provide NIH and NIDCR with predictable, sustained and increased funding as soon as possible.

The President's Budget proposal slashes funding for biomedical funding across the board, including an over twenty percent cut to dental and craniofacial research. In contrast, 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 older Americans.

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. Without advances in oral health research in the fight against dental caries (tooth decay) and periodontal diseases, there would be an additional 18.6 million Americans aged 45 or older who will have lost all of their natural teeth. Perhaps most striking is that after the NIH/NIDCR-funded community water fluoridation research, now for every \$1 invested in this preventive measure, approximately \$38 is saved in dental treatment costs.

Despite these improvements, however, treating oral health conditions remains extremely costly. According to CMS, the Nation spent \$117.5 billion on dental services in 2015. This is more than U.S. households spent on heart conditions (\$105.4 billion), diabetes mellitus (\$91.3 billion) or cancer (\$87.8 billion) according to 2014 AHRQ MEPS data. While tooth decay and gum disease are the most prevalent threats to oral health, complete tooth loss, oral cancer and craniofacial congenital anomalies, such as cleft lip and palate, impose massive health and economic burdens on Americans. Below for your reference are additional examples of the important research supported by NIDCR to address some of these topic areas:

—*Point of Care Diagnostics*: Salivary diagnostics are devices that draw and analyze saliva to test for conditions and infections such as HIV, human papillomavirus (HPV), substance abuse, caries, periodontitis and oral cancer. Specifically, recognizing the emergence of Zika virus as a significant public health issue, NIDCR is supporting researchers who are developing salivary diagnostics to test for Zika virus infection and provide rapid, inexpensive, point-of care detection.

—*E-Cigarettes*: According to the CDC the use of e-cigarettes has tripled among middle and high school students in 1 year. Currently, there is no scientific evi-

dence to support the safety of electronic cigarettes and initial studies indicate that a variety of chemicals are produced during the vaporization of nicotine and additives by these devices. In 2016, NIDCR funded seven ongoing research projects to investigate the effects of aerosols from e-cigarette vapors on the oral microbiome, oral epithelia and wound healing.

- Precision Medicine*: Precision medicine is an emerging approach for disease prevention and treatment that takes into account people’s individual variations in genes, environment, and lifestyle. NIDCR supports a diverse precision medicine portfolio including research on cancer, craniofacial developmental disorders, and salivary diagnostics.
- Enhanced Tissue Replacement and Regeneration*: NIDCR-funded scientists are developing new restorative materials with enhanced longevity and have developed effective techniques to enable the use of stem cells to form bone and cartilage for oral, dental and craniofacial purposes. The isolation and enrichment of pluripotent stem cells is also being explored, which would enhance the cells’ ability to regrow bone and cartilage. NIDCR recently funded a tissue engineering consortium that uses multidisciplinary teams to translate basic research into innovative tools and strategies to regenerate damaged and diseased tissues.
- HPV-Related Oral Cancer*: Scientists predict that oropharyngeal cancer will be the most common HPV-related cancer by 2020. In fact, HPV is now causing more oropharyngeal cancers than smoking. But simply identifying the presence of HPV in a mouth swab or a blood draw does not definitively indicate the presence of cancer. More research is needed for the early detection of HPV-related oropharyngeal cancer, as well as prevention and treatment approaches.
- Evidenced-Based Practice*: NIDCR supports a National Dental Practice Based Research Network (NDPBRN) headquartered at the University of Alabama at Birmingham School of Dentistry. A dental practice-based research network is an investigative union of practicing dentists and academic scientists. The network provides practitioners with an opportunity to propose or participate in research studies that address daily issues in oral healthcare. These studies help to expand the profession’s evidence base and further refine care.
- Orofacial Pain and Temporomandibular Joint Disorders*: NIDCR supports the Orofacial Pain: Prospective Evaluation and Risk Assessment (OPPERA II) clinical research study, which will advance understanding of the common mechanisms underlying temporomandibular joint disorder (TMD) and other overlapping pain conditions. The wealth of information in this large cohort makes OPPERA II a unique resource for identifying common mechanisms as well as differences in overlapping pain conditions.

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. Many complex systemic diseases, ranging from TMD to autoimmune disorders, such as Behcet’s, and to ectodermal dysplasias, have a major oral component. Through research into the basic science that is clearly needed to better understand these diseases; through the discovery of biomarkers for better diagnosis and clinical care; and by the development of new and improved tools for disease management and treatment, NIDCR has provided hope for these patients and their families that their lives will one day be improved.

In addition to NIH, our members urge you to provide \$35.8 million for the Title VII Health Resources and Services Administration (HRSA) programs training the dental health workforce, \$19 million for the Centers for Disease Control and Prevention (CDC) Division of Oral Health, \$170 million for the National Center for Health Statistics (NCHS) and \$364 million for the Agency for Healthcare Research & Quality (AHRQ).

Finally, with the return of full sequestration next year we strongly urge Congress to avoid making further reductions in these programs and work to replace the scheduled sequestration cuts through a package that is balanced—both in how such relief is paid for and how it is applied to defense and NDD programs.

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

[This statement was submitted by Raul Garcia, President, American Association for Dental Research and the Friends of National Institute of Dental and Craniofacial 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 800 schools of nursing that educate over 477,000 students and employ more than 19,000 full-time faculty members. AACN respectfully requests that the Subcommittee invests in America's health in fiscal year 2018 by providing \$244 million for HRSA's Nursing Workforce Development programs (authorized under Title VIII of the Public Health Service Act [42 U.S.C. 296 et seq.]), at least \$2 billion above the fiscal year 2017 funding level for the National Institutes of Health, in addition to funds included in the 21st Century Cures Act (Public Law 114-255). Included in this funding level, AACN requests \$160 million for the National Institute of Nursing Research (NINR).¹ Lastly, we urge the Subcommittee to provide \$380 million for the National Health Service Corps (NHSC) in fiscal year 2018.

As integral members of the healthcare team, and as the largest sector of the workforce with four million licensed providers and students,^{2,3} nurses collaborate with other professions and disciplines to improve the quality of health and healthcare in America. Nurses serve in a multitude of settings, including hospitals, long-term care facilities, community centers, local and State health departments, schools, workplaces, and patients' homes. Registered Nurses (RNs) and Advanced Practice Registered Nurses (APRNs; including Nurse Practitioners (NPs), Certified Registered Nurse Anesthetists (CRNAs), Certified Nurse-Midwives (CNMs) and Clinical Nurse Specialists (CNSs)) treat and educate patients across the entire life span and ensure individuals follow through with care plans for optimal health outcomes. These programmatic requests will help ensure that communities across the Nation have access to high-quality nursing care by supporting the education, research, and workforce components of the nursing profession.

Request: \$244 million for the Title VIII Nursing Workforce Development Programs in fiscal year 2018.

For over 50 years, the Nursing Workforce Development programs have helped build the supply and distribution of highly-educated nurses. The Federal funding yields short and long-term returns on investment that link directly to the diversity, quality, and accessibility of healthcare services.

Return on Investment: Increasing Diversity and Access to Primary Care to Meet Patients' Needs

Title VIII programs address the need for a diverse nursing workforce that can provide quality healthcare for a culturally-diverse patient population and reduce health disparities. The Title VIII Nursing Workforce Diversity (NWD) program recruits and retains students from disadvantaged backgrounds underrepresented in nursing. In Academic Year 2015–2016, the NWD program trained 7,337 students. In addition, grantees partnered with 595 clinical training sites, of which approximately 44 percent were in medically underserved communities.⁴

In Academic Year 2015–2016, the Advanced Nursing Education (ANE) Program supported 10,238 nursing students and partnered with 2,596 healthcare delivery sites, 51 percent of which were in primary care settings.⁴ ANE grants prepare our Nation's future APRNs and other nurses requiring a graduate degree.

A living example of success is the Pittsburg State University's (PSU) Irene Bradley School of Nursing in Pittsburg, Kansas. PSU is a recipient of the Title VIII ANE and NWD programs and has clinical training sites in nine counties ranked in the bottom quartile of the State's Health Index.⁵ The Title VIII funds support family nurse practitioner students who are providing quality primary care services to these vulnerable populations.

AACN urges the Subcommittee to preserve funding for each of the Nursing Workforce Development programs, including those that were proposed to be eliminated

¹The Ad Hoc Group for Medical Research, of which AACN is a member, requests at least \$2 billion above the fiscal year 2017 funding level for NIH, in addition to funds included in the 21st Century Cures Act. The request level of \$160 million for NINR denotes the same percentage increase for NIH applied to NINR.

²National Council of State Boards of Nursing. (2017). Active RN Licenses: A profile of nursing licensure in the U.S. as of February 23, 2017. Retrieved from: <https://www.ncsbn.org/6161.htm>.

³The American Association of Colleges of Nursing. (2017). Snapshot of U.S. nursing education, 2016. Retrieved from: <http://www.aacn.nche.edu/government-affairs/resources/policy-briefs>.

⁴Health Resources and Services Administration. (2017). Justifications of estimates for appropriations committees. Retrieved from: <https://www.hrsa.gov/about/budget/budgetjustification2018.pdf>.

⁵American Association of Colleges of Nursing. (2017). Title VIII: Community impact across the Nation. Retrieved from: <https://uploads.knightlab.com/storymapjs/7924760c006b72aeafa6215145aeb2e0/community-impact-title-viii/index.html>.

in the President's fiscal year 2018 budget: Advanced Nursing Education; Nursing Workforce Diversity; Nurse Education, Practice, Quality, and Retention; Nurse Faculty Loan Program; and Comprehensive Geriatric Education.⁶ These programs are vital investments to support the supply and distribution of qualified nurses to meet our Nation's healthcare needs.

Request: \$2 billion above the fiscal year 2017 funding level for the National Institutes of Health, in addition to funds included in the 21st Century Cures Act (Public Law 114-255). Included in this amount is \$160 million for the National Institute of Nursing Research.

Return on Investment: Data-driven Research to Promote Care Across the Lifespan

As one of the 27 Institutes and Centers at the National Institutes of Health, NINR develops knowledge to build the scientific foundation for reducing disease and promoting health and wellness across the entire lifespan. Nurse scientists, often working collaboratively with other health professionals, generate and translate new findings in cross-cutting facets of healthcare and biomedical research, including big data and data science, precision health, and genomics.

In addition, NINR allots a generous portion of its budget towards training new nursing scientists, thus helping to sustain the longevity and success of the nursing research pipeline. According to 2016–2017 AACN data, there are 4,873 research-focused doctoral students within AACN member schools, many of whom will also serve as faculty in our Nation's nursing schools.⁷ NINR research opportunities, such as the Symptoms Research Methodologies Boot Camp, integrate data science into nursing research to discover new technologies and methods to improve patient care.⁸

An NINR-supported nurse scientist Jacquelyn Taylor, PhD, RN, FAAN, Associate Dean of Diversity and Inclusion and Associate Professor of Nursing at the Yale School of Nursing, is conducting innovative work to improve patient outcomes. As the principal investigator on a 5-year study, Dr. Taylor evaluates health disparities in hypertension in the African-American population. Her goal is to develop nursing interventions to prevent and reduce gene-environment risks associated with hypertension.⁹

America's patients depend on funding for the critical work of nurse scientists, such as Dr. Taylor's, to help improve health, cure diseases, and deliver quality care.

Request: \$380 million for the National Health Service Corps in fiscal year 2018.

Return on Investment: Increasing Access to Care in Rural and Underserved Areas

According to HRSA, as of January 2017, there were over 65 million individuals living in Health Professional Shortage Areas.¹⁰ Moreover, according to the U.S. Bureau of Labor Statistics, the projected employment of NPs, CRNAs, and CNMs is expected to grow 31 percent between 2012 and 2022.¹¹ APRNs are a real solution to the challenge of employing high-quality providers in primary care and underserved communities. The National Health Service Corps Scholarship Program and Loan Repayment Program reach the millions living in underserved communities by providing financial support to graduate health professions students and clinicians (including APRNs) who are committed to practicing in these regions. To ensure the programs' stability, and more importantly, that necessary care reaches America's patients, it is imperative that these programs receive an annual discretionary appropriation in addition to any mandatory funding.

⁶The Title VIII Comprehensive Geriatric Education program was combined into a broader HRSA Geriatric Workforce Enhancement Program.

⁷American Association of Colleges of Nursing. (2017). 2016–2017 Enrollment and graduations in baccalaureate and graduate programs in nursing. Washington, D.C.

⁸National Institute of Nursing Research. (2017) Advancing nursing research through data science. Retrieved from: <https://www.ninr.nih.gov/researchandfunding/datascience>.

⁹National Institute of Nursing Research. (2017). Nurse scientist receives Presidential Early Career Award. Retrieved from: <https://www.ninr.nih.gov/newsandinformation/newsandnotes/taylor-pecase>.

¹⁰Health Resources and Services Administration. (2017). 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.

¹¹U.S. Bureau of Labor Statistics. (2014). Occupational outlook handbook. Nurse anesthetists, nurse midwives, and nurse practitioners. Retrieved from: <http://www.bls.gov/ooh/healthcare/nurse-anesthetists-nurse-midwives-and-nurse-practitioners.htm>.

Thank you for considering AACN's requests for fiscal year 2018. If you have any questions, or if AACN can be of assistance, please contact AACN's Director of Government Affairs Lauren Inouye, at Linouye@aacn.nche.edu or 202-463-6930 ext. 271.

[This statement was submitted by Juliann G. Sebastian, PhD, RN, FAAN, Board Chair, American Association of Colleges of Nursing.]

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF COLLEGES
OF OSTEOPATHIC MEDICINE

The American Association of Colleges of Osteopathic Medicine (AACOM) represents the 33 accredited colleges of osteopathic medicine in the United States. These colleges are accredited to deliver instruction at 48 teaching locations in 31 States. Six of the colleges are publicly controlled, 27 are private institutions. In the 2016-17 academic year, colleges are educating nearly 27,000 future physicians—more than 20 percent of U.S. medical students.

AACOM strongly supports restoring funding for discretionary Health Resources and Services Administration (HRSA) programs to \$7.48 billion; funding for key priorities in HRSA's Title VII programs under the Public Health Service Act; \$59 million for the Primary Care Training and Enhancement (PCTE) Program; \$4 million for the Rural Physician Training Grants; \$25 million for the Centers of Excellence (COE); \$20 million for the Health Careers Opportunity Program (HCOP); \$49.1 million for the Scholarships for Disadvantaged Students (SDS) Program; \$35 million for the Geriatrics Education Centers (GECs); and \$40 million for the Area Health Education Centers (AHECs); the reauthorization of the Teaching Health Center Graduate Medical Education (THCGME) Program; \$380 million in funding for the National Health Service Corps (NHSC); at least \$2 billion over the enacted fiscal year 2017 funding level of \$34.1 billion for the National Institutes of Health (NIH), in addition to funds provided through 21st Century Cures for targeted initiatives; and \$364 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 special and underserved populations, as well as increase minority representation in the healthcare workforce. AACOM supports total funding of \$580 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 PCTE Program, the Rural Physician Training Grants, the COE, the HCOP, the SDS Program, the GECs, and the AHECs.

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 58 percent of primary care health professional shortage areas are rural. AACOM supports the inclusion of \$4 million for 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 \$25 million for the COE Program and strongly opposes the elimination of this vital program in the President's fiscal year 2018 budget.

The HCOP Program 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 an appropriation of \$20 million for HCOP and strongly opposes the elimination of this important program in the President's fiscal year 2018 budget.

The SDS Program provides scholarships to health professions students from disadvantaged backgrounds with financial need, many of whom are underrepresented minorities. AACOM supports increased funding of \$49.1 million for the SDS Program and strongly opposes the elimination of this vital program in the President's fiscal year 2018 budget.

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 \$35 million for the GECs and strongly opposes the elimination of the Geriatrics Program in the President's fiscal year 2018 budget.

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 work 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 an appropriation of \$40 million for the AHEC Program in fiscal year 2018 and strongly opposes the elimination of this vital program in the President's fiscal year 2018 budget.

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).

AACOM commends Congress for reauthorizing the THCGME Program through fiscal year 2017 in the bipartisan Medicare Access and CHIP Reauthorization Act of 2015. However, a lack of continued funding greatly hinders the program's training of primary care physicians and has severely impacted recruitment efforts. Therefore, AACOM strongly urges Congress to reauthorize the THCGME Program this year.

In fiscal year 2011, the THCGME Program commenced with few more than 10 residency programs to train just over 60 residents in the Nation's underserved rural and urban communities. In the current 2016–17 academic year, there are approximately 740 residents being trained in 59 HRSA-supported teaching health center (THC) residencies in 27 States. According to HRSA, physicians who train in THCs are three times more likely to work in such centers and more than twice as likely to work in underserved areas. In 2015, 66 percent of the residents who completed the THCGME Program continued to practice in the States where they were residents. The continuation of this program is critical to addressing primary care physician workforce shortages and delivering healthcare services to underserved communities most in need.

The NHSC supports physicians and other health professionals who practice in health professional shortage areas across the U.S. In fiscal year 2016, the NHSC had nearly 10,500 primary care clinicians providing healthcare services. The NHSC projects that a field strength of approximately 8,600 primary care clinicians will be in health professional shortage areas in fiscal year 2018. In addition, more than 1,200 students, residents, and health providers receive scholarships or participate in the Student to Service Loan Repayment Program to prepare to practice. AACOM was pleased to see a 2-year extension of this program in the Medicare Access and CHIP Reauthorization Act of 2015 (PL: 114–10) for fiscal year 2016 and fiscal year 2017. However, the appropriations committees retain primary responsibility for funding the administrative functions of the NHSC and for avoiding lapses in future years. Therefore, AACOM supports the stability and sustainability of this critical program by requesting that the Subcommittee provide \$380 million for the NHSC Program.

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 \$2 billion over the fiscal year 2017 enacted level of \$34.1 billion for NIH, in addition to funds provided through 21st Century Cures for targeted initiatives.

AHRQ supports research to improve healthcare quality, reduce costs, advance patient safety, decrease medical errors, and broaden access to essential services. AHRQ plays an important role in producing the evidence base 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 to preserve AHRQ's current programs while helping to restore its critical healthcare safety, quality, and efficiency initiatives. Therefore, AACOM recommends \$364 million in base discretionary funding, consistent with fiscal year 2015 levels, and strongly opposes the consolidation of AHRQ into 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 2018 appropriations for the National Institutes of Health (NIH). AAI recommends an appropriation of at least \$35 billion for NIH for fiscal year 2018 (in addition to any funding provided to support the 21st Century Cures Act) to fund promising new and important ongoing research; to encourage the world's most talented scientists, trainees, and students to pursue biomedical research careers in the United States; and to enable NIH to continue to serve as an independent voice for, and strong leader of, the Nation's biomedical research enterprise.

WHY THE IMMUNE SYSTEM—AND IMMUNOLOGY RESEARCH—MATTERS

As the body's primary defense against viruses, bacteria, parasites, toxins, and carcinogens, the immune system can protect its host from a wide range of infectious diseases, including influenza, and from chronic illnesses, such as cancer. But the immune system can underperform, leaving the body vulnerable to disease, such as those caused by human immunodeficiency virus (HIV) and Zika virus; and it can go awry, attacking normal organs and tissues and causing autoimmune diseases including allergy, asthma, inflammatory bowel disease, lupus, multiple sclerosis, rheumatoid arthritis, and type 1 diabetes. Immunologists study how the immune system works; how it may 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 others, such as anthrax, smallpox, and plague, that could be used as bioweapons.

RECENT DISCOVERIES HARNESS THE POWER OF THE IMMUNE SYSTEM TO PREVENT AND FIGHT DISEASE

Using the Immune System to Treat Cancer.—Immunotherapy, which uses a patient's own immune system to fight disease, is transforming the treatment of cancer. NIH-funded basic researchers identified inhibitory receptors on immune cells that can be blocked, facilitating the immune system's ability to destroy tumor cells; clinical researchers then discovered that immunotherapy could fight cancer with much less toxicity than standard chemotherapy or radiation.¹ This research has contributed to the development of checkpoint inhibitor drugs, such as pembrolizumab (Keytruda®) and nivolumab (Opdivo®), which have recently received Food and Drug Administration (FDA) approval for the treatment of several cancer types, including melanoma, lymphoma, kidney, and head and neck cancer.² In October 2016, Keytruda® was approved by the FDA for the treatment of lung cancer, marking the first time that immunotherapy could be used as the initial treatment option for these patients (before standard options such as chemotherapy).³ In another promising approach to immunotherapy, NIH-supported clinical trials are examining the use of genetically engineered immune cells to treat many cancers, including kidney, bone, brain, and skin, as well as leukemia and lymphoma.⁴ When combined with conventional approaches, these immune cells can enhance treatment results and permit the use of lower doses of conventional therapies, reducing harmful side ef-

¹Chen, L. and Han, X. 2015. Anti-PD-1/PD-L1 therapy of human cancer. *J. Clin. Invest.* 125: 3384–3391.

²See <https://www.cancer.gov/about-cancer/treatment/drugs> for list of drug approvals.

³<https://www.fda.gov/Drugs/InformationOnDrugs/ApprovedDrugs/ucm526430.htm>.

⁴<https://clinicaltrials.gov/NCT01218867, NCT02107963, NCT00924326, NCT02153580>; Johnson, L.A., et al. 2017. Driving gene-engineered T cell immunotherapy of cancer. *Cell Research* 27: 38–58.

fects and providing a treatment option for cancers that do not respond solely to conventional drugs.⁵

New Way to Prevent and Treat Allergies.—Peanut allergies, which occur in 1–2 percent of people in the United States, continue to increase.⁶ Death due to peanut allergy remains the number one cause of food-related anaphylaxis, and no treatment or cure exists. An NIH-funded study showed that the early introduction of peanut-containing foods significantly decreased the development of peanut allergy among children at high risk.⁷ For individuals who already have peanut allergies, an ongoing NIH-sponsored clinical trial testing a wearable patch that delivers a small amount of peanut protein through the skin is showing great promise. The treatment, called epicutaneous immunotherapy or EPIT, trains the immune system to tolerate peanut-containing foods and has been shown to be safe and well-tolerated.⁸ These studies have revealed new insight into the prevention and treatment of peanut—and potentially other—allergies.

Development of Vaccines and Treatments for Emerging Infectious Diseases.—NIH-funded research plays a key role in the development of vaccines and treatments to combat epidemics and other major public health threats. Researchers are working urgently to develop a vaccine to protect against the Zika virus, which can hamper fetal development and cause birth defects (including microcephaly).⁹ To contain this virus, which continues to spread (with over 41,000 cases reported within the U.S. and its territories as of May 2017), NIH-funded researchers have developed a promising DNA-based vaccine that is now being tested in a clinical trial.¹⁰ Progress has also been made in developing a therapeutic strategy to protect against Ebola virus, which recently killed more than 11,300 individuals in West Africa.¹¹ In pre-clinical studies, NIH-funded scientists identified an antibody cocktail that was able to neutralize Ebola and protect against disease, even when administered after viral exposure.¹² Advances have also been made in efforts to protect against the Dengue virus: a vaccine candidate developed by NIH researchers has shown protection against infection and is now being tested in a multi-center Phase 3 clinical trial.¹³

NIH'S ESSENTIAL ROLE IN THE BIOMEDICAL RESEARCH ENTERPRISE

As the Nation's main funding agency for biomedical research, NIH supports the work of “more than 300,000 members of the research workforce” located at universities, medical schools, and other research institutions in all 50 States, the District of Columbia, and several U.S. territories.¹⁴ More than 80 percent of its budget supports the work of these scientists through about 50,000 grants; about 10 percent of its budget supports roughly 6,000 researchers and clinicians who work at NIH facilities in Maryland, Arizona, Massachusetts, Michigan, Montana and North Carolina.¹⁵ NIH funding strengthens the economies of the States where these research-

⁵Deniger, D.C., et al. 2017. A Pilot Trial of the Combination of Vemurafenib with Adoptive Cell Therapy in Patients with Metastatic Melanoma. *Clin. Cancer Res.* 23: 351–62.; Zhang, W., et al. 2016. Treatment of CD20-directed Chimeric Antigen Receptor-modified T cells in patients with relapsed or refractory B-cell non-Hodgkin lymphoma. *Sig. Transd. Tar. Ther.* 1: 16002.

⁶Togias, A., et al. 2017. Addendum guidelines for the prevention of peanut allergy in the United States: Report of the National Institute of Allergy and Infectious Diseases-sponsored expert panel. *J. Allergy Clin. Immunol.* 139: 29–44.

⁷Du Toit, G., et al. 2015. Randomized Trial of Peanut Consumption in Infants at Risk for Peanut Allergy. *N. Engl. J. Med.* 372:803–13.

⁸Jones, S.M., et al. 2016. Epicutaneous immunotherapy for the treatment of peanut allergy in children and young adults. *J. Allergy Clin. Immunol.* DOI: 10.1016/j.jaci.2016.08.017.; <https://www.niaid.nih.gov/news-events/skin-patch-treat-peanut-allergy-shows-benefit-children>.

⁹Singh, M.V., et al. 2017. Preventive and therapeutic challenges in combating Zika virus infection: are we getting any closer? *J. Neurovirol.* DOI:10.1007/s13365-017-0513-4.

¹⁰<https://www.cdc.gov/zika/index.html>; Dowd, K.A., et al. 2016. Rapid development of a DNA vaccine for Zika virus. *Science* 354: 237–240.; <https://www.nih.gov/news-events/news-releases/phase-2-zika-vaccine-trial-begins-us-central-south-america>.

¹¹<http://www.who.int/csr/disease/ebola/en/>.

¹²Corti, D., et al. 2016. Protective monotherapy against lethal Ebola virus infection by a potentially neutralizing antibody. *Science* 351: 1339–1342.

¹³Kirkpatrick, B.D., et al. 2016. The live attenuated dengue vaccine TV003 elicits complete protection against dengue in a human challenge model. *Sci. Transl. Med.* 8: 330–336.; <https://www.niaid.nih.gov/news-events/dengue-vaccine-enters-phase-3-trial-brazil>.

¹⁴<http://www.nih.gov/sites/default/files/about-nih/strategic-plan-fy2016-2020-508.pdf>; <http://www.nih.gov/about-nih/what-we-do/budget>; <https://report.nih.gov/award/index.cfm?ot=&fy=2016&state=&ic=&fm=&orgid=&distr=&rfa=&om=n&pid=#tab1>.

¹⁵See footnote 14; https://www.training.nih.gov/resources/intro_nih/other_locations.

ers live and work; in 2015, it supported nearly 380,000 jobs across the United States.¹⁶

NIH also provides invaluable scientific leadership. Through congressional testimony and frank dialogue, NIH advises our Nation's elected and appointed leaders on scientific advancements, needs, and threats. This open exchange is essential to ensuring that urgent and long-term scientific needs are addressed, and that taxpayer funds directed to NIH are well-spent. In addition, as the leader of our Nation's biomedical research enterprise and the steward of more than \$34 billion in taxpayer dollars, NIH governs the conduct of scientific research and fosters collaborations between government and academia; between U.S.-based scientists and their international colleagues, who are invaluable to our Nation's research enterprise; and between government and industry, which depends on the innovative and sometimes high-risk basic research supported by NIH to fuel their own advances in drug and medical device development.¹⁷ These NIH leadership responsibilities, which include consultation with, and notice to, a broad and diverse stakeholder community, require skilled personnel. Therefore, AAI is deeply concerned that NIH continues to be adversely affected by an ongoing government hiring freeze. Although NIH is apparently able to hire for "essential patient care staff vacancies," the Washington Post reported that there are numerous staffing prohibitions and that "some support positions," including those that impact patient care, "remain vacant."¹⁸ This same report indicated that some personnel "spoke on the condition of anonymity for fear of funding retaliation." Both the hiring freeze and the inability of NIH personnel to speak freely about its adverse impact on patient care or on the advancement of research are deeply troubling.

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

Recent NIH funding increases, including \$2 billion in both fiscal year 2016 and fiscal year 2017, have helped restore some of the purchasing power that NIH lost from years of inadequate budgets that were eroded further by biomedical research inflation.¹⁹ Although AAI is extremely grateful to Congress for these funding increases (and for the Cures Act's fiscal year 2018 authorization of \$496 million to supplement regular NIH appropriations), AAI remains concerned that NIH's purchasing power is still estimated to be about 16 percent below what it was in fiscal year 2003. In addition to limiting ongoing and promising new research and delaying discoveries that might lead to new treatments or cures, these funding constraints have a deleterious impact in other ways, forcing some productive researchers to lay off staff, close their labs, or move overseas, where support for biomedical research continues to grow.²⁰ Perhaps most importantly, inadequate or uncertain funding is deterring many promising young people from pursuing careers in biomedical research, threatening the viability of the next generation of researchers, doctors, professors, and inventors. Regular, predictable, and robust funding increases for NIH, through the timely passage of annual appropriations bills, would strengthen and stabilize NIH and the biomedical research enterprise.

TRUMP BUDGET WOULD DEVASTATE NIH AND THE BIOMEDICAL RESEARCH ENTERPRISE

AAI is extremely alarmed that President Trump's fiscal year 2018 budget proposal for NIH includes, among many other concerns, the following: (1) an unprecedented and disastrous budget cut of about 21 percent that would cause irreparable damage to NIH and to ongoing research across the Nation; (2) the elimination of the Fogarty

¹⁶ Ehrlich, Everett. NIH's Role in Sustaining the U.S. Economy—2017 update. United for Medical Research, http://www.unitedformedicalresearch.com/advocacy_reports/nih-role-in-sustaining-the-u-s-economy-2017-update/.

¹⁷ http://www.help.senate.gov/imo/media/Innovation_for_Healthier_Americans.pdf; http://conservativeireform.com/wp-content/uploads/2016/09/CRN_MedicalResearch.pdf.

¹⁸ Sun, Lena H. Washington Post. <https://www.washingtonpost.com/news/to-your-health/wp/2017/05/19/nearly-700-vacancies-at-cdc-because-of-trump-administration-hiring-freeze/>

¹⁹ According to Sun, the Centers for Disease Control and Prevention (CDC) has nearly 700 vacancies as result of the freeze. Although AAI is not submitting testimony on the CDC budget, we note that NIH and CDC work very closely together on many urgent domestic and international public health matters, and that a crippled, understaffed, or underfunded CDC, in addition to the damage this would cause to CDC and public health, will almost certainly cripple related efforts at NIH.

¹⁹ Federation of American Societies for Experimental Biology. NIH Research Funding Trends: fiscal year 1995–2016 <http://www.faseb.org/Portals/2/PDFs/opa/2017/NIH%20Grants%20Slideshow.pptx>.

²⁰ Moses, H., et al. 2015. The Anatomy of Medical Research: US and International Comparisons. JAMA 313: 174–189.

International Center, which would seriously impede NIH's ability to promote global health and prevent pandemics and other international health crises;²¹ and (3) the implementation of an immediate 10 percent cap on indirect costs to research institutions, which could drive many independent research institutions out of business and cause fiscal havoc at many others.²² We urge Congress to prevent all budget cuts to NIH and to consider carefully, following stakeholder input, any proposed changes to NIH to ensure that they would benefit—and not harm—the world's most respected biomedical research agency and its de facto leader.

CONCLUSION

AAI greatly appreciates the subcommittee's continued strong bipartisan support for NIH and biomedical research through annual appropriations and additional appropriations to support the 21st Century Cures Act initiatives. We urge Congress to continue to engage in frank dialogue with both NIH leaders and stakeholders to ensure that the best science continues to be funded. For fiscal year 2018, AAI recommends a regular appropriation of at least \$35 billion for NIH and additional funding for the 21st Century Cures initiatives.

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

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 2016 and fiscal year 2017, and mandatory increases for the NIH as part of the 21st Century Cures Act to spur the development and implementation of medical innovations. To ensure future medical research advancements in fiscal year 2018 and beyond, ACC urges members of Congress to appropriate the following funds towards agencies doing vital work in cardiovascular disease (CVD) treatment and prevention: \$36 billion for the NIH, with \$3.4 billion going towards the National Heart Lung & Blood Institute (NHLBI) and \$1.9 billion towards the National Institute of Neurological Disorders & Stroke (NINDS) to increase the NIH's purchasing power and preserve U.S. leadership in research; \$175 million towards the CDC's Division for Heart Disease and Stroke Prevention to strengthen heart disease prevention efforts at State and local levels, \$5 million towards CDC's Million Hearts to prevent 1 million heart attacks and strokes by 2022, \$37 million towards CDC's WISEWOMAN to help uninsured or under-insured women prevent or control heart disease, \$7 million towards CDC congenital heart research to study its effects over the lifespan, and \$210 million towards CDC's Office on Smoking and Health to maintain the program's cost-effective tobacco control efforts.

The ACC is a 52,000-member medical society that is the professional home for the entire cardiovascular care team. The mission of the College is to transform cardiovascular care and 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, provides professional medical education, promotes cardiovascular research and bestows credentials on cardiovascular specialists who meet stringent qualifications. The Journal of the American College of Cardiology (JACC), which publishes peer-reviewed research on all aspects of cardiovascular disease, is the most widely read cardiovascular journal worldwide. JACC is ranked number one among cardiovascular journals worldwide for its scientific impact.

Increase Funding at the National Institutes of Health

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

²¹ Despite its relatively small budget, Fogarty's mission (to "[support] and [facilitate] global health research . . . and [train] the next generation of scientists to address global health needs") is essential in a world where disease knows no borders. (See <https://www.fic.nih.gov/About/Pages/mission-vision.aspx>) With more than 80 percent of Fogarty's extramural grant budget providing salary and other support to U.S. scientists (and all grants engaging U.S. investigators), providing continued funding for Fogarty is a wise investment in advancing global health security and emergency preparedness. (See <https://www.fic.nih.gov/About/Pages/role-global-health.aspx>).

²² AAI would support a review of the formula used to determine the level of indirect costs appropriate for each institution, but believes that a uniform cap of 10 percent, or any cap implemented immediately, could be disastrous for many research institutions.

in the country and responsible for 1 in every 4 deaths.¹ More than 92 million Americans currently suffer from some form of CVD 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 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 \$36 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 lysing blood clots. These biomedical advancements have contributed to a 71 percent³ decrease in death rates due to cardiovascular disease. We recommend that NHLBI be funded at \$3.4 billion to maintain current activities and investment towards 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, and obesity. 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 \$1.9 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 treatment and affordable detection. We recommend that the CDC Division for Heart Disease and Stroke prevention be funded at \$175 million to continue its prevention activities among the most vulnerable communities.

Launched in 2012 and co-led by the CDC and Center 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. We recommend that \$37 million be allocated for WISEWOMAN to provide preventative 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 No. 1 birth defect in the U.S. 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. The national tobacco education campaign, Tips from Former Smokers, has motivated more than 5 million⁴ people to quit smoking, and at least 400,000 quit for good. We recommend that OSH be funded at \$210 million to continue leading the Nation's efforts in preventing chronic diseases caused by tobacco use.

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

²Research Funding for Cardiovascular Disease Facts; American Heart Association. https://www.heart.org/idc/groups/heart-public/@wcm/@adv/documents/downloadable/ucm_474109.pdf.

³HHS/NIH/NHLBI fiscal year 2017 Congressional Justification Report; https://www.nhlbi.nih.gov/sites/www.nhlbi.nih.gov/files/Final%20NHLBI%202017%20CJ_R508_v1.pdf.

⁴Office on Smoking and Health; Centers for Disease Control and Prevention. <https://www.cdc.gov/tobacco/about/osh/>.

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 Mary Norine Walsh, MD, FACC, President, American College of Cardiology.]

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 2018. ACP is the largest medical specialty organization and the second-largest physician group in the United States. ACP members include 148,000 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 2018, ACP is urging funding for the following proven programs to receive appropriations from the Subcommittee:

- Health Resources Services Administration (HRSA), \$7.48 billion;
- Title VII, Section 747, Primary Care Training and Enhancement, HRSA, \$71 million;
- National Health Service Corps (NHSC), HRSA, \$380 million in total program funding;
- Agency for Healthcare Research and Quality (AHRQ), \$364 million;
- Centers for Medicare and Medicaid Services (CMS), Program Management, Program Operations for Health Insurance Marketplace, \$535 million;
- Centers for Disease Control and Prevention (CDC), \$7.8 billion;
- Appropriate fully authorized funding to fight the opioid crisis for fiscal year 2018.

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. With increased demand, current projections indicate there will be a shortage of 14,900 to 35,600 primary care physicians by 2025. (IHS Inc., prepared for the Association of American Medical Colleges. 2016 Update, *The Complexities of Physician Supply and Demand: Projections from 2013 to 2025*. April 5, 2016. Accessed at: https://www.aamc.org/download/458082/data/2016_complexities_of_supply_and_demand_projections.pdf). HRSA is responsible for improving access to health-care services for people who are uninsured, isolated or medically vulnerable. Without critical funding for vital workforce programs, this physician shortage will only grow worse. A strong primary care infrastructure is an essential part of any high-functioning healthcare system, with over 100 studies showing primary care is associated with better outcomes and lower costs of care (http://www.acponline.org/advocacy/where_we_stand/policy/primary_shortage.pdf). Therefore we urge the Subcommittee to provide \$7.48 billion for discretionary HRSA programs for fiscal year 2017 to improve the care of medically underserved Americans by strengthening the health workforce.

The health professions' education programs, authorized under Title VII of the Public Health Service Act and administered through (HRSA), support the training and education of healthcare providers to enhance the supply, diversity, and distribution of the healthcare workforce, 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, Primary Care Training and Enhancement program at \$71 million, in order to maintain and expand the pipeline for individuals training in primary care. The Section 747 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 Title VII 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 \$380 million in total program funding for the National Health Service Corps (NHSC). Since the enactment of the Affordable Care Act (ACA), the NHSC has awarded over \$1.5 billion in 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 9,700 primary-care clinicians, NHSC members are providing culturally competent care to over 10 million patients at 16,000 NHSC-approved healthcare sites in urban, rural, and frontier areas. The increase in funds would expand NHSC field strength to over 10,150 and would serve the needs of more than 10.7 million patients, helping to address the health professionals' workforce shortage and growing maldistribution. The programs under NHSC have proven to make an impact in meeting the healthcare needs of the underserved, and with increased appropriations, they can do more. For fiscal year 2018, the NHSC's funding situation is particularly dire and faces a funding cliff because its mandatory funding is set to expire.

The Agency for Healthcare Research and Quality (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 \$364 million, restoring the agency to its fiscal year 2015 enacted level after a cut in fiscal year 2016. 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 \$535 million in funding for the Centers for Medicare and Medicaid Services, Program Management, Program Operations for Marketplaces. This funding would allow the Federal Government to continue to administer the insurance marketplaces as authorized by the ACA 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 the requested funds, it will be much more difficult for the Federal Government to operate and manage a federally-facilitated exchange in those States, raising questions about where and how their residents would obtain and maintain coverage.

The Center for Disease Control and Prevention's mission is to collaborate to create the expertise, information, and tools needed to protect their health—through health promotion, prevention of disease, injury and disability, and preparedness for new health threats. ACP supports \$7.8 billion overall for this mission, including: Injury Prevention and Control, Gun Violence Prevention Research, \$10 million, for studying the effects of gun violence and unintentional gun-related injury on public health and safety; and such discretionary funds needed to continue to fight the Zika virus in fiscal year 2018.

The ACP supports appropriations for the fully authorized amount under the Comprehensive Drug Addiction and Recovery Act (CARA) of 2016 for fiscal year 2018 and the \$500 million in the 21st Century Cures Act for fiscal year 2018 to fight the opioid crisis.

The College is keenly aware of the fiscal pressures facing the Subcommittee today, but strongly believes the United States must invest in these programs in order to achieve a high performance healthcare system, build capacity in our primary care workforce and public health system. The College greatly appreciates the support of the Subcommittee on these issues and looks forward to working with Congress as work on the fiscal year 2018 appropriations process.

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

PREPARED STATEMENT OF THE AMERICAN CONGRESS OF OBSTETRICIANS AND GYNECOLOGISTS

The American Congress of Obstetricians and Gynecologists, representing more than 58,000 physicians and partners in women's health, is pleased to offer this statement to the Senate Committee on Appropriations, Subcommittee on Labor, Health and Human Services, Education, and Related Agencies. We thank Chairman

Blunt, Ranking Member Murray, and the entire Subcommittee for this opportunity to provide comments on some of the most important programs to women's health.

ACOG is extremely troubled by the Trump Administration's fiscal year 2018 budget and the disastrous impact it would have on women's health. The President's budget slashes funding for scientific research, public health, patient access, and quality healthcare. We urge the Subcommittee to flatly reject this proposal, and instead work to raise spending caps imposed by sequestration and invest in critical public health and research programs to improve women's health.

Today, the United States trails many other nations in maternal health outcomes. ACOG believes that investing in research and translating that research into evidence-based care for women and babies is necessary to improve maternal and infant health. We urge you to make funding of the following programs and agencies a priority in fiscal year 2018.

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

To conduct robust research, it is critical to collect uniform, accurate and comprehensive data. 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 upgrading antiquated systems and improving the quality and accuracy of vital statistics reporting. For fiscal year 2018, ACOG requests \$170 million for NCHS.

The Pregnancy Risk Assessment Monitoring System (PRAMS) at the Centers for Disease Control and Prevention (CDC):

PRAMS surveys new mothers with questions on a range of topics, including what their insurance covered, whether they had stressful experiences during pregnancy, when they initiated prenatal care, and what kinds of questions their doctor covered during prenatal care visits. By identifying trends and patterns in maternal health, CDC researchers and State health departments are better able to identify factors leading to preterm births. ACOG requests adequate funding to expand PRAMS to all U.S. States and territories.

Biomedical 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 incidents. NICHD's 2012 Scientific Vision identified the most promising research opportunities for the next decade. Goals include determining the complex causes of prematurity and developing evidence-based measures for its prevention within the decade, understanding the long-term health implications of assisted reproductive technology, and understanding the role of the placenta in fetal health outcomes.

NICHD's Human Placenta Project will help improve maternal and fetal birth outcomes. In addition, adequate levels of research require a robust research workforce. The years of training combined with uncertainty in receiving grant funding are major disincentives for students considering a career in this field. This has resulted in a huge gap between low number of women's reproductive health researchers being trained and the immense need for research. We urge continued investments in the Women's Reproductive Health Research (WRHR) Career Development program, Reproductive Scientist Development Program (RSDP), and the Building Interdisciplinary Research Careers in Women's Health (BIRCWH) programs to address the shortfall of women's reproductive health researchers. ACOG supports at least an additional \$2 billion for NIH over fiscal year 2017, including a proportionate amount for NICHD in fiscal year 2018.

Maternal and Child Health Block Grant at Health Resources and Services Administration (HRSA):

The Maternal and Child Health Block Grant at HRSA is the only Federal program that exclusively focuses on improving the health of mothers and children. Early healthcare services help keep women and children healthy, eliminating the need for later costly care. Every \$1 spent on preconception care for a woman with diabetes can save up to \$5.19 by preventing costly complications. Even so, block grant funding has been significantly diminished. Over \$90 million has been cut from the Block Grant since 2003. ACOG requests \$880 million for the Block Grant in fiscal year 2018 to maintain its current level of services.

Title X Family Planning Program (HRSA):

Family planning and interconception 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 other-

wise have access to these services. Title X clinics accounted for \$5.3 billion in healthcare savings in 2010 alone. For every \$1 spent on publicly funded family planning services, Medicaid and other public expenditures saved \$7.09. ACOG supports \$327 million for Title X in fiscal year 2018 to sustain its level of services.

Maternal Health Initiative (HRSA):

The Maternal and Child Health Bureau (MCHB) launched the Maternal Health Initiative to foster the notion of “healthy moms make healthy babies.” As part of this effort, ACOG has convened the National Partnership on Maternal Safety to identify key factors to reduce maternal morbidity and mortality. For fiscal year 2018, ACOG requests, at a minimum, level funding for MCHB to advance this important work.

Safe Motherhood, Maternity and Perinatal Quality Collaboratives at CDC:

The Safe Motherhood Initiative at CDC works with State health departments to collect information on pregnancy-related deaths, track preterm births, and improve maternal outcomes. Through Safe Motherhood, CDC funds State-based Maternity and Perinatal Quality Collaboratives that improve birth outcomes by encouraging evidence-based care, including reducing early elective deliveries. ACOG urges you to reinstate PREEMIE preterm birth sub-line at \$2 million in fiscal year 2018, and fund the Safe Motherhood Initiative at \$46 million to help States expand or establish Maternity and Perinatal Quality Collaboratives.

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 their infants. However, little is known about the effects of most drugs on the woman and her child. ACOG strongly supports 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. NICHD is leading the Task Force’s efforts, and we look forward to supporting its work and findings to ensure that pregnant women have access to safe and effective medications.

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 \$364 million for AHRQ in fiscal year 2018, which is consistent with the fiscal year 2015 funding level for the agency.

The Department of Health and Human Services (HHS) Response to Zika Virus: 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 2018 and beyond to address the full span of activities necessary to track, treat, and ultimately prevent Zika infections. 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 2018.

Diagnosing and Treating Maternal Depression at 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 was pleased to see Congress address maternal depression in Sec. 10005 of Public Law 114–255 by authorizing a new grant program at HHS to expand screening and treatment for pregnant and postpartum women. ACOG urges you to fully fund the program at \$5 million for fiscal year 2018, 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 Con-

gress for reauthorizing the Pregnant and Postpartum Women (PPW) program funded through SAMHSA in Sec. 501 of Public Law 114–198, and providing flexibility for innovative pilot programs to address service gaps for pregnant and postpartum women, including out-patient settings. However, SAMHSA cannot make funds available for pilot programs that fit women’s needs unless funding for the PPW Program exceeds fiscal year 2016 levels. ACOG urges you to fund the PPW program at \$16.9 million for fiscal year 2018 to ensure funds are available for innovative programs that may better serve women and their families.

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

PREPARED STATEMENT OF THE AMERICAN DENTAL EDUCATION ASSOCIATION

The American Dental Education Association (ADEA) represents all 66 U.S. dental schools, 700 dental residency training programs, nearly 600 allied dental programs, as well as more than 12,000 faculty who educate and train the nearly 50,000 students and residents attending these institutions. ADEA submits this testimony on the HHS budget for the record and for your consideration as you begin prioritizing fiscal year 2018 appropriation requests.

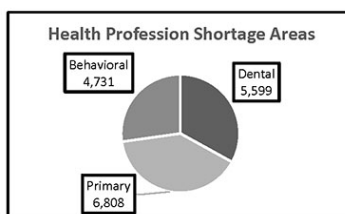
ADEA’s academic dental institutions educate and train future oral health providers and dental and craniofacial researchers. As one of the largest safety-net providers of dental care in the United States, these dental schools provide significant care to the uninsured and underserved populations. Given the fact that research has proven that there is an indivisible link between good oral health and overall health, it is imperative that adequate funding be provided to programs that facilitate access to dental care and continues cutting-edge dental and craniofacial research which seeks to reduce the burden of oral disease.

ADEA’s dental schools’ 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 oral health care safety nets in the United States, providing more than \$74 million in uncompensated health care annually to the uninsured and under-insured.

ADEA urges you to adequately fund and protect funding for Title VII Oral Health Training programs at HRSA and funding for the NIDCR at the NIH. Title VII facilitates access to dental care to millions of Americans and NIDCR fosters globally recognized cutting-edge dental and craniofacial research.

As you deliberate funding for fiscal year 2018, ADEA respectfully urges your support for the following funding requests:

I. \$35.9 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 postdoctoral pediatric, general and public health dentistry residency training. The investment made by Title VII not only educates dentists, dental therapists and dental hygienists, but also expands access to care for underserved communities since much of the care is provided in community-based settings located in health profession shortage areas.

Additionally, Section 748 addresses the shortage of professors in dental schools with the dental faculty loan repayment program and faculty development courses for those who teach pediatric, general or public health dentistry and dental hygiene. There are currently more than 200 open, budgeted faculty positions in dental schools. These two programs provide schools with assistance in recruiting and retaining faculty. ADEA is increasingly concerned that with projected restrained fund-

ing, the dental research community will not be able to grow and that the pipeline of new researchers 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 challenges of an increasingly diverse U.S. population.

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

The Area Health Education Centers (AHEC) program is targeted at enhancing 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 training with diverse populations. ADEA strongly encourages the Committee to continue funding the vitally important AHEC program.

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

Dental 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 are grateful for the increase NIDCR received in fiscal year 2015, however the increased funding was allocated to required NIH-wide initiatives. We are likewise excited about the prospect of a further increase based on the Committee recommendations for fiscal year 2017. The requested increase for fiscal year 2018 will provide for real growth to ensure continued progress for NIH and NIDCR to meet the goals of the 21st Century Cures Act, Public Law 114-255. Through NIDCR grants, dental researchers in academic dental institutions have enhanced the quality of the Nation's dental and overall health. Dental researchers are poised to make dramatic breakthroughs, such as restoring natural form and function to the mouth and face as a result of disease, accident, or injury; and diagnosing systemic disease (such as HIV and certain types of cancer) from saliva instead of blood and urine samples. These breakthroughs and countless others, which continue America's role as a global scientific leader, require adequate funding.

III. Centers for Disease Control and Prevention (CDC) Division of Oral Health

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

IV. \$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 like periodontal disease and tooth decay. The Dental Reimbursement Program (DRP) is a cost-effective Federal/institutional partnership providing partial reimbursement to academic dental institutions for costs incurred in providing dental care to people living with HIV/AIDS. Simultaneously, the program provides educational and training opportunities to dental students, residents and allied dental students. However, DRP reimbursement only averages 26 percent of the dental schools' unreimbursed costs. The current reimbursement rate is unsustainable. Adequate funding of the Ryan White Part F programs will help ensure that people living with HIV/AIDS receive necessary oral healthcare.

ADEA thanks you for your consideration of these funding requests and looks forward to working with you to ensure the continuation of these critical programs to ensure the oral and systemic health and well-being of the Nation.

Please use ADEA as a resource on any matter pertaining to dental education and training of the dental workforce under your purview. For additional information con-

tact: Yvonne Knight, J.D., ADEA Chief Advocacy Officer at Knighty@adea.org or (202) 513-1165.

PREPARED STATEMENT OF THE AMERICAN DIABETES ASSOCIATION

For fiscal year 2018, the American Diabetes Association (Association) urges the Subcommittee to continue increasing 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 \$25 million for the National Diabetes Prevention Program (National DPP) at CDC.

Nearly 30 million Americans live with diabetes and 86 million Americans have prediabetes. As a practicing endocrinologist focusing on diabetes since 1977, I have witnessed remarkable progress in the last 40 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, diabetes will cause 200 Americans to undergo an amputation, 136 to enter end-stage kidney disease treatment, and 1,795 to develop severe retinopathy that can lead to vision loss.

In addition to the horrendous physical toll, diabetes is economically devastating to our country and individuals with the disease. A 2014 report found the total annual cost of diagnosed and undiagnosed diabetes, prediabetes, and gestational diabetes in our country has skyrocketed by an astonishing 48 percent over 5 years, to \$322 billion. 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 2018.

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 (as a result 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 in the long term. 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 take action to lower that risk. 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, dieticians, 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 Association requests funding of \$2.165 billion for NIDDK in fiscal year 2018 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 2018 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:

- 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 Association urges Congress to provide \$185 million in fiscal year 2018. 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 86 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 Secretary of Health and Human Services announced that 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. As a result, the National DPP will be covered as a Medicare benefit starting in 2018.

The Association urges Congress to provide \$25 million for the National DPP in fiscal year 2018 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 and continue to manage its recognition program to ensure sites follow the evidence-based curriculum and achieve the same high level of results.

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's fiscal year 2018 appropriations decisions to reflect the necessity of taking action in light of the human and economic burden of this horrendous disease. The Association and I look forward to working with you 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 2018. This recommendation is based on the fiscal year 2016 budget for IES while accounting for inflation and reflects 4 percent real growth. This recommendation is also consistent with the request from the Friends of IES coalition, in which we are a leading member.

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.

We recognize that fiscal year 2018 will be an extremely difficult budget year and particularly so for the LHHS and Education subcommittee. Nonetheless, 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 our gains based on rigorous research.

We share the goal of educating the next generation of our citizens to be able to flexibly deal with a complex world and to contribute with new skills and capacities to workforce productivity. We also appreciate the impulse to save dollars today, but we are concerned that budget reductions of relatively small proportion in the short term would interrupt the very knowledge base and data infrastructure on which the public, education professionals, and policy makers rely.

The Institute of Education Sciences 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. 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.

With the passage of the Every Student Succeeds Act as well as the Evidence-Based Policymaking Commission Act, we see a bipartisan commitment to scientific research and to evidence-based decisionmaking that necessitates our collective support. As States develop their plans, we see that the ESSA evidence requirements when selecting interventions is increasing the demand for the very work of IES.

Since IES was created in 2002, it has made visible scientifically-based contributions to the progress of education. Yet, we in the United States 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. IES needs increased funding to continue our progress, using rigorous research to inform educational innovation, practice, and policy.

IES is composed of four national centers: National Center for Education Statistics (NCES), National Center for Education Research (NCER), National Center for Special Education Research (NCER) and National Center for Education Evaluation (NCEE). Each serves a critical role and all work collaboratively to deliver the research and evidence to best address our Nation's most pressing education challenges and improve the quality of education in the U.S.

National Center for Education Statistics (NCES)

NCES, founded in 1867, is the second oldest and among the most highly regarded of the 13 principal Federal statistical agencies in the United States. It collects, analyzes, and reports on education data and statistics on the condition of education in our country; conducts long-term longitudinal studies and surveys; and supports international assessments in accordance with the highest methodological standards and practices for data confidentiality and data security.

Federal, State, and local policy makers rely on over two dozen NCES-supported survey programs, assessments, and administrative data sets, as do schools, educators, and researchers across the country. NCES's annual report, *The Condition of Education*, presents a comprehensive statistical overview of U.S. early childhood, K–12, and postsecondary education. Whether talking about U.S. competitiveness in STEM education or answering questions about higher education completion, Congressional offices rely on these statistics each and every day.

NCES also provides technical assistance to public and private education agencies and to States improving their statistical systems. Grants from the Statewide Longitudinal Data Systems (SLDS) program encourage States to build capacity to link data between early childhood, K–12, and postsecondary systems and into the workforce.

NCES has made tremendous progress revising all assessments—national and international—from paper-and-pencil administration to digitally-based assessments. This conversion will facilitate better and more efficient measurement of what students know and can do, and better align with how students are taught in schools today and eventually lead to cost savings. The National Assessment of Education Progress (NAEP), known as the “nation's report card,” is currently in the field with its first assessment of mathematics and reading delivered primarily digitally.

NCES is actively supporting States' use of data in education. All education agencies can receive technical support as they improve their educational systems through expanding internal capacity, implementing new uses of the data already within their systems, and managing proper data sharing across their State's local agencies and independent research groups.

National Center for Education Research (NCER)

NCER supports research activities to improve the quality of education and thereby, increase student academic achievement, reduce the achievement gap between high-performing and low-performing students, and increase access to and completion of postsecondary education. Allow me to provide a couple of recent examples of NCER-funded research leading to improvements in the classroom and student learning as well as to college access that continue long past the termination of the grant.

The NCER-funded evaluation of a new math curriculum for early learners, called *Building Blocks*, contributed information essential to the development of that tool. *Building Blocks* boosted math achievement scores and closed achievement gaps between children from different economic backgrounds. Since the publication and dissemination of these results, *Building Blocks* has been adopted by 262 school districts. The software, which can be purchased separately from the curriculum, is now being used in 444 districts, representing 1,147 schools or pre-K centers and approximately 5,600 classrooms across the U.S.

NCER-funded research demonstrated how simplification of Free Application for Federal Student Aid (FAFSA) can reduce paperwork burden and improve college

outcomes, by transferring information from income tax forms onto the FAFSA for families with college-age children in North Carolina and Ohio who earned under \$45,000 per year. The program increased college enrollment by 20 percent for young adults already out of high school.

National Center for Special Education Research (NCSEER)

NCSEER supports research that investigates how to improve developmental and education outcomes for infants, toddlers, children, and youth with, or at risk of developing, disabilities. NCSEER-funded research is helping to promote a culture of high expectations for all students, changing norms and expectations for what students with disabilities are capable of accomplishing. For example, newly developed and tested literacy and math curricula are shattering expectations for what students with significant intellectual disabilities can achieve. More than 6,000 teachers across 1,290 districts are using a literacy skills curriculum, Early Literacy Skills Builder, which was developed and pilot-tested under a NCSEER grant.

National Center for Education Evaluation and Regional Assistance (NCEE)

NCEE conducts evaluations of large-scale educational projects and Federal education programs and advances the use of IES knowledge by informing the public and reaching out to practitioners with a variety of dissemination strategies and technical assistance programs. The new and improved What Works Clearinghouse (WWC) provides valuable information on the findings and methodologies of evaluations of various education practices and policies.

Thank you for the opportunity to submit written testimony in support of \$670 million for the Institute of Education Sciences for fiscal year 2018. 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

Dear Chairman Blunt, Ranking Member Murray, and members of the Subcommittee:

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 2018 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 and healthcare research outlined by President Trump in his “skinny budget” for fiscal year 2018, and are concerned about what these cuts will mean for the care and health of older adults. Specifically, the proposal calls for the health professions programs within HRSA to receive a \$403 million cut which would likely zero out funding for the Geriatrics Workforce Enhancement Program (GWEP). The proposal would also reduce essential funding for the NIH by nearly \$6 billion.

We urge you to reject this outline, and ask that the Subcommittee consider the following funding levels for these programs in fiscal year 2018:

- \$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 anticipated fiscal year 2017 funding 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 our Nation’s seniors, 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 2010 and 2050 to 88.5 million or 20 percent of the population; and those 85 and older will increase threefold to 19 million. To ensure that our Nation is prepared to meet the unique healthcare needs of this rapidly growing population, we request that Congress provide additional investments necessary to expand and enhance the geriatrics workforce, which is an integral component of the primary care workforce, and to foster groundbreaking medical research.

PROGRAMS TO TRAIN GERIATRICS HEALTHCARE PROFESSIONALS

Geriatrics Workforce Enhancement Program (\$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 who account for 80 percent of our Medicare expenditures, has been shown to reduce common and costly conditions—such as falls, polypharmacy, and delirium—that are often preventable with appropriate care.

The Geriatrics Workforce Enhancement Program (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 is encouraged by elements of this new approach, we are 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 will be dedicating 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 2018 appropriation of \$51 million for the Geriatrics Workforce Enhancement Program. Specifically, increased funding could launch eight new GWEP centers, targeted to underserved and rural communities, and provides \$100,000 to each of the 44 existing and eight new GWEP centers to reestablish the GACA program.

RESEARCH FUNDING INITIATIVES

National Institutes of Health (Additional \$500 Million Over Fiscal Year 2017)

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, 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 anticipated fiscal year 2017 funding level in the fiscal year 2018 budget for biomedical, behavioral, and social sciences aging research efforts across the NIH. The AGS also supports an additional \$400 million for NIH-funded Alzheimer's disease and related dementias research over the anticipated fiscal year 2017 funding level.

The Federal Government spends a significant and increasing amount of funds on healthcare costs associated with age-related diseases. By 2050, for example, the number of people age 65 and older with Alzheimer's disease and related dementias is estimated to reach 13.8 million—nearly triple the number in 2016—and is projected to cost more than \$1 trillion. 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 account for more than 75 percent of Medicare and other Federal health expenditures. Continued and increased Federal investments in scientific re-

search 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.

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 30 million volunteers and supporters, the American Heart Association commends Congress for boosting funding for the National Institutes of Health (NIH) and Centers for Disease Control (CDC) heart disease and stroke prevention programs, and mandatory increases for NIH in 21st Century Cures. We applaud Congress for placing a continued emphasis on the relationship between disease burden and funding levels. The association firmly believes that fact-based disease burden measures should help guide and inform Congress and policymakers when allocating research and prevention funding and setting program priorities for fiscal year 2018.

The association recently released a study that projects a steep increase in prevalence, medical costs, and subsequent burden of Cardiovascular Disease (CVD) on Americans through 2035. It can be found at: www.heart.org/burden. We trust that it can be a useful tool to properly align resources to help reduce the heavy toll CVD places on our Nation's health and economy.

As the Nation's No. 1 killer and most costly disease, CVD, including heart disease and stroke, tops the disease burden list. In 2014, stroke and heart failure were 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, new projections show that by the year 2035, 45 percent of U.S. adults will live with CVD at an annual cost of over \$1 trillion. And, a recent study found declining heart disease and stroke death rates have flattened to less than 1 percent a year since 2011. In 2015, heart disease and stroke death rates increased nearly 1 percent and 3 percent, respectively, for the first time since 1993, according to CDC.

Nonetheless, heart disease and stroke research and prevention remain disproportionately underfunded when compared to the devastating burden and suffering CVD inflicts. And despite a \$30-to-\$1 return on investment, NIH continues to invest a meager 4 percent of its budget on heart research, a mere 1 percent on stroke research, and a scant 2 percent on other CVD research. Congress must address this glaring disparity beginning with the fiscal year 2018 appropriations process.

The American Heart Association challenges Congress to enhance, protect, and preserve NIH and CDC resources. Our mission is to build healthier lives free of cardiovascular diseases and stroke. Leveraging disease burden measures is crucial to achieving that worthy goal.

FUNDING RECOMMENDATIONS: INVESTING IN THE HEALTH OF OUR NATION

Despite the renewed threat CVD poses to our Nation's long-term health and economic stability, research that could ultimately develop a cure goes unfunded. Inadequate and unreliable funding are two of the most intractable problems we face. However, our budget recommendations are both fiscally responsible and address the massive burden CVD exacts upon all of us.

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

Robust NIH-funded research helps prevent and cure disease, revolutionizes patient care, drives economic growth, advances innovation, and maintains U.S. leadership in pharmaceuticals and biotechnology. NIH remains the world's leader of basic research—the foundation for all medical advances—and an essential Federal Government function the private sector cannot replace. But, our Nation's competitive edge in research has been eroded in recent years by scarce resources.

In addition to improving health, NIH produces a solid return on investment. In 2014, NIH supported more than 400,000 U.S. jobs and nearly \$60 billion in economic activity. Every \$1 in NIH funding created \$2 in economic activity in 2007. Yet, due to inadequate resources since 2003, NIH has lost more than 19 percent of its purchasing power. Ironically, this decline has occurred at a time of unprecedented scientific opportunity as other countries, like China, wisely increased investments in science—in some cases, by double digits. These cuts have disheartened early U.S. career scientists who may decide against pursuing 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 5 years to give the agency stable, predictable and sustained resources to continue to restore its purchasing power and advance heart and stroke research.

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

NIH research is vital to cutting rising CVD death rates. Today, scientists are closer to discoveries that could result in cutting-edge treatments and even cures. In addition to saving lives, NIH studies can produce substantial cost savings. For example, investments in the NIH Women's Health Initiative postmenopausal estrogen plus progestin trial generated an economic return of \$140 for every \$1 invested and led 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)

Past declines in CVD death rates has been a result of NHLBI research. However, current funding is not commensurate with CVD disease burden, nor does it allow researchers to capitalize on investments that have led to major advances. For example, a revolutionary clinical trial showed that a systolic blood pressure goal of 120 mm Hg in adults over age 50 cut heart attack, heart failure, and stroke by 25 percent and death by 27 percent, compared to the standard treatment target of 140 mm Hg. Adoption of these new targets could save an estimated 100,000 lives.

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

Stroke continues to place a huge burden on our Nation's long-term health and economic stability. An estimated 795,000 Americans will suffer a stroke this year, and nearly 133,000 will die from it. Many of the 7 million survivors face grave physical, mental, and emotional distress. Stroke costs an estimated \$33 billion in medical expenses and lost productivity annually. And a new study projects that stroke's direct costs will more than double between 2015 and 2035.

NINDS investment in stroke must be significantly increased to build on advances in stroke research, including studies showing that a specific molecule plays a key role in brain repair after stroke. Enhanced stroke funding could boost the NIH Stroke Clinical Trials Network, including early stroke recovery; hasten translation of preclinical animal models into clinical studies; prevent vascular cognitive damage; expedite comparative effectiveness research trials; develop imaging biomarkers; refine clot-busting treatments; achieve robust brain protection; and promote the use of neural interface devices. Further resources are needed to support the BRAIN Initiative.

American Heart Association Advocates: We recommend that NHLBI be funded at \$3.3 billion and NINDS at \$1.8 billion.

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

CVD is largely preventable, but proven evidence-based prevention efforts are not fully executed due to insufficient resources. In addition to funding research and evaluation and developing a surveillance system, the Division for Heart Disease and Stroke Prevention (DHDSP) directs the Paul Coverdell National Acute Stroke Program. DHDSP, and with the Centers for Medicare & Medicaid Services, coordinate Million Hearts™ 2022 to prevent heart attacks and strokes. DHDSP runs WISEWOMAN, serving uninsured and under-insured, low-income women ages 40 to 64 through preventive health services, local healthcare referrals, and lifestyle changes.

American Heart Association Advocates: We join the CDC Coalition in asking for \$7.8 billion for CDC. The association requests \$175 million for the DHDSP to support, strengthen and expand heart disease and stroke prevention activities in State, local, and tribal public health departments, and enhance surveillance and research. We ask \$37 million to expand WISEWOMAN. And we request \$5 million for Million Hearts™ to exploit progress, rally communities and the healthcare sector to implement evidence-based interventions to prevent CVD in areas with highest burden by implementing the ABC's, backing innovative strategies to increase physical activity, using cardiac rehabilitation, and improving heart health.

CONCLUSION

New projections show cardiovascular disease, including stroke, will continue to inflict the highest disease burden on Americans. Our budgetary recommendations for NIH and CDC will save lives and reduce 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 Stephen Houser, Ph.D., President, American Heart Association.]

PREPARED STATEMENT OF THE AMERICAN INDIAN HIGHER EDUCATION CONSORTIUM

The following is a list of recommendations of the Nation's Tribal Colleges and Universities (TCUs) including Department, program, and amount sought for fiscal year 2018. Detailed information and justifications are contained in the full statement.

Department of Education

Office of Postsecondary Education

- HEA Title III–A, Sec. 316: \$60,000,000 (discretionary and mandatory)
- Perkins Career and Technical Education Programs (Sec. 117): \$10,000,000
- Reject cuts recommended in the President's Budget to TRIO programs, GEAR UP, and Federal Work-Study

Department of Health and Human Services

- Administration for Children and Families/Office of Head Start: \$8,000,000, from existing funds
- Substance Abuse and Mental Health Services Administration (SAMHSA): \$10,000,000

Institute of Museum and Library Services

- The Institute of Museum and Library Services (IMLS): Reject the President's budget recommendation to eliminate this vital program.

Tribal Colleges and Universities: A Sound Federal Investment

In August 2015, an economic impact study on the TCUs, conducted by Economic Modeling Specialists International (EMSI), revealed that the known TCU alumni impact is \$2.3 billion, which supports 28,778 jobs in the Nation. From a taxpayer's perspective, the study concluded that the total monetary benefits to taxpayers compared to their costs (equal to the Federal funds the TCUs received during the analysis year) yields a 2.4 benefit-cost ratio. In other words, for every Federal dollar invested in the TCUs, the taxpayers receive a cumulative value of \$2.40, over the course of students' working lives. 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 on investment of 16.6 percent, and the vast majority of TCU-trained workers remains in Indian Country and contributes to the local economy. TCUs benefit taxpayers through increased tax receipts and reduced demand for Federal social services; a win all-around.

The specific programmatic requests administered within the departments and agencies funded under the Labor-HHS, Education measure, are as follows:

U.S. DEPARTMENT OF EDUCATION

I. Higher Education Act Programs

- Strengthening Developing Institutions, Title III–A Sec. 316.*—TCUs urge the Subcommittee to restore the discretionary and mandatory funding for HEA Title III–A&F, Sec. 316 to \$60,000,000 in fiscal year 2018. Titles III and V of the Higher Education Act support institutions that enroll large proportions of financially disadvantaged students. The TCUs, which are truly 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; the average family annual income is less than \$18,000; and local unemployment rates often exceed 50 percent. The goal of HEA-Titles III and 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 American Indian students and their communities, 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 received subsequent cuts, including sequestration, until a small increase in

fiscal year 2016; but the TCUs still have not recovered from the earlier cuts to this vitally important program. In fiscal year 2016, the TCU section (Sec. 316) was the only Title III/V program that emerged from Conference in fiscal year 2016 with a funding level BELOW the level passed by either the House or Senate in their respective appropriations measures.

—*TRIO*.—Retention and support services are vital to achieving the goal of having the highest proportion of college graduates in the world by 2020. TRIO programs were created out of a recognition that college access is not enough to ensure advancement and that multiple factors work to prevent successful completion by many low-income and first-generation students and students with disabilities. In the final fiscal year 2017 consolidated appropriations bill, TRIO received a much needed \$50 million increase. It is critical that Congress rejects the cuts proposed in the President's budget and sustains and continues to increase support for TRIO programs so that low-income and minority students have the support they need to access and complete postsecondary education goals.

—*Pell Grants*.—The importance of Pell Grants to TCU students cannot be overstated. Eighty-five percent of TCU students receive Pell Grants, primarily because student income levels are so low and they have far less access to other sources of financial aid than students at State-funded and other mainstream institutions. At TCUs, Pell Grants are doing exactly what they were intended to do: they are serving 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. In addition to increasing TRIO programs funding, it is vitally important the Congress provide the maximum Pell Grant award level.

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 that which are providing vitally needed workforce development and job creation education and training programs to American Indians and Alaska Natives (AI/ANs) from tribes and communities with some of the highest unemployment rates in the Nation. Jayvion Chee of Rabbitbrush, NM is an example of a young Native student and his community, benefiting from this modest program. Jayvion was named as Navajo Technical University's (NTU) Student of the Year after spending a year working on a geographic information technology (GIT) degree project that assessed the potential impacts on water resources posed by hydraulic fracturing in San Juan County, NM. Jayvion used his education in NTU's GIT associate of applied science degree program to map current natural gas fracking wells to better understand the potential risks associated with the fracking process. Through his research, he found that 87 documented wells within the San Juan region could possibly lead to adverse impacts on local communities—including the land on which his grandfather resides. He has presented the results of his research at national STEM and education conferences around the country.

—*Native American Career and Technical Education Program (NACTEP)*.—NACTEP (Sec. 116) reserves 1.25 percent of appropriated funding to support American Indian 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*.—AIHEC requests that just \$8,000,000, which is eight one-hundredths or 0.08 percent of the \$9,600,000,000 last proposed for making payments under the Head Start Act, be designated for the TCU-Head Start Partnership program, as authorized in PL 110–134, so that TCUs can provide high-quality, culturally appropriate training for teachers and workers in Indian Head Start programs. In 2016, 73 percent of Head Start teachers nationwide held a required bachelor's degree; but only 39 percent of Head Start teachers in Indian Country (Region 11) met the requirement, and only 38 percent of workers met the associate-level degree

requirement. This disparity in preparation and teaching demands our attention: AI/AN children deserve—and desperately needed—qualified teachers. TCUs are ideal catalysts 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 programs. Before the program ended in 2007 (ironically, the same year that Congress specifically authorized the program in 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.

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

—*New TCU Opioid/Substance Abuse Research and Prevention Program.*—AIHEC requests that as part of the ongoing national opioid/prescription drug initiative, \$10 million be appropriated to establish a Tribal Colleges and Universities Substance Abuse/Behavioral Health Research and Prevention Initiative within SAMHSA to strategically identify and address the drug abuse and behavioral health issues impacting Native youth. The most at-risk population in the United States is American Indian and Alaska Native college-aged youth (ages 15–24). Suicide of friends, classmates, and relatives; alcohol and substance abuse; domestic violence and abuse; bullying; and extreme poverty are all too common to Tribal College students. In fact, a seminal behavior health survey of TCU students,¹ revealed that 50.4 percent of TCU students surveyed reported being physically intimidated, assaulted, or bullied/excessively teased by a peer. Twenty-four percent—almost one-quarter—reported having used opioids, compared to less than 9 percent of mainstream college students (in a 2013 national survey, which is the only comparable data available). Of the 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 data of this type due in large part to modest grants from the under-funded “Native American Research Centers on Health” program operated by the National Institutes of Health and the Indian Health Service (and in needed of increased funding). Data of this type has never been collected nationally among college students, but the TCUs know that we must get a handle on this problem before it spirals out of control. Without serious, sustained, and community-based intervention, it will rapidly spiral out of control. Already, the death rate among American Indians from heroin overdose has increased 236 percent between 2010 and 2014. The Centers for Disease Control and Prevention (CDC) reported that in 2014, American Indians were dying at double or triple the rates of African-Americans and Latinos from opioid, including heroin, addiction.

As engaged, place-based institutions, Tribal Colleges 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 modest tribal drug abuse prevention programs and an ongoing effort with Historically Black Colleges and Universities, seems an appropriate agency to administer a TCU Behavioral Health Research and Prevention Initiative to assist TCUs, working with local communities and researchers, in taking strategic steps to identify the behavioral health challenges, develop or adapt innovative and community-practiced intervention strategies, forge relationships with local and regional non-profit providers, and create and test models that can be replicated and adapted at other TCUs and tribal communities. This targeted approach will help ensure that tribal youth have the same chance as others to become healthy, productive adults who will greatly benefit their local communities and the Nation as a whole.

THE INSTITUTE OF MUSEUM AND LIBRARY SERVICES

AIHEC requests that Congress rejects the recommendation included in the President’s budget to eliminate the Institute of Museum and Library Services (IMLS).

¹TCU-CCC Baseline Survey Conducted in 22 TCUs Nationally between March 2015 and 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.

IMLS is critically important to sustaining and growing TCU libraries, many of which are also the public library for their communities. Recently, six TCUs received IMLS enhancement 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 American Indian studies—now required to be offered in Wisconsin public schools. These kits will be accessible through the library shared catalog that includes 30 libraries in Northwestern WI. In conjunction with TCUs, IMLS is instrumental in preserving tribal culture, and elimination of IMLS would be devastating to generations present and future. In the North Slope Region of Alaska alone, seven public libraries, operated through Ilisaġvik College in Barrow, would be forced to close, leaving the most isolated Americans with no access to library or reading services.

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 and careful consideration of our fiscal year 2018 appropriations needs and requests.

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 57,000 members in academic, public, school, government, and special libraries. Libraries are not-for-profit entities yet produce dramatic impacts for businesses and millions of Americans every day in communities large and small throughout the Nation.

Every year, libraries of all kinds nationwide are visited over 1.4 billion times: an average of 2,663 visits per minute, Mr. Chairman. Libraries serve a vital and unique role in communities across the country by providing an incredible range of services, including many on-line services making today's technology-laden libraries true 24-hour enterprises that are so much more than those of even 20 years ago. Consider:

- 100% offer free access to the Internet, often the only access for many;
- 97% help patrons complete government forms online;
- 95% assist kids with their homework and offer summer reading programs;
- 90% train children and adults in computer literacy and other online skills;
- 77% provide online health resources;
- 73% aid patrons with job applications and interviewing skills;
- 68% help users use databases to find job openings;
- 48% provide entrepreneurs and small business owners with online resources;
- 36% offer dedicated work space for mobile workers; and
- More than 400 of them even make 3D printers available to their patrons!

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 that assist and empower students, families, businesses, veterans, families with differently-abled members, and many others.

Specifically, ALA urges the Subcommittee to include in its fiscal year 2018 appropriations bill \$186.6 million for programs under the Library Services and Technology Act (LSTA) administered by the Institute of Museum and Library Services (IMLS), and \$27 million for the IAL program under the Department of Education (DOE). Both programs enjoy substantial and bipartisan support in both chambers of Congress. Indeed, the Subcommittee recently received Dear Appropriator letters supporting both programs signed by 45 Senators for LSTA and 37 for IAL, both record high levels of support over ALA's 15-year history with such letters.

The bulk of LSTA funds are distributed to each State through IMLS according to a population-based grant formula. Each State must provide a 34 percent match and determines without Federal direction how to 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 among many thousands made possible by LSTA over time, Mr. Chairman:

- The San Juan Island Library in Washington, uses an LSTA grant to develop its “Library Now” mobile app that puts library resources at the fingertips of its island patrons. The ability to access resources, databases, reserve books, or ask questions at any time is bringing the library directly into the homes and business of the community.
- Montana used its LSTA grant to benefit libraries across the State. The Montana State Library, for example, developed: a Shared Catalog accessible in 87 of the 97 public libraries in the State; a statewide training program for library directors, staff, and trustees ensuring that Montana libraries remain relevant and current to their patrons; and a statewide pilot makerspace program that helped build STEM/STEAM education skills for youths aged 10–17; and
- The Goodnow Library in Sudbury, Massachusetts, improved materials for the visually and hearing impaired with an LSTA grant. The library purchased new “assistive technology” and trained patrons and staff on the devices. The goal was to make the library a “community center that includes the whole community.”

Patrons described above were the direct beneficiaries of the LSTA “Grants to States” program administered by IMLS. Such grants support veterans, entrepreneurs, job seekers, tax payers, children, and many others throughout our Nation. The unfortunate truth is, Mr. Chairman, the President’s proposal to eliminate LSTA funding, in fact any cut to LSTA, will jeopardize vital and highly cost-effective programs that benefit millions of Americans in every State, and help build our economy one job and one community at a time.

Accordingly, Mr. Chairman, ALA asks that you and the Subcommittee provide \$186.6 million for LSTA in fiscal year 2018 to ensure that Americans of all ages continue to have access to the life-sustaining, -affirming and -expanding resources that their trusted local libraries provide. ALA respectfully submits, Mr. Chairman, 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 2016’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 childhood literacy for such children is crucial to their learning to read, which is crucial to their—and the Nation’s—economic futures. Studies have shown that developing early childhood reading proficiency is directly correlated to success in K–12 and college education and in careers. IAL also supports parental engagement in their children’s reading life, and focuses on promoting student literacy from birth through high school. IAL grants have been awarded during the life of the program to almost every State in the Nation. Schools across the country have received grants, including the Northwest Artic Borough School District in Alaska, Perry School District in Kentucky, Starkville Oktibbeha Consolidated School District in Oklahoma, and Dillon School District Four in South Carolina, among others.

For American families living in poverty, access to reading materials is severely limited. Children in such households have fewer books in their homes than their peers, which hinders their ability to prepare for school and to stay on track. IAL helps bridge that gap. Accordingly, we urge the Subcommittee and full Committee to foster this work by continuing to invest \$27 million in IAL.

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

Respectfully,

[This statement was submitted by Janice LaChance, Acting Executive Director, American Library Association, Washington Office.]

PREPARED STATEMENT OF THE AMERICAN NATIONAL RED CROSS AND 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 Con-

gress 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 2018 at \$60 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 over 20 million children. In part due to the Measles & Rubella Initiative, global measles mortality dropped 79 percent, from an estimated 651,600 deaths in 2000 to 134,200 in 2015 (the latest year for which data is available). During this same period, measles deaths in Africa fell by 85 percent. However, approximately 367 children died every day in 2015 from a virus that can be countered with 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 easily than the flu or the Ebola virus. The 2014–2015 Ebola outbreak in Guinea, Sierra Leone and Liberia killed a total of 11,310 people in those countries, while in 2014, more than 100,000 measles deaths occurred. In fact, one person infected with measles can infect up to 18 others if s/he has not been vaccinated. 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 low-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 \$1.15 billion and provided technical support in 88 developing countries on vaccination campaigns, surveillance and improving routine immunization services. From 2000 to 2015, an estimated 20.3 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 2000–2015, measles vaccines were the single greatest contribution to reducing preventable child deaths. Thanks to the efforts of CDC along with our other partners, measles went from the fifth leading cause of death in 2000 to the fourteenth in 2015.

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 vitamin A, which is crucial for preventing blindness in under nourished children, de-worming medicine to reduce malnutrition, insecticide treated bed nets to help prevent malaria, and screening for malnutrition. Doses of oral polio vaccines are also frequently distributed 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 of these diseases. The delivery of multiple child health interventions during a single campaign is far less expensive than delivering the interventions separately, and 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 in-

vestment for measles immunization was particularly high, at \$58 saved for every \$1 invested.

Last year, 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 2020 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. Last year, the Measles & Rubella Initiative faced a funding shortfall of US \$73.6 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.

By controlling measles and rubella cases in other countries, U.S. adults and children are also being protected from the diseases. 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. Measles can also cause severe complications such as pneumonia and encephalitis.

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 US, 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 and until 2016, 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 20.3 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 2018, the American Red Cross and the United Nations Foundation respectfully request an increase of \$10 million, for a total allocation of \$60 million. This investment will allow CDC to intensify measles and rubella control and elimination activities, protect 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 David Meltzer, General Counsel and Chief International Officer, American National Red Cross and Kathy Calvin, President and Chief Executive Officer, United Nations Foundation.]

PREPARED STATEMENT OF THE AMERICAN PHYSIOLOGICAL SOCIETY

The American Physiological Society (APS) thanks the subcommittee for its ongoing support of the National Institutes of Health (NIH). The \$2 billion funding boost you provided in fiscal year 2017, following on the \$2 billion increase you provided in fiscal year 2016, 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 critical effort by increasing the NIH budget to at least \$35 billion in fiscal year 2018.

Federal investment in research is critically important because breakthroughs in basic and translational research are the foundation for new drugs and therapies that help patients, fuel our economy, and provide jobs. Moreover, the Federal Government is the primary funding source for discovery research through competitive grants awarded by the NIH. The private sector may develop new treatments, but it relies upon federally-funded research to identify where innovation opportunities

can be found. This system of public-private partnership has been critical to U.S. leadership in the biomedical sciences.

Federal research dollars also have a significant impact at the local level: Approximately 84 percent of the NIH budget is awarded throughout the country to some 35,000 researchers. They in turn use these grant funds to pay research and administrative staff, purchase supplies and equipment, and cover other costs associated with their research. According to a 2016 report, NIH research funding in fiscal year 2015 supported more than 350,000 jobs nationwide, generating more than \$60 billion in new economic activity.¹

The \$2 billion increases Congress provided NIH in fiscal year 2016 and 2017 are important steps toward correcting the effects of sequestration and years of declining budgets. To set the agency on a more sustainable path forward, we urge you to provide predictable annual budget increases that will allow the scientific enterprise to keep up with the rate of inflation and move in new directions.

In recent years, the NIH has embarked upon important initiatives for the agency, including the National Cancer Moonshot, the Precision Medicine Initiative and the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative. These initiatives focus resources on critical areas of scientific opportunity that are ripe for innovation, but it is important to bear in mind that these projects are only possible because of decades of basic research. NIH must continue to invest in creative investigator-initiated research to advance our knowledge and create future opportunities for innovation.

Over the past several decades, NIH has used a merit-based peer review system to identify and fund the best research proposals. As a result, Americans can expect to live longer and healthier lives. However, significant challenges still loom for our Nation: An aging population will continue to strain an already stressed system of healthcare in the US. As the baby boom generation continues to age, we can expect to see increases in diseases that affect an aging population including diabetes, heart disease, and cancer. Developing better ways to detect and treat these diseases will reduce disease burden and ultimately help manage the strain that will be placed on the American healthcare system. New and emerging infectious diseases such as the Zika virus have highlighted the need to have a strong research infrastructure in place and a cadre of highly trained researchers ready to respond to an epidemic; using the results of decades of basic research to quickly learn about how infectious diseases spread and make people sick. To continue to be able to address these and other challenges on the horizon, the NIH needs additional resources.

The APS joins the Federation of American Societies for Experimental Biology (FASEB) in urging that NIH be provided with no less than \$35 billion in fiscal year 2018.

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 10,000 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 Dennis Brown, Ph.D., President, American Physiological Society.]

PREPARED STATEMENT OF THE AMERICAN PSYCHOLOGICAL ASSOCIATION

The APA is the largest scientific and professional organization representing psychology in the US: its membership includes over 116,000 researchers, educators, clinicians, consultants and students. APA works to advance the creation, communication and application of psychological knowledge to benefit society and improve people's lives. Many programs in the Labor-HHS-Education bill impact science, education, and the populations served by clinical psychologists.

APA is grateful for the Subcommittee's visionary support of effective health, education and training programs, and we urge you to maintain that support in the face of the austere and short-sighted Administration's fiscal year 2018 budget. The extreme cuts proposed in the President's budget would severely hinder the work of scientists, educators and clinicians in psychology, reduce the care of patients and the underserved, and reduce support for the education and training of psychology students.

¹ <http://www.unitedformedicalresearch.com/wp-content/uploads/2016/05/NIH-Role-in-the-Economy-FY15-FINAL-5.23.16.pdf>.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Administration for Community Living.—APA supports \$187.5 million in funding to help older adults and people with disabilities live independently and fully participate in their communities.

Administration on Children and Families.—APA supports \$1.7 billion in funding for the Social Services Block Grant for fiscal year 2018, 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:

- \$109 million for the Child Abuse Prevention and Treatment Act (CAPTA).
- Increasing funding for the Child Care and Development Block Grant to \$2.962 billion.
- Increasing funding for Head Start to \$9.6 billion.
- \$1.3 billion for the Unaccompanied Children Program.

Centers for Disease Control and Prevention (CDC).—As a member of the CDC Coalition, APA supports an appropriation of \$7.8 billion for CDC programs in fiscal year 2018. APA supports \$236 million for the CDC National Injury Prevention and Control Center, including for programs and research on the prevention of suicide, intimate partner violence, sexual violence, youth violence, child maltreatment, and prescription drug overdose; \$50 million for Rape Prevention and Education; \$25 million for the expansion of the National Violent Death Reporting System to all 50 States and DC; and \$10 million for firearm violence prevention research. APA also recommends \$170 million in budget authority for the National Center for Health Statistics.

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 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.

The President's budget would eliminate the Graduate Psychology Education Program, the Behavioral Health Workforce Education and Training Program, and the Geriatric Workforce Enhancement Program, which would together reduce mental health workforce training by nearly \$100 million. APA supports robust investments in these critical mental health workforce training programs, which are providing innovative inter-professional training to build and maintain a diverse psychology workforce competent to develop and apply evidence-based, culturally competent behavioral and psychosocial assessments and interventions in integrated healthcare.

APA strongly supports funding of \$300 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 recommends that a portion of funding for the Maternal and Child Health Bureau be used to raise awareness of the availability of depression screening to pregnant women. APA encourages the subcommittee to support incorporation of depression screening into the Title V programs administered by HRSA.

National Institutes of Health (NIH).—APA urges the Committee to reject the 21 percent cut in the President's fiscal year 2018 budget. Bipartisan support for investment in health research will bring advances for which Congress can take justifiable pride. Psychological scientists are supported by almost all of NIH's 27 institutes and centers and are well represented in trans-NIH initiatives such as BRAIN and the Common Fund's Science of Behavior Change. Behavioral research is critical to NIH's mission: the National Academy of Medicine recently reaffirmed that over 50 percent of premature mortality in the U.S. is due to behaviors such as smoking, sedentary lifestyle, and alcohol and other drug consumption. Understanding how best to encourage behavior change, and maintaining that change over time, is at the heart of much research on diabetes, cancer prevention, healthy aging and addictions.

APA thanks this subcommittee for its leadership in securing \$32.1 billion for NIH in the fiscal year 2016 omnibus spending bill and appreciates the \$2 billion increase in the fiscal year 2017 omnibus bill. As a member of the Ad Hoc Group for Medical Research, APA requests a \$2 billion increase for NIH beyond fiscal year 2017 in addition to the 21st Century Cures supplement. If this Nation is to continue to accelerate the development of life-changing cures, pioneering treatments, and innovative

prevention strategies, it is essential to sustain predictable increases in the NIH budget.

Substance Abuse and Mental Health Services Administration.—APA urges the Subcommittee to reject the Administration’s proposed cuts to this agency, especially the 22 percent reduction in the Community Mental Health Services Block Grant. 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. To ensure critical access for children to high quality and evidence-based mental and behavioral health services, APA recommends \$72 M for Project AWARE (Advancing Wellness and Resilience in Education) and level funding for the National Child Traumatic Stress Network.

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 the current funding level of \$35.4 million for the State and Tribal Youth Suicide Prevention Program for fiscal year 2018. APA urges Congress to support the full authorization levels of \$7 million for the Campus Mental and Behavioral Health Program and \$6 million for the Suicide Prevention Resource Center, as adopted by the passage of the 21st Century Cures Act (Public Law No. 114–255).

Agency for Healthcare Research and Quality (AHRQ).—APA requests \$364 million in budget authority—\$30 million over the current level. AHRQ plays a critical role in the research continuum—and psychological scientists are on the vanguard of a range of health issues from applying the science of human factors and data analytics to improve the usability and safety of health information technology to conducting systematic reviews comparing cognitive behavioral therapy to second-generation antidepressants in relieving symptoms of mild to severe major depressive disorder. Lastly, to help combat the opioid epidemic, AHRQ research is helping optimize the delivery of behavioral and pharmacotherapies for the treatment of this devastating substance use disorder in a variety of healthcare settings.

DEPARTMENT OF EDUCATION

APA has a strong interest in robust funding for Every Student Succeeds Act’s Title IV programs, especially the Student Support and Academic Enrichment grants. This program will help school districts identify and assess their own comprehensive needs and support learning through investments in accelerated study, mental health services, bullying prevention, problem solving and conflict resolution, positive behavioral interventions and supports, and social and emotional learning. We know from research that a positive school environment and strong school supports can make a significant difference in learning outcomes for students. Further, APA supports strong 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; and the Federal Work Study program, which is available to graduate students with demonstrated financial need.

Institute for Education Sciences.—As a member of the Friends of IES, APA requests \$670 million for the Institute of Education Sciences in fiscal year 2018. Adequate funding for all IES programs in fiscal year 2018 will enable the Institute to best support important research, data collection and statistical analysis, and dissemination. This work contributes to a growing evidence base that informs effective and efficient educational practice and policy across the Nation.

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 \$7.8 billion and the Health Resources and Services Administration at \$7.48 billion in fiscal year 2018.

Centers for Disease Control and Prevention.—We believe Congress should support CDC as an agency and urge a funding level of \$7.8 billion in fiscal year 2018. We are deeply disappointed that the president’s proposed fiscal year 2018 budget would cut CDC’s program level funding by nearly \$1.2 billion or nearly 17 percent below fiscal year 2017 levels. Many important programs at CDC would be impacted, including cuts to environmental health programs, efforts that protect against infectious disease, protect the public against public health emergencies, assure occupa-

tional health and safety, prevent the spread of HIV, promote global health and address our Nation's chronic disease epidemic. In addition, we are extremely concerned about efforts to repeal the Prevention and Public Health Fund through efforts to repeal the Affordable Care Act, and the impact the loss of this funding would have on CDC's annual budget. The Prevention and Public Health Fund currently accounts for 12 percent of CDC's budget and the committee and Congress must ensure that CDC's budget remains whole in the face of efforts to repeal the ACA.

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 our Nation's State and local health departments to help them protect communities in the face of public health emergencies, and other critical CDC preparedness and response activities. Unfortunately, the president's budget proposal would slash nearly \$140 million from CDC's public health preparedness and response activities.

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 the recent multi-State measles outbreak to pandemic flu preparedness, 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. Unfortunately, the president's budget proposal would cut more than \$70 million from CDC's National Center for Emerging and Zoonotic Infectious Diseases and more than \$37 million from the National Center for Birth Defects and Developmental Disabilities. These centers have played a critical role in responding to the Zika virus by funding surveillance, vector control programs and enhancing laboratory testing capacity at the State and local level and by supporting surveillance, research, and prevention activities aimed at birth defects and developmental disabilities.

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. While it is well understood that chronic diseases cost our Nation billions of dollars each year, the president's budget would cut more than \$220 million from CDC's chronic programs that help States fund programs to prevent and reduce heart disease and stroke, diabetes, obesity, tobacco use and cancer among others.

The National Center for Environmental Health protects public health by helping to control asthma, protect from threats associated with natural disasters and climate change, reduce, monitor and track exposure to lead and other hazards and ensure access to safe and clean water. We urge you to support and adequately fund all of the important programs within the center including the Safe Water program, the National Environmental and Public Health Tracking Network, the Climate and Health program, the Childhood Lead Poisoning Prevention program, the Environmental Health Laboratory program and the Asthma program. We also urge you to restore funding for the Built Environment and Health program which was eliminated in 2016. Unfortunately, the president's budget would reduce funding for NCEH by nearly \$25 million below fiscal year 2016 levels and would completely eliminate the Climate and Health program.

In 2015, opioids killed more than 33,000 individuals nationwide. CDC is working to provide States with resources for opioid overdose prevention programs and to ensure that health providers have the information they need to improve opioid prescribing and prevent addiction and abuse. We urge the committee to continue to provide CDC with the resources it needs to help assist States and health providers to combat this dangerous epidemic. While we are pleased the National Center for In-

jury Prevention and Control would receive level funding for addressing the opioid epidemic in the president's budget, the Center's budget is cut overall by \$19 million below fiscal year 2017 levels and funding for the Elderly Falls program and the Injury Control Research Centers are completely eliminated. We urge the committee to restore these cuts and adequately fund all efforts to prevent injuries and minimize their consequences.

The development of antimicrobial resistance is occurring at an alarming rate and far outpacing the struggling research and development of new antibiotics. We urge you to continue support for the CDC Antibiotic Resistance Initiative and CDC's efforts to bolster State and local health department efforts in prevention and control activities, enhanced data collection and surveillance and antimicrobial stewardship. Unfortunately, the president's budget proposal would cut more than \$22 million from these important efforts.

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. HRSA's discretionary budget authority is far too low to meaningfully respond to growing or emerging health demands such as the Zika virus and the opioid epidemic, while still addressing our Nation's persistent health needs. In fiscal year 2017, HRSA's discretionary budget authority was nearly 17 percent below the fiscal year 2010 level, and the president's fiscal year 2018 budget proposes to cut an additional \$674.5 million from HRSA's discretionary budget authority. The Nation faces a shortage of health professionals, and a growing and aging population which will demand more healthcare. Additionally, like the people they serve, the Nation's health workforce is also aging and approaching retirement, which will put additional stress on the healthcare system as they exit the workforce. HRSA grantees are well positioned to address these issues, but additional funding is required to effectively do so. For fiscal year 2018, we recommend restoring HRSA's discretionary budget authority to the fiscal year 2010 of \$7.48 billion.

HRSA programs have been successful in improving the health of people at highest risk for poor health outcomes. HRSA has contributed to the decrease in infant mortality rate, a widely used indicator of the Nation's health. The infant mortality rate decreased 14 percent from 2005 to 2015. People receiving care through the Ryan White HIV/AIDS Program achieve significantly higher viral suppression in comparison to the national average, which is central to preventing new HIV infections. The number of annual HIV infections has declined 18 percent between 2008 to 2014. And the Title X Family Planning Program has helped prevent over 901,000 unintended pregnancies in 2015. A strong investment from Congress is needed to build on these health improvements 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 24.2 million patients in underserved communities. Close to half of these health centers serve rural populations. Health centers deliver comprehensive, cost-effective care and have demonstrated their ability to reduce the use of costlier providers of care.

- Health Workforce* supports the education, training, scholarship and loan repayment of a broad range of health professionals. These are the only Federal programs focused on filling the gaps in the supply of health professionals, 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. While it has been well documented that increasing diversity among health professionals is associated with improved access to care for minority patients, the president's budget proposes to eliminate all programs designed to increase diversity in health professions, along with proposing to eliminate other important workforce programs.

- 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. The president's budget proposes to eliminate multiple MCH programs, including Autism and Other Developmental Disorders, Sickle Cell Service Demonstrations, Universal Newborn Hearing Screening, Emergency Medical Services for Children and Heritable Disorders.

- 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 533,000 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. Unfortunately, the president's budget proposes to eliminate the AIDS Education and Training Centers and the Special Projects of National Significance, which supports the development, evaluation and dissemination of innovative models of care to increase the retention rate and improve health outcomes of RWHAP clients.
- 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. The president's budget proposes cutting over 50 percent of funding for the Federal Office of Rural Health Policy by significantly reducing funding for Rural Health Policy Development, Rural Health Outreach Grants and Telehealth, and eliminating Rural Hospital Flexibility Grants and State Offices of Rural Health. We need to invest more in rural health, not less, and we thank the subcommittee for recognizing this need and providing an increase for HRSA's rural health programs in fiscal year 2017.
- Healthcare System* programs increase the access and availability of life-saving marrow, cord blood and donor organs for transplantation. Additionally, the Healthcare System Bureau supports poison control centers, the Nation's primary defense against injury and death from poisoning. PCCs play an important role in combatting the opioid epidemic by helping to define and trace the problem, and responding to calls from healthcare providers seeking treatment advice for the patient. However, it is expected to become more difficult to maintain inbound call volume with level funding given the increase in emergency room visits due to opioid overdoses.

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 become a healthier Nation.

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

PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR NUTRITION

Dear Chairman Blunt and Ranking Member Murray:

Thank you for the opportunity to provide testimony regarding fiscal year 2018 appropriations. The American Society for Nutrition (ASN) respectfully requests at least \$35 billion dollars for the National Institutes of Health (NIH) and \$170 million dollars for the Centers for Disease Control and Prevention/National Center for Health Statistics (CDC/NCHS) in fiscal year 2018. 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 (National Institutes of Health) 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 makes 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, U.S. death rates from heart disease and stroke have decreased by more than 60 percent, and the proportion of older adults with chronic disabilities has dropped by one-third. 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. A decade of flat-funding, followed by sequestration cuts, has taken a significant toll on NIH's ability to support research. Such economic stagnation is disruptive to training, careers, long-range projects and ultimately to progress. Increasing the NIH budget by at least \$2 billion dollars would help to restore the funding that was lost to sequestration and support additional competing research project grants. ASN recommends at least \$35 billion dollars for NIH in fiscal year 2018, to enable NIH to fund more R01 grants while still providing much needed increases to other parts of the portfolio. NIH needs sustainable and predictable budget growth in order 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 2018 funding level of \$170 million dollars for NCHS, \$10 million more than in fiscal year 2017, to help ensure uninterrupted collection of vital health and nutrition statistics, and help cover the costs needed for technology and information security maintenance and upgrades that are necessary to replace aging survey infrastructure.

The 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 the area of 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.

To continue support for the agency and its important mission, ASN recommends a fiscal year 2018 funding level of \$170 million for NCHS. Sustained funding for NCHS can help to ensure uninterrupted collection of vital health and nutrition statistics, and will help to cover the costs needed for technology and information security upgrades that are necessary to replace aging survey infrastructure.

Thank you for the opportunity to submit testimony regarding fiscal year 2018 appropriations for the National Institutes of Health and the CDC/National Center for Health Statistics.

Sincerely,

[This statement was submitted by Mary Ann Johnson, Ph.D., R.D., 2017-2018 President, American Society for Nutrition.]

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF NEPHROLOGY

KIDNEY RESEARCH FUNDING

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 requests a \$2 billion increase for the National Institutes of Health (NIH) over final fiscal year 2017 levels, with a proportional increase for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) for fiscal year 2018. A January 2017 Government Accountability Office report highlighted the pressing need for this investment in kidney research and innovation; annually, the costs for care of the approximately 650,000 patients in the Medicare End-Stage Renal Disease (ESRD) program exceed the budget allocation for the entire NIH. The society therefore requests an additional \$150 million per year above the current funding levels to support a Special Statutory Funding Program for Kidney Research at NIDDK. Investing in research to address this imbalance, delivering better outcomes for patients and bringing greater value to the Medicare program, should be an urgent priority. ASN also requests \$251 million for the Department of Health and Human Services (HHS) to execute a kidney prize competition, with \$125 million appropriated for fiscal year 2018 and the balance to be appropriated as designated by the Secretary of HHS.

Patients with kidney failure require either dialysis or a kidney transplant to live. Because there are not enough available organs for every patient who needs a kidney, most Americans with kidney failure rely on dialysis at an annual cost to Medicare of approximately \$87,000 per patient. In 1972, Congress made a commitment to provide Medicare coverage for every American with kidney failure so all Americans who needed dialysis or qualified for a transplant would have access to this life-saving therapy.

Consequently, ESRD is the only health condition Medicare automatically provides coverage for regardless of age and income. At an annual cost of nearly \$33 billion—more than NIH's entire budget of approximately \$31 billion—the Medicare ESRD Program represents more than 7 percent of Medicare's budget even though ESRD patients represent approximately 1 percent of the Medicare population. Despite the burden of kidney disease, ASN analysis of the GAO report data demonstrate that NIH funding for kidney research is the equivalent of just 1.7 percent of the annual total cost of care for kidney failure in Medicare.

Prize Competition for Artificial Kidney

Although the Federal Government is committed to caring for every American with kidney failure, for decades we have seen too few new therapies for kidney patients. Recognizing the imperative for innovative approaches to foster innovation from both public and private sectors, as confirmed by the GAO report, the American Society of Nephrology recently announced its pledge of \$7,000,000 to launch a prize competition incentivizing the development of an artificial kidney to improve the quality of life for patients with kidney diseases. The society aims to partner with Federal agencies to execute this catalyst for innovation. As ASN has committed a significant amount (\$7,000,000) of its own resources and budget, the society seeks to partner with the Department of Health and Human Services (HHS), including relevant agencies within it, the Department of Defense (DoD), and the Department of Veterans Affairs (VA), by requesting a commitment of \$251,000,000 to help support this prize competition that, by definition, only pays for success in the development of an alternative to current renal replacement therapy. Of the \$251 million appropriation, \$125 million would be made available for fiscal year 2018 and the balance would be appropriated as designated by the Secretary of HHS. This funding for HHS would be in total the equivalent of approximately one half of 1 percent in total of the Federal Government's annual cost of care for dialysis patients in Medicare and patients with advanced kidney disease in the Veterans Health Administration. Under a prize competition, ASN estimates that as many as 25 teams might compete, generating not only one winning team's artificial kidney, but numerous others that could have a sizeable impact on the market and patients' therapeutic options.

Investing in breakthroughs at NIDDK

Finally, 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 deter-

mine 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 stark findings in the January 2017 GAO report document that kidney diseases are a common burden on patients and require expensive therapies. Increased Federal funding for kidney disease research should be a national priority. The Special Statutory Funding Program for Type 1 Diabetes Research NIDDK is a successful model that has led to transformative breakthroughs—diabetes patients are on the cusp of access to an artificial pancreas—and should serve as a model to foster similar breakthroughs in kidney therapeutics. ASN believes the Type 1 Diabetes model—an additional \$150 million per year over 10 years—should be replicated in kidney research in the form of a Special Statutory Funding Program for Kidney Research. This long-overdue investment—annually, equivalent to less than one half of 1 percent of the annual Medicare expenditures on kidney failure—for NIDDK-funded kidney research above the current funding level would pay dividends from health and economic standpoints. By strengthening our nation’s investment in novel therapies, we can improve the lives of the more than 40 million Americans affected by kidney diseases and curb the startling costs associated with treating kidney failure.

Should you have any questions or wish to discuss NIDDK kidney research in more detail, please contact Rachel Meyer, Director of Policy and Government Affairs of the American Society of Nephrology, at rmeyer@asn-online.org.

ABOUT 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 17,000 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 THORACIC SOCIETY

SUMMARY: FUNDING RECOMMENDATIONS

(In millions \$)

National Institutes of Health	At least \$36 billion
National Heart, Lung & Blood Institute	3,300
National Institute of Allergy & Infectious Disease	4,961
National Institute of Environmental Health Sciences	735
Fogarty International Center	74.6
National Institute of Nursing Research	152
Centers for Disease Control and Prevention	7,800
National Institute for Occupational Safety & Health	339.1
Asthma Programs	29
Div. of Tuberculosis Elimination	243
Office on Smoking and Health	220
National Sleep Awareness Roundtable (NSART)	1
National COPD Action Plan	
COPD research through NHLBI	25
COPD tracking, surveillance and reporting through CDC	4

The ATS’s 15,000 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, tuberculosis, occupational lung disease, asthma, and critical illness.

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 tuberculosis. But sequestration, annual funding cuts and a lack of inflationary adjustments over the past decade have eroded the NIH research budget. In order to con-

tinue to accelerate the development of life-saving cures and treatments and innovative prevention interventions, it is essential to ensure strong, predictable funding increases across the full spectrum of NIH-supported research. The ATS is also concerned that due to reductions in Federal research funding, there is a lack of opportunities for young investigators who are the future of scientific innovation. We ask the subcommittee to reject the President's proposed 19 percent funding reduction to the NIH and instead provide at least \$36 billion in funding for the NIH in fiscal year 2018, in addition to funds included in the 21st Century Cures Act for targeted initiatives.

Despite the fact that lung disease is the third leading cause of death in the U.S., lung disease 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 lung 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 lung disease, research funding must grow.

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. 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.

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 urges Congress to reject the President's fiscal year 2018 budget proposal to cut CDC by \$1.2 billion and instead provide a funding level of \$7.8 billion for the CDC in fiscal year 2018.

COPD

Chronic Obstructive Pulmonary Disease (COPD) is the third 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. In 2010, the estimated economic cost of lung disease in the U.S. was \$186 billion, including \$117 billion in direct health expenditures and \$69 billion in indirect morbidity and mortality costs.

In May of this year, the National Heart Lung and Blood Institute released the COPD National Action Plan to address the growing health and economic burden of COPD in the U.S. The COPD National Action Plan calls for investments in research and public health programs, as well as contributions from patient, professional and health industry organizations, to improve the prevention, detection, treatment of COPD in the U.S. We urge the Subcommittee to carefully review the COPD National Action Plan and make an allocation of \$25 million in new funds to support COPD research at NIH and an additional allocation of \$4 million for the CDC to expand its COPD tracking, surveillance and reporting capabilities. We believe these

early investments to implement the COPD National Action Plan will be cost-savings investments to better address the growing burden of COPD in the U.S.

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 the Congress reject the President's budget proposal to eliminate OSH and instead provide a total funding level of \$220 million for the Office of Smoking and Health in fiscal year 2018.

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 2018 that funding for CDC's National Asthma Control Program be maintained at a funding level of at least \$30.596 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 2018 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 1.8 million lives each year. In the U.S., every State reports cases of TB annually and in 2015, the CDC reported the first national increase in TB cases in over 20 years. Drug resistant tuberculosis was identified as a serious public health threat to the U.S. in the 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 Comprehensive Tuberculosis Elimination Act (CTEA, Public Law 110–392), enacted in 2008, reauthorized programs at CDC with the goal of putting the U.S. back on the path to eliminating TB. The ATS recommends a funding level of \$243 million in fiscal year 2018 for CDC's Division of TB Elimination, as authorized under the CTEA, and urges the NIH to expand efforts to develop new tools to address TB. Additionally, in recognition of the unique public health threat posed by drug resistant TB, we urge BARDA to support research and development into new drug-resistant TB diagnostic, treatment and prevention tools.

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 \$4,961 billion for the National Institutes of Allergy and Infectious Disease (NIAID) to spur research into rapid new diagnostics, new treatments and other activities and \$512 million for the Biomedical Advanced Research and Development Authority (BARDA) to support antimicrobial research and development.

RESEARCHING AND PREVENTING OCCUPATIONAL LUNG DISEASE

As Congress considers funding priorities for fiscal year 2018, 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 Marc Moss, MD, President, American Thoracic Society.]

PREPARED STATEMENT OF AMFAR, THE FOUNDATION FOR AIDS RESEARCH

Dear Chairman Blunt and Ranking Member Murray:

Thank you for the opportunity to submit testimony to the Senate Subcommittee on Labor, Health and Human Services, Education, and Related Agencies. amfAR, The Foundation for AIDS Research is a leading organization dedicated to the support of HIV/AIDS research. As your Subcommittee begins drafting the fiscal year 2018 funding legislation for the Department of Health and Human Services and related agencies, we ask that you maintain the necessary funding so that our country can continue to address HIV/AIDS in the United States.

Currently, 1.2 million Americans are living with HIV in the United States, and an estimated 37,600 new infections occurred in 2014. Though a lifelong infection, consistent treatment can help people live healthy lives. However, the rapid increase in opioid use lends new urgency to the fight against HIV, since injection drug use is a major risk factor for the acquisition of both HIV and hepatitis C. In 2015, Indiana experienced its largest HIV outbreak of all time, in which both HIV and hepatitis C spread rapidly through networks of injection drug users in Scott County. Although the number of injection drug users in New York City is four times the total population of Scott County, Indiana, at the height of the epidemic more people were infected with HIV in Scott County in just 3 months than the total number of PWID infected in New York City in an entire year. However, achieving epidemic control is only achievable when everyone can access preventive and treatment health services. While we are grateful to the Committee for maintaining funding for almost all domestic HIV and related programs, we are disappointed that Ryan White Part C was cut by \$4 million, and CDC STD Prevention was cut by \$5 million. As you craft the fiscal year 2018 bills, we urge you to prioritize the restoration of funding for these two very important programs. Specifically, in the fiscal year 2018 budget, we are asking Congress to approve:

An increase of \$145.8 million for the Ryan White HIV/AIDS Programs for a total of \$2.465 billion, distributed in the following manner: 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, and Part F/SPNS: \$34 million.

The Ryan White HIV/AIDS Program acts as the payer of last resort, providing medications, medical care, and essential coverage completion services to approximately half a million uninsured, and/or underinsured individuals living with HIV in the United States. The program has been successful in achieving more than 83 percent (an increase of over 21 percent since 2010) viral suppression, compared to just 30 percent of all HIV-positive individuals nationwide. This is due not only to

access to expert quality healthcare and effective medications, but also to the patient centered, comprehensive care that the program provides.

A key role of the Ryan White Program is to provide care completion services to clients who have public or private insurance, including services inadequately covered by private insurance including case management, mental health and substance use services, adult dental services, transportation, legal, and nutritional support services. The Ryan White Program, particularly the AIDS Drug Assistance Program, assists with premiums, deductibles, and cost-sharing so that clients can access comprehensive and effective medical care and treatment without cost barriers.

Many Ryan White Program clients live in States that have not expanded Medicaid and must rely on the Ryan White Program as their only source of HIV/AIDS care and treatment. This is particularly true in the South, which accounts for an estimated 44 percent of all people living with HIV, and where death rates from HIV in some States are triple that of other regions. According to the CDC, fewer people living with HIV in the South are aware of their infection than any other region in the country, and thus fewer people are receiving treatment and may transmit to others. Providing robust funding for Ryan White is particularly important to these jurisdictions in this changing and uncertain healthcare landscape.

We request that the CDC Division of HIV Prevention receive a total of \$822.7 million in fiscal year 2018, an increase of \$67 million (note: this does not include the request for DASH).

There has been incredible progress in the fight against HIV/AIDS over the last 35 years. The CDC recently reported that between 2008 and 2014, the number of new HIV infections declined by 18 percent, resulting in an estimated cost savings in medical care of \$14.9 billion. However, there are still an estimated 37,600 new infections each year. While HIV is declining in certain communities, historical progress is threatened by the rise in injection drug use in recent years; indeed, 1 in 10 HIV diagnoses are among people who inject drugs. Additionally, the burden of HIV and AIDS is not evenly distributed across States and regions. The South is disproportionately impacted, containing 50 percent of the new HIV infections in 2014, while representing only 37 percent of the U.S. population.

Preventing HIV will require continued funding for the CDC Division of HIV Prevention so that the CDC and its State, local, and community-based grantees can maintain recent gains and intensify prevention efforts in communities where HIV is most prevalent, through HIV testing programs, targeted prevention interventions, public education campaigns, and surveillance activities. Through expanded HIV testing efforts, largely funded by the CDC, the number of people who are aware of their HIV status continues to increase. The CDC is the only organization that performs national and subnational monitoring and surveillance of disease outbreaks, serving a critical role in the rapid identification of, and response in, the communities where outbreaks occur.

We request that the CDC's Division of STD Prevention receive a total of \$192.3 million in fiscal year 2018, an increase of \$40 million.

An essential component to our HIV prevention strategy must include strong investments in STD prevention programs at the CDC. Rates of chlamydia, gonorrhea, and syphilis have surged to a 20 year high; 2015 was the fourth year in a row of double digit increases of syphilis rates and congenital syphilis (syphilis transmitted from a woman to a fetus) have risen four-fold in the last 3 years, in conjunction with large increases in rates of drug resistance. These increases threaten to undue progress made in HIV prevention, given that having an existing STD biologically increases the risk of HIV acquisition. The CDC estimates that nearly 20 million new STD infections occur every year in the U.S., which account for \$16 billion in healthcare costs. Public health infrastructure has been continually strained by budget reductions and health departments across the country cannot address these growing epidemics alone.

We request that the CDC's Division of Viral Hepatitis receive a total of \$70 million in fiscal year 2018, an increase of \$36 million.

New cases of hepatitis C virus (HCV) have nearly tripled in the past 5 years. There are nearly 55,000 new hepatitis transmissions each year, and the CDC estimates that between 2010 and 2014 the country saw a more than 150 percent increase in new HCV infections. Similar to the factors that resulted in the 2015 HIV and HCV outbreak in Scott County, Indiana, these new hepatitis infections are largely driven by increases in injection drug use. Of the nearly 5.3 million people living with viral hepatitis in the U.S., as many as 65 percent are not diagnosed. Hepatitis is the leading cause of liver cancer, a lethal and fast-growing cancer, and the number of HCV-related deaths now surpasses the number of deaths associated for all other notifiable infectious diseases combined. The CDC's Division of Viral Hepatitis (DVH) is currently funded at only \$34 million for the entire country, well

below the CDC's \$308 estimated need for the national viral hepatitis program. We have the tools to prevent this growing epidemic, but only with significantly increased funding can there be an adequate level of testing, education, screening, treatment, and the surveillance needed to reduce new infections and eliminate hepatitis in the U.S.

We urge you to maintain the current appropriations language that allows access to syringe services in those jurisdictions that are experiencing or at risk for a significant increase in HIV or hepatitis infections due to injection drug use.

Sharing injection materials is an efficient route of viral transmission that allows the direct transfer of infected blood into the bloodstream. The CDC recently reported that the number of new HIV infections among people who inject drugs have declined by 56 percent between 2008 and 2014, due in large part to syringe service programs at the State and local level. However, these declines might be in jeopardy given the recent increase in opioid use in many parts of the country and insufficient access to services like syringe exchange programs, particularly in rural communities. Syringe service programs are a proven effective tool to reduce the spread of HIV and HCV from injection drug use, as well as link people drug treatment and healthcare. This has been recognized by the Federal Government, which now allows Federal funding to be used for all syringe service program costs, beside the purchase of needles, in jurisdictions that are experiencing or at risk for an HIV/HCV outbreak due to injection drug use.

Consistent with the most recent Trans-NIH AIDS Research By-Pass Budget Estimate for fiscal year 2017, we request that HIV research at the NIH receive a total of \$3.225 billion in fiscal year 2018.

AIDS research supported by the NIH is far reaching and has supported innovative basic science for better drug therapies, behavioral and biomedical prevention interventions, and has saved and improved the lives of millions around the world. AIDS research at NIH has proved the efficacy of pre-exposure prophylaxis (PrEP), the effectiveness of treatment as prevention, and the first partially effective AIDS vaccine. However, without increases in HIV research, advances in cure research will be stopped in their tracks, gains made in newer more effective HIV treatments and vaccines will be slowed, and funding will be insufficient to support young researchers who are critical to the future of HIV and other diseases research. In addition to all benefits this research has provided to the field of HIV/AIDS, discoveries made in one area of research often benefit the treatment of a wide variety of human diseases. AIDS research has contributed to the development of effective treatments for cancer, hepatitis, heart disease, and osteoporosis. This research has also provided insights into new ways of treating autoimmune diseases and severe vision loss.

We ask that you reject any effort to decrease or eliminate the Fogarty International Center as part of the National Institute for Health.

The Fogarty International Center is a bipartisan initiative created to promote collaborative research partnerships between U.S. scientists and their international counterparts to drive forward important biomedical advances, particularly on important diseases like Zika, HIV, or Ebola. About 5,000 scientists worldwide have been trained through Fogarty programs and the center funds over 400 research and training projects at 100 U.S. universities around this country. In fact, more than 80 percent of Fogarty's extramural grant budget goes to U.S. academic institutions. Brazilian ultrasound specialists who had been trained under a Fogarty grant were among the first to detect early signs of brain deformity in fetuses with Zika and U.S.-trained workers helped to halt the spread of Ebola in Nigeria. Fogarty's work with partners in other countries is important to our biosecurity and surveillance capacity and serves as a diplomatic resource. Of considerable interest to U.S. national security is the Fogarty Center's Division of International Epidemiology and Population Studies (DIEPS), which conducts research on domestic and U.S. countermeasures for pandemic influenza and potential bioterror agents. Losing DIEPS would hamper our Nation's ability to respond to emerging public health threats.

We request that the CDC Division of Adolescent and School Health receive a total of \$50 million in fiscal year 2018, an increase of \$16.9 million.

More than one in five new HIV infections are among young people between the ages of 13 and 24. DASH is a unique source of support for our Nation's schools, helping education agencies provide school districts and schools with the tools to implement high-quality, effective, and sustainable programs to reduce HIV, other STDs, and unintended pregnancies among adolescents. The most recent CDC School Health Profiles revealed that less than half of all high schools and only 20 percent of middle schools provide all of the CDC-identified sexual health topics. In addition to supporting critically needed adolescent health behavior reporting and research, increased funding to DASH would help build schools' capacity to implement quality

sexual health education, support student access to healthcare, and enable safe and supportive environments.

We request the Minority AIDS Initiative (MAI) be funded at \$610 million in fiscal year 2018, an increase of \$183 million. Please note that most of these funds are contained within the budgets of the programs described above.

Racial and ethnic minorities in the U.S. are disproportionately impacted by HIV/AIDS. African Americans, more than any other racial/ethnic group, continue to bear the greatest burden of HIV in the U.S. In 2015, while African Americans only comprise 12 percent of the US population, they accounted for 45 percent of all HIV diagnoses. In 2014, Hispanics accounted for almost a quarter of all new HIV infections despite representing only 17 percent of the U.S. population. The Minority AIDS Initiative aims to improve the HIV-related health outcomes for racial and ethnic minorities and reduce HIV-related health disparities. The resources for MAI supplement other Federal HIV/AIDS funding and are designed to encourage capacity building, innovation, collaboration, and the integration of best practices. The HHS Secretary MAI Fund supports cross-agency demonstration initiatives to support HIV prevention, care and treatment, and outreach and education activities across the Federal Government.

CONCLUSION

Maintaining funding for the CDC and the Ryan White HIV/AIDS Program are vitally important to addressing the public health threats of HIV, HCV, and opiate abuse. Cuts to these programs would make no appreciable contribution to deficit reduction and would leave communities vulnerable to outbreaks of disease, patients without access to lifesaving treatment, and hamper our ability to monitor patterns of disease. We appreciate the continuous support of these programs from this Subcommittee and respectfully request robust funding in fiscal year 2018.

Sincerely,

PREPARED STATEMENT OF THE AMPUTEE COALITION

Dear Chairman and Committee Members:

The Amputee Coalition appreciates the opportunity to provide testimony to the committee regarding the Administration for Community Living, and specifically, funding for the National Limb Loss Resource Center. The Amputee Coalition is a 501(c)(3) nonprofit organization representing the more than two million Americans living with limb loss as well as those born with limb difference, their family members, caregivers, and friends. Our mission is to reach out and empower people affected by limb loss to reach their full potential through education, support, and advocacy, and to promote limb loss prevention.

With a sizeable community already, and more than 500 amputations being performed every day throughout the United States, there remains a significant number of Americans seeking information, support and programs that can help individuals with recovery, readjustment, and community reintegration. As stewards of a competitive cooperative agreement that funds the National Limb Loss Resource Center, the Amputee Coalition provides unparalleled programs, information, resources, and support for people living with or affected by limb loss and limb difference.

To this end, the Amputee Coalition is requesting level funding of \$2.81 million to support the National Limb Loss Resource Center, funded under the Department of Health and Human Services, Administration for Community Living.

For more than 30 years, the Amputee Coalition has worked to serve the limb loss community and has relied (and continues to rely) on support from private donations, sponsorships, memberships, and Federal support. Since 1997, Federal funding has helped support a cooperative agreement to fund the National Limb Loss Resource Center to enhance the impact and ability to serve the unique and distinct needs of the limb loss population. In the past 20 years, the limb loss community has seen significant advancements in patient care and technology advancements as well as the availability of resources, programs and information to learn about recovery, how to live well with limb loss, and how to reintegrate into the community.

In addition to supporting a unique and diverse population, funding for the National Limb Loss Resource Center has also provided improvements in patient outcomes and mental health through the Amputee Coalition's Certified Peer Visitor Program, the Promoting Amputee Life Skills (PALS) program, and the Amputee Coalition's Well Being project. The Amputee Coalition has also been successful in leveraging grant dollars to further the impact of programs and services and enhance the quality of programs and resources provided. This leveraging includes the development and management of interagency and intergovernmental partnerships (as

well as external partnerships), which have provided even greater value and impact to the community.

Examples of areas the Amputee Coalition has leveraged funding with intergovernmental partnerships over the years includes work around education and prevention with Native American communities as part of the ACL's Title VI programs, work with Department of Homeland Security (DHS) and the Transportation Security Administration (TSA), and Centers for Medicare/Medicaid Services (CMS), as well as the Amputee Coalition's partnerships with the Department of Defense (DoD) and Veterans Affairs (VA).

Moreover, both the DoD and VA implement the Amputee Coalition's peer support program and provide access to materials, resources, and educational and community reintegration events for wounded warriors and veterans. Each of these resources and programs are established, in part, with funding for the National Limb Loss Resource Center. Without continued funding support for the National Limb Loss Resource Center, there would be a significant gap in information made available to the general community, as well as our service members and veterans living with limb loss. In fact, the VA, as part of their Amputation System of Care stated in their performance evaluation of the Amputee Coalition's partnership with them that, "VHA clinicians report the materials are of the highest quality and relates to their practice," and that "market research showed this vendor to offer materials at the most reasonable cost. If we [VA] were to produce the same materials available the cost and time would far exceed the contract costs."

In addition to intergovernmental partnerships, the Amputee Coalition also works with clinicians, researchers, and patients to evaluate and provide direction on areas to improve patient outcomes and access to care. With up to 55 percent of amputations resulting from vascular disease and diabetes, primary and secondary prevention programs and resources are a significant priority for the limb loss community. The Amputee Coalition works with strategic partners on these prevention initiatives and to develop resources that reduce impacts on individuals, reduce healthcare costs, and make it easier for individuals to remain active and contributing members of their communities. For the nearly 45 percent of amputations that are a result of trauma, information and resources are necessary to meet the unique needs of caring for an individual's residual limb, and educating individuals about overuse syndrome, pain management, and living with limb loss so as to reduce or eliminate additional health complications that can result from this lack of information.

While it's important to eliminate duplicative efforts across departments or funding mechanisms in the Federal budget this issue doesn't exist for the limb loss community. The funding for the National Limb Loss Resource Center under the ACL is the only place in the Federal budget that specifically targets resources, programs and services for all Americans living with limb loss, including our wounded warriors and veterans. The Amputee Coalition recognizes and values the roles that Aging and Disability Resource Centers (ADRC's), Centers for Independent Living (CIL's), and Assistive Technology (AT) grants provide, and the care provided to wounded warriors and veterans by the DoD and the VA. This is why the Amputee Coalition partners with and refers individuals to these entities when appropriate and likewise these entities partner with the Amputee Coalition so as to ensure there is no duplication of efforts. With that being said, ADRC's, CIL's, and AT grants do not currently create or distribute materials specific to people with limb loss and limb difference, nor do they provide programs or services that are specific to meeting the unique needs of people with limb loss. While these entities serve broad disability populations, they are not readily equipped to address the more specific recovery, re-adjustment, and community reintegration needs that the National Limb Loss Resource Center provides for people living with or affected by limb loss and limb difference.

The limb loss community values the commitments Congress and past administrations have made to support the National Limb Loss Resource Center, and it's important to recognize that support has constituted an investment that continues to pay dividends by regularly continuing to improve resources and programs and further the impact to those living with or affected by limb loss and limb difference. This investment and the knowledge, information, resources and programs that have resulted over the past 20 years highlights the fact that the resources offered by the National Limb Loss Information Center are not easily or readably replicated or comparable to the information available for broader disability populations that ADRC's and CIL's tend to serve in their communities.

Some of the additional programs and resources offered through funding support for the National Limb Loss Resource Center and which are not duplicative or easily replicated by any other entities include:

- Specific resources related to the unique recovery and rehabilitation process for people living with limb loss
- Unique pain management information resources dealing with neuropathic pain as well as physical pain accompanying limb loss
- Conferences and community events that serve to address the needs of the limb loss community and provide networking and support opportunities
- Camps for children living with limb loss so they may meet mentors who can provide guidance and direction and which provide opportunities for children to meet peers and have the same opportunities as other children to grow up and be leaders and active members of their community
- Peer support programs that match people seeking support with trained and certified volunteers who have a similar level of limb loss which resulted from a similar cause, who are of a similar age, and more, which provides unmatched support that can't be accomplished by meeting with someone who hasn't shared the same experience and recovery process
- Video resources and webinars that meet specific needs for people living with limb loss as well as family members, caregivers, and supporters
- Partnerships and support for community projects and resources
- Partnerships with leading rehabilitation hospitals, research entities, and professional associations which seek to advance patient care and outcomes for the limb loss community
- Ability to utilize designated funds to support individuals during a time of crises/disaster that results in individuals being affected by limb loss, including most recently, the Haiti Earthquake of 2010 and the Boston Marathon Bombing of 2013

With a resource center staff certified by the Alliance of Information and Referral Systems (AIRS), more than 40 unique publications and brochures to cover all of the different issues affecting people living with limb loss, a master trainer on staff to certify volunteer peer visitors, and a network of over 360 support groups and 750 certified peer visitors, the Amputee Coalition has worked to ensure people living with limb loss have access to the best resources, support, and programs available to serve their needs.

The Amputee Coalition strongly believes that continued Federal funding at a level of \$2.81 million for the National Limb Loss Resource Center is necessary to continue these vital programs and services for the over two million Americans living with limb loss and the countless more who are at risk for amputation or who may be impacted by limb loss in the future, including our wounded warriors and veterans.

Thank you in advance for your time and consideration, and for your support for Americans living with limb loss and limb difference.

Sincerely,

[This statement was submitted by Jack Richmond, President/CEO, and Dan Berschinski, Board Chair, Amputee Coalition.]

PREPARED STATEMENT OF THE ARTHRITIS FOUNDATION

On behalf of the 54 million adults and children living with doctor-diagnosed arthritis in the U.S., 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 2018. 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 2018.

Arthritis affects 1 in 5 Americans and is the leading cause of disability in the U.S., according to CDC. It limits the daily activities of nearly 23 million Americans and causes work limitations for 40 percent of the people with the disease. This translates to \$156 billion a year in direct and indirect costs from two forms of arthritis alone—osteoarthritis (OA) and rheumatoid arthritis (RA). There is no cure for arthritis, and for some forms of arthritis like OA, there is no disease-modifying pharmaceutical treatment. Research is critical to build towards a cure, to develop better treatments with fewer severe side effects, and to 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. It 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 Enhance Fitness 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. Because of this support, we know that 1 in 5 Americans has doctor-diagnosed arthritis, including 29 percent of people in Missouri and 24 percent of people in Washington, and 694,000 of those people in Missouri and 657,000 of those people in Washington are limited by their arthritis. CDC was able to complete 16 publications in 2016, including updated prevalence statistics, rates of obesity among people with arthritis, and updated estimates of the number of Americans who will have arthritis by 2040: a staggering 78 million. 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, and combined with previous flat funding, 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 2018 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 3 States, support more national grants, and increase its investment in public health research. Therefore, we urge you to fund the CDC Arthritis Program at \$16 million in fiscal year 2018.

NATIONAL INSTITUTES OF HEALTH

As previously stated, there is no cure for arthritis, and for some forms of the disease, no effective pharmaceutical treatments. Even for auto-immune 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, such as: how 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 2018 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 2018 Labor-HHS-Education appropriations bill, we urge you to fund the CDC Arthritis Program at \$16 million and provide sufficient funds to the NIH in order to continue the investment in improving the lives of people with arthritis.

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, and Advance CTE, representing the State and territory leaders of our Nation's Career and Technical Education (CTE) system, we 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 will 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 U.S. Department of Education, Office of Career, Technical, and Adult Education, to \$1.3 billion in the fiscal year 2018 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, tech centers and community colleges, providing capacity-building resources through need-based formulas. 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 prepares 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 individuals, States and communities across the country. In Wisconsin, taxpayers receive \$12.20 in returns for every dollar invested in the technical college system. Secondary CTE program completers account for more than \$13 million in annual tax revenues in Tennessee, while every dollar invested in secondary CTE programs in Washington State yields a \$9.00 return. Students involved in CTE programs also experience these direct returns.¹ The average high school graduation rate for students concentrating in CTE programs is 93 percent,² compared to the national adjusted cohort graduation rate of 83 percent.³ CTE students were significantly more likely than their non-CTE counterparts to report developing problem-solving, project completion, time management, critical-thinking and other essential skills while in high school.⁴ Additionally, 81 percent of high school dropouts say relevant, real-world learning opportunities would have kept them in school and on track to graduate.⁵

Federal support for CTE is especially critical now, as overall funding has not kept pace with the demand for CTE programs. In 2014, Philadelphia public schools received 11,000 applications for only 2,500 available spaces at CTE programs in the district. A survey of school districts in Massachusetts found that at least 4,600 stu-

¹ Association for Career and Technical Education, "Investing in Career and Technical Education Yields Big Returns," 2016, https://www.acteonline.org/uploadedFiles/What_is_CTE/Fact_Sheets/ROI_of_CTE_map_2016.pdf.

² U.S. Department of Education, Office of Career, Technical, and Adult Education, Consolidated Annual Report (CAR) for the Carl D. Perkins Career and Technical Education Act of 2006.

³ U.S. Department of Education, National Center for Education Statistics, "The Condition of Education 2017," May, 2017, <https://nces.ed.gov/programs/coe/>.

⁴ Lekes et al., National Research Center for Career and Technical Education, University of Minnesota, "Career and Technical Education Pathway Programs, Academic Performance, and the Transition to College and Career," May, 2007. http://www.nrccte.org/sites/default/files/publication-files/cte_pathway_programs.pdf.

⁵ Civic Enterprises in association with Peter D. Hart Research for the Bill and Melinda Gates Foundation, "The Silent Epidemic Perspectives of High School Dropouts," March, 2006, <https://docs.gatesfoundation.org/Documents/thesilentepidemic3-06final.pdf>.

dents were on waiting lists for CTE programs statewide.⁶ In a portion of New Jersey's CTE system, there are 2.5 applicants for every available seat.⁷

Congressional appropriations for the Perkins programs have been persistently underfunded in spite of continued calls from policymakers and the public for expanding career education and skills training opportunities. Funding for the Perkins Basic State Grant is still \$5.4 million below its pre-sequestration level. From fiscal year 2007 through fiscal year 2016, total Perkins grant funding to States declined by 13 percent (a 23 percent decline when adjusted for inflation)—nearly \$170 million less in funding available to support CTE. In fact, over 20 States receive a Basic State Grant that is at or below the amount they received in 1998.

President Trump recently claimed that his Administration was, “working to ensure our workers are trained for the skilled technical jobs that will, in the future, power our country.” Despite the positive messages about CTE from the president and Secretary DeVos, the fiscal year 2018 budget request would result in deep cuts to programs directly serving CTE students. It proposes a \$168 million (15 percent) cut in funding for the Perkins Basic State Grant. The cut would be so deep that it would actually trigger a “hold harmless” provision in the Perkins Act and its “ratable reduction” rule, which means that certain States would see disproportionately larger cuts to their funding allocations before all States are reduced.⁸ States like South Carolina, Connecticut, Florida, Colorado, Georgia and Nevada would lose between 17 and 52 percent under this plan.⁹

In letters to this subcommittee, the Nation's governors and chief state school officers reaffirmed their support for Perkins funding. The governors asserted, “The Federal funding stream for Perkins must remain strong to ensure students are prepared for a 21st century economy.”¹⁰ At a time when millions of job openings go unfilled due to growing skills gap, the president should double-down on our investment in CTE, not propose drastic cuts.

The Administration has requested an additional \$20 million for Perkins National Programs to implement a new competitive grant that would support certain CTE programs in STEM fields. By the Administration's own estimate, only five secondary/postsecondary consortia grantees would receive funding through this competition.¹¹ The proposal would invariably create winners and losers among CTE programs, particularly disadvantaging those that serve rural and high-needs area that often lack the resources to compete for Federal funding. Moreover, creating a new, untested grant program run by the U.S. Department of Education is inconsistent with the Administration's stated goal of devolving greater authority to States and local education providers. It is our position that limited Federal resources for education and job training are better directed to proven, formula-driven programs that serve all students.

Increasing the Perkins Basic State Grant to \$1.3 billion could support approximately 1.7 million additional students¹² with expanded access to CTE programs of study that create seamless career pathways, career guidance and counseling services, updated technology and equipment in the classroom, and professional development opportunities for teachers. This request has been endorsed by 34 Senators who have championed a strong Federal investment in CTE, including distinguished members of this subcommittee. We appreciate your continued leadership and thoughtful consideration of this request. We look forward to working with the subcommittee on advancing this critical investment in our Nation's workforce. Please feel free to contact Mitch Coppes (mcoppes@acteonline.org), ACTE's Legislative and Regulatory Affairs Manager, or Kathryn Zekus (kzekus@careertech.org), Advance

⁶Uvin, Johan, Lul Tesfai, Sharon Miller, U.S. Department of Education, Office of Career, Technical, and Adult Education blog, “Let's Commit to Giving CTE Students the Opportunity They Demand and Deserve,” February, 2016, <https://sites.ed.gov/octae/2016/02/12/lets-commit-to-giving-cte-students-the-opportunity-they-demand-and-deserve/>.

⁷Forsyth, Kathryn, New Jersey Council of County Vocational-Technical Schools blog, “NJ 101.5 Highlights the Value of Career and Technical Education and Opportunities in Trade and Technical Careers,” September, 2016, <http://www.careertechnj.org/nj-101-5-highlights-the-value-of-career-and-technical-education-and-opportunities-in-trade-and-technical-careers/>.

⁸20 U.S. Code § 2321(a)(5).

⁹U.S. Department of Education, fiscal years 2016–2018 State Tables, May, 2017, <https://www2.ed.gov/about/overview/budget/statetables/18stbyprogram.pdf>.

¹⁰Letter from the National Governors Association to U.S. Senate and House of Representatives Appropriations Subcommittees on Labor, Health and Human Services, Education and Related Agencies, May, 2017.

¹¹U.S. Department of Education, fiscal year 2018 Justifications of Appropriations Estimates to the Congress, Career, Technical, and Adult Education, May, 2017, <https://www2.ed.gov/about/overview/budget/budget18/justifications/m-ctae.pdf>.

¹²Estimate of per-student investment based on CAR enrollment data, 2014–15, and funding for Career and Technical Education State Grants in the Consolidated Appropriations Act, 2016.

CTE's Senior Associate, Federal Policy, should you have any questions about our comments.

PREPARED STATEMENT OF THE ASSOCIATION FOR CLINICAL AND TRANSLATIONAL
SCIENCE AND THE CLINICAL RESEARCH FORUM

(COLLECTIVELY THE COALITION FOR CLINICAL AND TRANSLATIONAL SCIENCE OR CCTS)
FISCAL YEAR 2018 APPROPRIATIONS RECOMMENDATIONS

- CCTS joins the broader medical research community in thanking Congress for providing a \$2 billion funding increase for NIH for fiscal year 2017 and in requesting a subsequent \$2 billion funding increase for fiscal year 2018 to bring NIH's budget up to \$36.1 billion (consistent with the necessary level of funding identified through the Cures effort).
- Please provide the National Center for Advancing Translational Sciences (NCATS) with a funding increase proportional to the overall NIH increase for fiscal year 2018 to facilitate expansion and advancement of important programs, including the Cures Acceleration Network and the Clinical and Translational Science Awards.
- Please continue to provide a specific annual allocation for the Clinical and Translational Science Awards (CTSA) program at NCATS and increase fiscal year 2018 funding to \$545 million (a \$29 million increase).
- Please provide the Institutional Development Awards (IDeA) program at the National Institute of General Medical Sciences with a subsequent fiscal year 2018 increase of \$15 million to bring total funding for the program up to \$348 million.
- Please provide the Research Centers at Minority Institutions (RCMI) program at the National Institute on Minority Health and Health Disparities with a \$5 million funding increase in fiscal year 2018 to bring RCMI funding up to not less than \$63.1 million.
- CCTS joins the broader medical research community in asking Congress to reverse the recent trend of cuts for the Agency for Healthcare Research and Quality (AHRQ) by providing \$363.7 million in fiscal year 2018, a restoration of funding to the fiscal year 2015 (pre-cut) level.
- Please continue to support research training and career development activities at AHRQ, specifically established "K" and "T" award mechanisms.

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 (CRF)

CRF 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, CRF has grown to sixty members from academia, industry, and volunteer health organizations. CRF 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, CRF 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

Thank you for your leadership on the Cures Act. The additional resources made available for NIH are of critical importance and have the potential to bolster emerging scientific activities as well as support the career development pipeline for young investigators. However, the promise of Cures requires meaningful annual appropriations as specific funds for cancer, precision medicine, and brain activities are not sufficient to adequately support important research across all Institutes and Centers. Moreover, the lack of a substantial NIH appropriation for fiscal year 2018 would put further downward pressure on pay lines, limit new scientific opportunities, and continue to de-incentivize a career in medical research for the next generation of medical investigators.

CCTS joins the larger medical research and patient care community in thanking Congress for providing a \$2 billion fiscal year 2017 funding increase for NIH (along with increases for CTSA's and the IDeA program). Recent investment in NIH is already advancing key programs and addressing critical needs. However, any progress is fragile and could easily be undone by adopting cuts, controversial resource management policies, or even level-funding. At this time, crucial please sustain the investment in NIH moving into fiscal year 2018.

Thank you also for your continued commitment to important clinical and translational research programs at NIH focused on improving how research is conducted, particularly through connections and collaboration. In addition to continuing to invest in programs like CTSA's, IDeA, and RCMI. When the CTSA program was conceptualized and established, it was designed to revolutionize research and modernize how research is conducted. The CTSA program is meant to link at least 60 centers through meritorious awards and be fully funded at about \$750 million. While the funding level is currently just over \$500 million, just over 60 centers are supported and a 2103 review by the Institute of Medicine found that the program was effectively working towards its goals. CCTS thanks Congress for the ongoing commitment to CTSA's, the maintenance of the specific funding for the program, and the thoughtful protection of the goal and scope of the program.

We find it unfortunate that misperceptions about the unique role of AHRQ and the agency's value to public health persist. NIH cannot absorb the mission of AHRQ as outlined in the president's fiscal year 2018 budget request to Congress. Moreover, funding cuts continue to hamstring and erode programs of tremendous value to patients and providers. For fiscal year 2018, we hope Congress will restore funding for AHRQ to fiscal year 2015 levels (about \$363 million).

Thank you for your consideration of these requests. CCTS is happy to serve as a resource if you would like any additional information on how policy decisions and funding impact key programs and the research training and career development pipeline.

[This statement was submitted by Harry P. Selker, MD, MSPH, Association for Clinical and Translational Science and the Clinical Research Forum (collectively the Coalition for Clinical and Translational Science or CCTS).]

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 \$34 million for HAI research activity conducted by the Agency for Healthcare Research and Quality (AHRQ) and \$4.7 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 2018, 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 track outbreaks similar to antibiotic resistant Salmonella Heidelberg that affected eight States in 2016. Eight of the 21 individuals infected required hospitalization. Reporting networks supported by the Antibiotic Resistance Solutions Initiative enable a timely response infections and/or outbreaks across jurisdictions.

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), catheter-associated urinary tract infections (CAUTI), surgical site infections (SSI),

methicillin-resistant *Staphylococcus aureus* (MRSA), and *Clostridium difficile* infections reported by more than 6,000 hospitals, and bloodstream infections reported by more than 7,000 dialysis 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 \$34 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 DISEASES

SHEA and APIC support \$4.7 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 2018 APPROPRIATIONS

National Institutes of Health

—As a member of the Ad Hoc Group for Medical Research, APS (Association for Psychological Science) recommends \$36.1 billion for NIH in fiscal year 2018, a \$2 billion increase (and \$9.2 billion above the Administration's request for NIH) that should be spread across all Institutes and Centers.

- 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 people who urgently need them now.
- Strengthen support for basic behavioral science research and training at NIH, in recognition that many of the most pressing health concerns facing this Nation—including cancer, heart disease, suicide, addiction, violence, teen pregnancy, health disparities, diabetes, are behavioral in their origins, manifestations, and solutions, and it is critical to understand the fundamental “active ingredients” involved in the connections between health and behavior.

HRSA’s Bureau of Health Workforce

- APS supports \$7.48 billion for the Health Resources and Services Administration’s discretionary programs in fiscal year 2018, and within that, a minimum of the fiscal year 2017 omnibus funding level for HRSA’s Bureau of Health Workforce. This is \$1.98 billion and \$68.1 million more than requested by the Administration, respectively.
- APS encourages the Committee to adopt bill and report language to expand eligibility for workforce programs 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.

Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to provide testimony as you consider funding priorities for fiscal year 2018. 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 and its representation at the national and international level. 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 drug and alcohol 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 \$36.1 billion, an increase of \$2 billion for the National Institutes of Health in fiscal year 2018. 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 to NIH, there are a number of programs within the jurisdiction of the subcommittee that are important to APS, including the Health Resources Services Administration’s (HRSA) Bureau for Health Workforce Training Programs. We join the Friends of HRSA, an advocacy coalition of more than 175 national organizations, in recommending \$7.48 billion for discretionary Health Resources and Services Administration programs in the fiscal year 2018 bill.

RECOGNIZING THE LEADERSHIP OF THE SUBCOMMITTEE

Mr. Chairman, APS appreciates your leadership and the leadership of this Subcommittee in supporting public health service programs. Your support is greatly recognized and appreciated. We applaud the Committee’s leadership in making progress in these important areas and to allocating increased funding to these programs during periods of fiscal austerity. We are particularly grateful for your leadership in securing a \$2 billion increase for the NIH in fiscal year 2017.

NATIONAL INSTITUTES OF HEALTH

As previously noted, APS recommends an fiscal year 2018 funding level of \$36.1 billion for the NIH, which would enable real growth over biomedical 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 popu-

lation-based sciences. The Administration's request to cut NIH funding by \$7.2 billion is reckless and short sighted. Cuts to NIH of such unprecedented magnitude 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 the inadequate recognition of the role of behavior in health, as reflected in the imbalance in behavioral science priorities at many institutes within NIH. Specifically, we share the concern of 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. APS believes that the individual, social, and economic burdens of these conditions will not begin to be alleviated until there is a more comprehensive research approach to mental illness. 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 shares the concern of the 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. The Committee believes that the individual, social, and economic burdens of these conditions will not begin to be alleviated until there is a more comprehensive research approach to mental illness. Therefore the Committee urges NIMH 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.

HRSA'S BUREAU OF HEALTH WORKFORCE

APS joins the Friends of HRSA in recommending restoring HRSA's discretionary budget to the fiscal year 2010 level of \$7.48 billion or \$1.98 billion more than requested by the Administration for fiscal year 2018. HRSA is the primary Federal agency responsible for improving health, and does so through supporting access to quality health services, a skilled workforce and innovative programs. In fiscal year 2016, HRSA's discretionary budget authority was nearly 18 percent below the fiscal year 2010 level. Restoring funding to HRSA will allow the agency to more effectively fill preventive and primary healthcare gaps

HRSA's Bureau of Health Workforce (BHW) improves the health of underserved and vulnerable populations by strengthening the health workforce and connecting skilled professionals to communities in need. To that end, HRSA's two psychology education training programs—Graduate Psychology Education (GPE) Program and Behavioral Health Workforce Education and Training (BHWET) Program—produce graduates to work in clinical psychology practice upon completion of their program. It is important that the authorizing legislation (the Public Health Services Act, Section 756 (a) (2)) be updated to permit these two programs to include in their candidate pool those psychologists who graduate from programs accredited by the Psychological Clinical Science Accreditation System (PCSAS), a new accreditation system established after the last amendments to the Public Health Services Act.

Currently, the authorization specifically says the Secretary may make grants for the “. . . training of psychology graduate students for providing behavioral and mental health services. . . .” However, the authorizing legislation requires that applicants come from programs that are accredited by accrediting organizations recognized by the Department of Education (DoEd). This language needs to be updated to reflect accreditation changes that have occurred since this eligibility requirement was established. In September 2012, the Council for Higher Education Accreditation (CHEA) recognized the Psychological Clinical Science Accreditation System (PCSAS) and since that date PCSAS has accredited 33 clinical psychological doctoral programs which are recognized to be among the 50 top programs in the country. In order to ensure that HRSA's health workforce programs have access to the best qualified applicants and programs the Committee is urged to add the necessary language to update the eligibility requirements.

CHEA is the largest higher education accrediting organization in the U.S.; it is a national body formed by 3,000 universities which reviews and screens applications from organizations to serve as accrediting bodies for the professions. CHEA is widely recognized as a primary voice for accreditation and quality assurance, and is in every way equal to DoEd in accrediting higher education programs. Therefore, in order to update the Public Health Services Act, APS urges the Committee to include the following language in the fiscal year 2018 bill:

At the end of the section providing appropriations for HRSA add the following: "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 appreciates the opportunity to provide testimony to you on behalf of these paramount needs of the Nation.

[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 147 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 160,000 faculty members, 83,000 medical students, 115,000 resident physicians, and thousands of graduate students and postdoctoral trainees in the biomedical sciences. In fiscal year 2018, 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: an increase of at least \$2 billion over fiscal year 2017 for the National Institutes of Health (NIH), in addition to funds included in the 21st Century Cures Act for targeted initiatives; \$364 million in budget authority for the Agency for Healthcare Research and Quality (AHRQ); \$580 million for the Title VII health professions and Title VIII nursing workforce development programs, and \$300 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 and HRSA's National Health Service Corps. The AAMC appreciates the Subcommittee's longstanding, bipartisan efforts to strengthen these programs.

National Institutes of Health.—Congress's long-standing 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. More than 80 percent of the NIH's budget is competitively awarded through more than 57,000 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. At least half of this funding supports life-saving research at America's medical schools and teaching hospitals, where scientists, clinicians, fellows, residents, medical students, and trainees work side-by-side to improve the lives of Americans through research. This partnership is a unique and highly-productive relationship, one that lays the foundation for improved health and quality of life and strengthens the Nation's long-term economy.

The AAMC thanks Congress for the bipartisan support that resulted in the inclusion of \$34.1 billion in the fiscal year 2017 omnibus spending bill for medical research conducted and supported by the NIH. Likewise, the AAMC is deeply grateful to the Subcommittee for its bipartisan commitment to continue this budget trajectory with an increase for NIH in fiscal year 2018.

The AAMC is deeply concerned with the Administration's fiscal year 2018 budget proposal that would reverse investments in the NIH through a \$7.2 billion (21 percent) cut, primarily achieved through a 10 percent limitation on reimbursement for facilities and administrative (F&A) expenses. F&A costs are research costs, and the proposal to limit support provided to research institutions would be harmful to the success of the research enterprise and ultimately result in less research across the country. By the Administration's estimates, the proposal would lead to approximately 2,000 fewer grants compared to fiscal year 2016.

The AAMC urges the Subcommittee to reject the Administration's proposals. In fiscal year 2018, the AAMC supports the Ad Hoc Group for Medical Research recommendation that Congress appropriate an increase of at least \$2 billion above fiscal year 2017 for NIH, in addition to funds included in the 21st Century Cures Act for targeted initiatives. This funding level would enable real growth over biomedical inflation as an important step to ensuring stability in the Nation's research capacity over the long term. Moreover, our recommendation would help advance the scientific momentum envisioned by the 21st Century Cures Act—enacted with broad bipartisan support—in which the Innovation Account supplements the agency's base budget. Securing a reliable, robust budget trajectory for NIH will be 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. We also urge the Subcommittee not to lower the salary cap below Executive Level II of the Federal pay scale.

The AAMC continues to be concerned about the long-lasting impact of a stagnant or reduced NIH budget on the next generation of scientists, who see training funds threatened and the possibility of sustaining a career in research diminished. Of particular concern is the challenge of maintaining a cadre of clinician-scientists to facilitate translation of basic research to human medicine. NIH supports many innovative training programs and funding mechanisms that foster scientific creativity and exploration.

Scientific discoveries rely on support from Congress. 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.

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 joins the Friends of AHRQ in recommending \$364 million in budget authority for the agency in fiscal year 2018.

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. These research findings 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, loan guarantees, 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 NHSC.

In addition to promoting educational innovations and preparing the workforce for changing delivery systems, the programs also support faculty development, cur-

riculum 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.

Yet, the president's fiscal year 2018 budget proposes to eliminate all Title VII health professions and Title VIII nursing workforce programs under the Health Resources and Services Administration (HRSA), with the exception of providing level funding for the Title VII Health Care Workforce Assessment and the Nurse Corps Scholarship and Loan Repayment programs. The AAMC urges the Subcommittee to reject these proposals laid out in the president's budget, which would jeopardize the only federally funded programs designed to improve the supply, distribution, and diversity of the health professions workforce. The AAMC joins the Health Professions and Nursing Education Coalition (HPNEC) in recommending \$580 million for these important workforce programs in fiscal year 2018. 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 39,000 health professions students in over 8,000 sites across the country, including 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 Children's Hospitals Graduate Medical Education (CHGME) program. This 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 \$300 million in fiscal year 2018.

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 \$190,000, and total repayment can range from \$340,000 to \$406,000.

Along with other NHSC stakeholder organizations, the AAMC urges Congress to provide \$380 million for the NHSC in fiscal year 2018. 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 2018 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 2018 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 Nation'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 augments 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 220 trainers in 30 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) and the \$2 billion increase NIH received in fiscal year 2017. We continue to believe that science and innovation are essential if we are to continue 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 is extremely concerned by the Administration's fiscal year 2018 budget proposal to reverse these investments in the NIH with a \$7.2 billion (21 percent) cut, which the Administration estimates would lead to approximately 2,000 fewer research grants compared to fiscal year 2016. AIRI urges the Subcommittee to provide \$36.1 billion, an increase of \$2 billion above fiscal year 2017 enacted levels, for NIH in fiscal year 2018. Additionally, we urge you to reject the Administration's problematic proposal to cap the indirect cost rate for NIH grants at 10 percent, as it would hinder critical research efforts and the support needed to discover tomorrow's cures.

The Subcommittee's leadership in support of NIH is demonstrated by the \$2 billion increase provided in the final fiscal year 2017 omnibus appropriations bill. The continuing resolution (CR) in fiscal year 2017 created significant budget uncertainty for NIH, making 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 predictable funding in fiscal year 2018 with \$36.1 billion for NIH.

AIRI is particularly troubled by the Administration's proposal to cap the indirect cost rate (also known as facilitates and administrative costs, or F&A costs) for NIH grants at 10 percent. These F&A costs are real and essential costs of conducting research, and this proposed drastic cut would simply result in less life-enhancing research. Many independent research institutes would be forced to close under this proposal, and the research they are conducting will end, losing potential treatments and cures.

AIRI is a national organization of more than 80 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 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 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. Approximately 84 percent of the NIH's budget goes to more than 300,000 research positions at over 2,500 universities and research institutions located in every State.

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. NIH supports long-term competitiveness for American workers, forming one of the key foundations for U.S. industries like biotechnology, medical device and pharmaceutical development, and more. Unfortunately, continued erosion of the national commitment to medical research threatens our ability to support a medical research enterprise that is capable of taking full advantage of existing and emerging scientific opportunities.

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. AIRE member institutions are private, stand-alone research centers that set their sights on the vast frontiers of medical science. AIRE institutes are specifically focused on pursuing knowledge around the biology and behavior of living systems and applying that knowledge to improve human health and reduce the burdens of illness and disability.

AIRE 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 to concerns over funding, AIRE member institutes oppose legislative 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. Such policies hinder AIRE members' research missions and their ability to recruit and retain talented researchers. AIRE also does not support legislative language limiting the flexibility of NIH to determine how to most effectively manage its resources while funding the best scientific ideas.

AIRE 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, AIRE member institutes focus primarily on scientific inquiry and discovery, allowing them to respond quickly to the research needs of the country.

AIRE members 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 initiatives focusing on career development and recruitment of a diverse scientific workforce are important to innovation in biomedical research and public health. However, one of the most destructive and long-lasting impacts of the decline in the NIH budget is on the next generation of scientists, who see training funds slashed and the possibility of sustaining a career in research diminished. The continued success of the biomedical research enterprise relies heavily on the imagination and dedication of a diverse and talented scientific workforce.

In addition, strong support for NIH is critical to the Nation's competitiveness. This country still has the most robust medical research capacity in the world, but that capacity simply cannot weather repeated blows such as persistent below-inflation funding levels, sequestration, and budget uncertainty from the CR, which jeopardize our competitive edge in an increasingly innovation-based global marketplace.

AIRE 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 \$36.1 billion, an increase of \$2 billion above fiscal year 2017 enacted levels, for NIH in fiscal year 2018. Additionally, we urge you to reject the Administration's problematic proposal to cap the indirect cost rate for NIH grants at 10 percent, as it would hinder critical research efforts and the support needed to discover tomorrow's cures.

PREPARED STATEMENT OF THE ASSOCIATION OF SCIENCE-TECHNOLOGY CENTERS

Chairman Blunt, Ranking Member Murray, and members of the subcommittee:

As interim CEO of the Association of Science-Technology Centers, (ASTC) I appreciate the opportunity to submit this written statement in support of the Institute of Museum and Library Services. ASTC represents 400 science centers in the US, in total welcoming over 93 million visitors a year to their exhibitions and programs,

offering an unmatched resource in informal science learning. Many of our members have benefitted from IMLS grants and delivered programs throughout the Nation. Furthermore, members share their expertise gained through these programs, further enhancing the capacity building of the field through effective collaboration. I respectfully urge the subcommittee to continue its investment in museums in fiscal year 2018 by fully funding the Office of Museum Services (OMS) at the Institute of Museum and Library Services (IMLS) at the authorized level of \$38.6 million. Most recently, a record 37 of your Senate colleagues joined a bipartisan letter calling for robust funding in fiscal year 2018 for the OMS at the IMLS.

While we appreciate the subcommittee's recommendation of \$31.269 million for OMS in its fiscal year 2017 omnibus, the proposed near elimination of the IMLS in the fiscal year 2018 Administration's proposed budget is alarming. This relatively small Federal competitive grant program is an important investment in fostering STEM education, inspiring a lifelong interest in science and bolstering local economies around the country.

These investments in science centers also have a multiplier effect across the Nation. As economic engines in their communities, science centers play an essential role in the Nation's educational infrastructure, spending more than \$2 billion a year on education. They are also community anchors, addressing challenges in the fields of engineering, technology, energy, health, and wellness.

IMLS is driven by its mission to inspire libraries and museums to advance innovation, lifelong learning, and cultural and civic engagement by providing leadership through research, policy development, and grant making. OMS offers and administers competitive grant programs that undergo a rigorous peer review process in an effort to identify well-designed projects in communities across the country.

For these reasons, we urge to support the OMS at IMLS at its authorized level of \$38.6 million.

Sincerely,

[This statement was submitted by Gillian Thomas, Interim CEO, Association of Science-Technology Centers.]

PREPARED STATEMENT OF THE ASSOCIATION OF STATE AND TERRITORIAL HEALTH OFFICIALS

On behalf of the Association of State and Territorial Health Officials (ASTHO), I respectfully submit this testimony on fiscal year 2018 appropriations for the Department of Health and Human Services (HHS). ASTHO is the national nonprofit organization representing the State and territorial public health agencies of the United States, U.S. Territories, and Washington, D.C. ASTHO's members, the chief health officials of these jurisdictions, are dedicated to formulating and influencing sound public health policy, and assuring excellence in state-based public health practice. Collectively, our members provide leadership to a public health workforce of over 100,000 public health professionals who are dedicated to protecting the health of our entire population by controlling infectious diseases, preventing chronic diseases and injuries, and promoting healthy lifestyles in diverse communities across States and territories.

Our work occurs largely outside of clinical or medical settings and is financed by State and Federal appropriations. From urban centers with world-class academic facilities to remote, rural areas of our country with limited access to healthcare, ASTHO's members provide the infrastructure and support to the safety net that protects and improves the health of millions of Americans. States and territories rely heavily on Federal public health partners at HHS and other Federal agencies to achieve broad impact and sustain high levels of success. Our Federal partners, including the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA), provide a level of financial support to health departments through grants and cooperative agreements that most State budgets simply cannot fulfill. In addition to State health agencies, our partners in local and tribal departments are the "boots on the ground" of our governmental public health system, and reductions in Federal support for this system will have direct and immediate negative impacts on our ability to respond to natural and manmade health threats, as well as critical activities and services that our Nation relies upon.

ASTHO is concerned that the unprecedented level of budget reductions proposed for public health programs in the President's fiscal year 2018 budget will have a detrimental impact on governmental public health programs. State and territorial health agencies are already facing many challenges in the current fiscal environment and will not be able to make up the Federal funding reductions. Today, Federal resources account for an average of nearly half of all State and territorial public

health department funding. Therefore, budget cuts in Federal public health programs will further erode State and local workforce levels through additional staffing reductions, and strain other areas of governmental public health agency budgets.

The old maxim of being penny-wise and pound-foolish applies to public health funding. It is through public health preparedness, health promotion, and disease prevention activities, the core work of State and territorial health agencies, that we will truly realize savings in our healthcare system. It is far more effective to prevent illness than to treat it. States and territories need continued Federal support for these population health efforts to produce long-term improvements in health and reduced spending on healthcare. ASTHO therefore urges Congress to provide \$7.8 billion for CDC and \$7.48 billion for HRSA in the fiscal year 2018 LHHS appropriations bill.

We are also extremely concerned that macro budget issues—including continued sequestration and a movement to increase defense spending at the expense of non-defense discretionary funding—will force public health budgets downward. Congress must build on the momentum generated in the fiscal year 2017 omnibus appropriations bill and provide public health with predictable, sustained funding as soon as possible.

Repeal of the Affordable Care Act has included elimination of the Prevention and Public Health Fund (PPHF) at the end of 2018. The impact the loss of this funding would have on CDC's annual budget is extremely concerning. The PPHF provides 12 percent of the CDC's budget and the Committee and Congress must ensure that CDC's budget remains whole in the face of efforts to repeal the ACA. Additionally, in the 8 years since the PPHF has been established (fiscal year 2010—fiscal year 2017), the fund has supplemented regular annual appropriations for many long-standing CDC, HRSA, and other HHS agency programs, in whole or in part, with financial resources. Today, some of these long-standing core public health programs are 100 percent supported by the PPHF, such as the Preventive Health and Health Services Block Grant (Prevent Block Grant), which was created in the Reagan Administration and has served our Nation well by allowing governmental public health agencies the flexibility to address their State and local public health priorities. States and territories use the dollars provided by the grant to offset funding gaps in other programs that address the leading causes of death and disability in their jurisdictions. Approximately 25 percent of Prevent Block Grant funds support critical investments that strengthen the ability of State health agencies to respond to public health threats.

The Prevent Block Grant is a critical source of funding for States and territories beyond chronic disease prevention. The potential loss of this funding, even with the proposed America's Health Block Grant, will slow our progress in addressing State health priorities. We urge Congress to reject its proposed elimination and provide \$170 million for the Prevent Block Grant in fiscal year 2018.

Strategies to prevent disease and promote well-being are crucial to improve health and reduce healthcare costs. This requires strengthening the public health infrastructure at the State and territorial levels to deliver essential public health services. ASTHO believes that increased resources should be appropriated for long-standing successful prevention efforts, including \$650 million for the CDC Section 317 Immunization Program and Program Operations and sustained funding for the CDC Chronic Disease Prevention and Health Promotion Program. These programs produce long-term savings in overall healthcare costs.

It is vital that States and territories continue receiving Federal funding to build emergency preparedness and response capacity across all communities and hospitals. Public health and public safety are inexorably tied together as States prepare for and respond to both natural and manmade public health threats. A collaborative national effort is critical and requires a clear understanding of roles and responsibilities among Federal, State, local, territorial, and tribal agencies in public health preparedness. State, territorial, and local public health have repeatedly demonstrated their robust capabilities to protect the health and safety of their populations, yet these capacities can degrade rapidly without the support of Federal grant programs, as well as community and business practices that foster coordinated planning and response. Federal grants such as CDC's Public Health Emergency Preparedness (PHEP) cooperative agreement and the Assistant Secretary for Preparedness and Response's Hospital Preparedness Program (HPP) help develop emergency-ready public health departments that are flexible, adaptable, and resilient.

We urge Congress to provide \$705 million in fiscal year 2018 for PHEP and \$350 million for HPP in fiscal year 2018. These grants provide the resources needed to build and support systems for communications, biothreat surveillance, information sharing, and more. As these valuable funding sources are cut, State and territorial health departments are faced with tough decisions to reduce, limit, or eliminate ac-

tivities required to ensure the emergency response capacity and safety of their jurisdictions.

Additionally, the current Zika outbreak is unprecedented and remains a significant public health threat, especially to pregnant women and their unborn fetuses. Over 200 individuals have been infected with Zika through local transmission in Texas and Florida, while nearly 5,000 Americans across the country have had travel-related infections. Among them are dozens of pregnant women whose pregnancies are at risk for the serious birth defects Zika can cause. Our members are on the front lines everyday protecting the public's health from the Zika virus along with a myriad of other threats. ASTHO appreciates Congress providing supplemental funding this past October for fiscal year 2017 to support States and territories in their efforts against Zika. With these resources, the Nation's public health system was able to put in place and carry out essential public health services targeted at Zika, including preparedness and response planning, public outreach and prevention education, disease surveillance and epidemiologic investigation, vector surveillance and control, laboratory testing and reporting, as well as birth defects monitoring through the establishment of a national registry. ASTHO urges Congress to work collaboratively to ensure continued funding and support so that State, territorial, and local public health departments and key Federal agencies can continue their work and fulfill their missions. Specifically, in addition to the \$705 million request for PHEP outlined above, ASTHO requests \$650 million for the HRSA Title V Maternal and Child Health Services Block Grant, \$152 million for the CDC National Center on Birth Defects and Developmental Disabilities, and \$630 million for the CDC National Center for Emerging and Zoonic Infectious Diseases.

Another lesson learned from the Zika outbreak, and many previous public health emergencies, is the need for a Public Health Emergency Fund that can rapidly support Federal, State, and local public health surge activities to address these emerging threats at the onset. We urge Congress to establish this funding mechanism as an alternative or precursor to the regular supplemental appropriations process that can take months to enact.

State and territorial health departments are on the front lines of responding to the current crisis in our country caused by substance misuse, addiction, and drug overdoses. We witness the consequences every day in the form of overdose deaths, substance-related interactions with the criminal justice and child welfare systems, HIV and hepatitis C infections, prenatal substance exposure effects, and the burden on the healthcare system. ASTHO's 2017 President's Challenge will continue to be a platform to focus on the role State and territorial public health plays in preventing addiction. We need to recognize that we all have a part to play in addressing the opioid epidemic. We urge Congress to provide \$125.5 million in funding for CDC Opioid Prescription Drug Overdose and Illicit Opioid Use Risk Factors to address the opioid crisis.

The mission of governmental public health is to keep all Americans healthy and safe and to prevent disease, injury, and premature death. Public health works at the local, State, and national levels to ensure health and well-being for the entire population, rather than just healthcare for individuals. To carry out this mission, the United States needs to strengthen its public health system at all levels to create the conditions that preserve health for the entire U.S. population, including the ability to address the underlying conditions that are leading to deadly and costly chronic diseases, and to rapidly slow or stop emerging diseases.

With the return of full sequestration next year and its potential impact on public health budgets, we strongly urge Congress to avoid making further reductions in these programs and work to replace the scheduled sequestration cuts through a package that is balanced—both in how such relief is paid for and how it is applied to defense and non-defense programs.

Thank you for the opportunity to submit this testimony. ASTHO and its members are ready to assist Congress and the Administration in our shared work of protecting and promoting the public's health.

[This statement was submitted by Jay C. Butler, MD, President, Association of State and Territorial Health Officials.]

PREPARED STATEMENT OF THE ASSOCIATION OF ZOOS AND AQUARIUMS

Thank you Chairman Blunt and Ranking Member Murray for allowing me to submit testimony on behalf of the Nation's 215 AZA-accredited zoos and aquariums. I urge you to reject efforts to eliminate the Institute of Museum and Library Services (IMLS) and instead include \$38.6 million for the IMLS's Office of Museum Services

in the fiscal year 2018 Labor, Health and Human Services, Education, and Related Agencies appropriations bill.

Founded in 1924, the Association of Zoos and Aquariums (AZA) is a nonprofit 501c(3) organization dedicated to the advancement of zoos and aquariums in the areas of conservation, education, science, and recreation. Accredited zoos and aquariums annually see more than 183 million visitors, collectively generate more than \$17 billion in annual economic activity, and support more than 166,000 jobs across the country. Over the last 5 years, AZA-accredited institutions supported more than 4,000 field conservation and research projects with \$160,000,000 annually in more than 100 countries. In the last 10 years, accredited zoos and aquariums formally trained more than 400,000 teachers, supporting science curricula with effective teaching materials and hands-on opportunities. School field trips annually connect more than 12,000,000 students with the natural world.

Aquariums and zoological parks are defined by the “Museum and Library Services Act of 2003” (Public Law 108–81) as museums. The Office of Museum Services awards grants to museums to support them as institutions of learning and exploration, and keepers of cultural, historical, and scientific heritages. Grants are awarded in several areas including educational programming, professional development, and collections management, among others.

As valued members of local communities, AZA-accredited zoos and aquariums offer a variety of programs ranging from unique educational opportunities for schoolchildren to conservation initiatives that benefit both local and global species. The competitive grants offered by the IMLS Office of Museum Services ensure that many of these programs, which otherwise may not exist because of insufficient funds, positively impact local communities and many varieties of species.

Unfortunately, current funding has allowed IMLS to fund only a small fraction of all highly-rated grant applications. Meanwhile, zoo and aquarium attendance has increased and the educational services zoos and aquariums provide to schools and communities are in greater demand than ever, as is the need for greater funding to develop these programs. AZA-accredited zoos and aquariums are essential partners at the Federal, State, and local levels in providing education and cultural opportunities that adults and children may otherwise never enjoy.

As museums, zoos and aquariums share the same mission of preserving the world’s great treasures, educating the public about them, and contributing to the Nation’s economic and cultural vitality. Therefore, I strongly encourage you to include \$38.6 million for the Institute of Museum and Library Services’ Office of Museum Services in the fiscal year 2018 Labor, Health and Human Services, Education, and Related Agencies appropriations bill.

Thank you for your consideration of our comments.

[This statement was submitted by Dan Ashe, President and CEO, Association of Zoos and Aquariums.]

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 2018 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.

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 in-

cluding 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 2018 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.

PREPARED STATEMENT OF STACEY BRESHEARS

My name is Stacey Breshears and my son, Braden, has Usher syndrome, the most common genetic cause of combined deafness and blindness. I write on behalf of the Usher syndrome community to urge Congress to reject the Administration’s cuts to the NIH and support predictable and sustainable increases to the NIH, NEI and NIDCD to continue progress towards viable treatments for those with Usher syndrome.

Cutting research funding would be damaging to the progress that the National Eye Institute (NEI) and the National Institute on Deafness and Communication Disorders (NIDCD) have made towards treatments for Usher syndrome. There is no cure for Usher syndrome. We urgently need more Federal funding to improve treatment options and outcomes for those impacted.

On behalf of the Usher Syndrome Coalition community, I also urge this committee to support the inclusion of report language prioritizing research into the treatment of Usher syndrome at the National Institutes of Health (NIH).

The Usher Syndrome Coalition community across the country is aware of and appreciates your support since our report language first appeared in the 2014 omnibus spending bill. But as I am sure you agree, Usher syndrome needs to become a higher priority at NIH until we have viable human treatments. Despite 3 years of appropriations language urging NIH to make Usher syndrome a higher priority, spending on Usher actually decreased by 11.6 percent from 2014 to 2015.

As you prepare the fiscal year 2018 Labor, Health and Human Services, Education bill, we respectfully request that you include the following report language with the objective of better defining the plan and measurements for the delivery of vision loss treatments for those with Usher syndrome:

Usher Syndrome.—The Committee is concerned that its previous requests for updates on the prioritization of Usher syndrome research at NEI and NIDCD have not resulted in the information being sought. The Committee continues to urge the NIH to prioritize Usher syndrome research at NEI and NIDCD. The Committee requests an update in the fiscal year 2018 budget request on steps NIH has taken to date and future plans to accelerate treatment options and improve patient outcomes for those with Usher syndrome. The update should include a description of the criteria in use by NIH to evaluate Usher syndrome related grant submissions to ensure the prioritization of those that accelerate human treatment options. The update should also include a timeline and deliverables that will be used to evaluate the progress made towards viable treatments for those with Usher syndrome.

In the United States, it is estimated that at least 20,000 people have this rare genetic disorder. This devastating and life changing condition has a similar effect on all of us with Usher and on our families. But, we all have different stories to tell.

This is Braden’s Story:

After a difficult delivery, Braden repeatedly failed his newborn hearing screening in the hospital. The nurses suggested he just wasn’t responding because of all the

trauma. At 2 months old and again at 4 months old, the test was repeated. We finally had to accept that Braden was, in fact, deaf. After receiving bilateral cochlear implants, we thought we had a handle on things and continued to move forward. Many times over, comments had been made to my husband and me: “Thankfully, it’s his ears and not his eyes.” Yeah, right. A few years later, the vision trouble began to be apparent. After referral of a couple of doctors and a number of tests, the diagnosis came for Usher syndrome. So, now our deaf child is going to lose his vision? This news, of course, caused us to evaluate everything in our life to make sure we are able to make the best choices we can for our son. Usher syndrome has opened our eyes to many things, while darkness is setting in for our son. Our self-evaluation and drawing even closer as a family and to God has been necessary to be able to cope with this diagnosis.

He is 12 years old now. He has a decreased window of peripheral vision, night-blindness, and color deficiency. His vision cannot be corrected to 20/20. He stumbles, trips, and always has bruises. But his laid back personality, problem-solving skills, and great attitude keep him going. He is an inspiration to those who know him and he never complains. I pray all the time for advances in research and technology so that he doesn’t have to be left in the dark one day.

People with Usher syndrome not only have the capacity to contribute to America’s future, they thirst for it. They want to be active members of society. Yet our country spends an estimated \$145 billion annually in direct and indirect costs for people with eye disorders and vision loss (June 2014 Prevent Blindness report). That doesn’t even include the costs associated with hearing impairment.

Until 2015, there was no way of knowing how much money NIH invested in Usher syndrome research. Through the efforts of the Usher Syndrome Coalition, this rare disease has been added as a new category in the NIH Categorical Spending list, the Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC). Through the RCDC system, we now have visibility into the total dollars spent on Usher syndrome, as well as the specific grants that were funded. More important to us than increasing the dollars invested in Usher syndrome research is ensuring those dollars are invested in the most impactful manner. We would also like to see a better ratio of intramural and extramural investment in Usher syndrome research. The NIH website budget page states that “more than 80 percent of the NIH’s funding is awarded through . . . competitive grants” and that “about 10 percent of the NIH’s budget supports projects conducted by . . . scientists in its own laboratories.” According to the RCDC NIH Categorical Spending list, 53.3 percent of overall investment on Usher syndrome research was intramural. Further, the investment does not seem to target the most pressing issue of vision loss as only \$5,991,000 (37.6 percent of the portfolio) targeted vision loss.

We would like to see a strategic plan put forth by the National Institutes of Health developed with both internal and external expertise containing clear measurements of progress. NIH investment should target those research areas that will most quickly bring about viable human treatments for the vision loss phenotype in Usher syndrome. There are technologies and techniques available today to manage the hearing loss and vestibular issues faced by those with Usher syndrome. These are not perfect and more investment is needed, but the priority should be to provide treatments that allow people with Usher syndrome to manage the vision loss as well as they currently manage the hearing and vestibular losses.

The dollars invested in Usher syndrome research are precious to all of us. We want to make sure they are spent as wisely as possible. I want the outcome to be different for Braden. My husband and I will continue to help him every way we can. By sharing Braden’s story, we are helping to raise awareness for the need of further research.

Thank you for reading Braden’s story.

PREPARED STATEMENT OF THE CAMPAIGN FOR TOBACCO-FREE KIDS

I am Matthew Myers, President of the Campaign for Tobacco-Free Kids. I am submitting this written testimony for the record 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 \$210 million for CDC’s OSH in the Labor-HHS-Ed appropriations bill for fiscal year 2018.

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 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) and wish they never started (about 90 percent).⁵ 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 1964.⁶ According to recent surveys, the smoking rate among adults declined nearly 39 percent and the smoking rate among high schoolers declined 70 percent between 1997 and 2015.⁷ 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 are living longer, healthier lives. Over the past 50 years, tobacco control measures have prevented at least eight million premature deaths from smoking.⁸ 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 dramatic medical innovations that occurred during this time.⁹

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 its inception, the campaign has motivated about five million smokers to make a quit attempt, helped approximately 500,000 smokers to successfully quit, and saved about 50,000 people from premature death.¹⁰ It costs

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/>.

²HHS, *The Health Consequences of Smoking—50 Years of Progress: A Report of the Surgeon General*, 2014.

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.

⁵And Fong, G., et al., "The Near-Universal Experience of Regret Among Smokers in Four Countries: Findings from the International Tobacco Control Policy Evaluation Survey," *Nicotine & Tobacco Research*, Vol. 6, Supplement 3, December 2004. CDC, "Quitting Smoking Among Adults—United States, 2000–2015," *Morbidity & Mortality Weekly Report* 65(22): 1457–1464, January 6, 2017, <https://www.cdc.gov/mmwr/volumes/65/wr/pdfs/mm6552a1.pdf>.

⁶HHS, *The Health Consequences of Smoking—50 Years of Progress: A Report of the Surgeon General*, 2014.

⁷Centers for Disease Control and Prevention, "Current Cigarette Smoking Among Adults—United States, 2005–2015," *Morbidity & Mortality Weekly Report*, 65(44): 1205–1211, November 11, 2016, http://www.cdc.gov/mmwr/volumes/65/wr/mm6544a2.htm?s_cid=mm6544a2_w. CDC, "Youth Risk Behavior Surveillance—United States, 2015," *MMWR*, 65(6), June 10, 2016. http://www.cdc.gov/healthyyouth/data/yrbs/pdf/2015/ss6506_updated.pdf.

⁸Holford, 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).

⁹Holford, T., et al, *JAMA*, January 8, 2014: 311(2).

¹⁰Centers 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.

just \$393 for each year of life saved, which is considered a “best buy” in public health.¹¹

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.¹²

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.¹³

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 2015.¹⁴

This Subcommittee approved \$210 million for OSH in its fiscal year 2017 appropriations bill, which was the enacted level for fiscal year 2016. However, the House Labor-HHS-Ed appropriations bill for fiscal year 2017 would have reduced funding for OSH by more than 50 percent, from \$210 million to \$100 million. We appreciate that the Consolidated Appropriations Act of fiscal year 2017 did not include the substantial funding reduction proposed in the House bill and instead provided \$205 million for OSH.

A reduction of the substantial size proposed in the House bill 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 are alarmed that the President’s budget request for fiscal year 2018 would eliminate all 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 says 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. Even with the \$500 million America’s Health Block Grant, the President’s budget request would reduce overall funding for CDC’s chronic disease prevention programs by \$222 million, a nearly 20 percent cut.

We urge the Subcommittee to again provide at least \$210 million for OSH for fiscal year 2018. 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 disease, respiratory disease, and other tobacco-caused diseases and more people dying years earlier than if they did not smoke.

¹¹ Xu, Xin, et al., “Cost-Effectiveness Analysis of the First federally Funded Antismoking Campaign,” *American Journal of Preventive Medicine*, 2014.

¹² Fiore, 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.

¹³ Dilley, 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.

¹⁴ U.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>.

Without urgent action, 5.6 million children alive today will die prematurely from a smoking-related disease.¹⁵

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.¹⁶

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 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, at a minimum, maintain existing investments to address 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 provide at least \$210 million for it to continue to prevent disease, save lives, and rein in future healthcare spending.

[This statement was submitted by Matthew L. Myers, President, Campaign for Tobacco-Free Kids.]

PREPARED STATEMENT OF THE CAMPAIGN TO INVEST IN AMERICA'S WORKFORCE

The Campaign to Invest in America's Workforce is a coalition of national organizations whose members help people of all ages and conditions raise their skills, and enable U.S. businesses that need skilled workers to compete in today's rapidly restructuring economy. We appreciate the opportunity to submit testimony about the funding of education and workforce programs administered by the Departments of Education, Labor, and Health and Human Services in fiscal year 2018.

Middle skill jobs—those requiring more than a high school diploma, but not a 4-year degree—make up 53 percent of today's labor market, but only 43 percent of U.S. workers are trained at this level. Further, by 2020, 65 percent of all jobs will require some level of postsecondary education. This skills gap leaves businesses struggling to find workers with appropriate skills, and it leaves workers without meaningful pathways to better-paying jobs.

Lawmakers understand the importance of investing in skills to achieve broadly shared economic growth and prosperity. Congress acknowledged the need to address this issue and to reform our Nation's workforce development strategy when it passed Workforce Innovation and Opportunity Act (WIOA) by wide bipartisan majorities. WIOA contains significant changes that will help better match employers with skilled employees, fewer and better-aligned performance metrics (including a measure of effectiveness in serving employers), a simpler structure for workforce development boards, and integration of best practices such as industry partnerships and career pathways.

Federal investments under WIOA, the Carl D. Perkins Career and Technical Education Act (Perkins Act), the Higher Education Act, and other key programs provide unprecedented potential to develop America's workers through access to effective workforce education and training. For this potential to be realized, however, sustained funding is required.

The administration's budget proposes significant funding cuts across a range of Federal programs, which would come on top of historic disinvestments in critical workforce and education programs and the already low caps on non-defense discretionary spending under the 2011 Budget Control Act. For example, funding for State workforce grants, which WIOA reformed to be more responsive to industry needs, have been cut by 38 percent since 2001. Since 2001, the number of students served by Adult Education has fallen from more than 2.7 million to 1.5 million, a decline of 44 percent. Funding, when adjusted for inflation, has fallen by 25.3 percent. Despite strong bipartisan support, career and technical education (CTE) programs that prepare workers for the jobs of tomorrow have been cut by 32 percent since 2001. AmeriCorps is authorized to provide opportunity for 250,000 youth and veterans to serve their country and gain in-demand skills but is only meets the needs of 80,000 participants.

¹⁵HHS, *The Health Consequences of Smoking—50 Years of Progress: A Report of the Surgeon General*, 2014.

¹⁶Xu, X et al., "Annual Healthcare Spending Attributable to Cigarette Smoking: An Update," *American Journal of Preventive Medicine*, 2014.

We simply cannot compete in an increasingly global economy if we keep cutting and eliminating effective programs while our competitors increase their investments in education and training.

WIOA Title I. The President's fiscal year 2018 budget proposes cutting State formula grants under Title I of WIOA by approximately 40 percent, substantially undercutting investments that annually help connect nearly 7,000,000 million adults and dislocated workers to employment and training opportunities in their local labor markets. The proposed cuts come would leave States and other partners without the critical resources necessary to advance the critical system improvements envisioned under WIOA.

President Trump's budget proposes to reduce funding under WIOA for youth services by 39 percent, effectively eliminating services, especially in rural areas, that help young people reenter education or obtain employment. Each year nearly 200,000 young people, most of whom are out of school and out of work, receive services through local programs that receive WIOA Youth funding. Of the 95,000 out-of-school youth who were served in fiscal year 2014, 71.5 percent of program exiters entered employment after leaving the program and 69.2 percent of program exiters attained credentials of some kind, at a cost of about \$3,400/youth.

Adult Education, WIOA Title II. 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.

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." Data from the Longitudinal Study of Adult Learning (LSAL), which recorded the educational and workforce experiences of a random sample of high school dropouts between 1998 and 2007, show that sustained participation in adult education increases the earnings of students. Using propensity score matching to control for observed differences between individuals who enrolled in adult education and those who did not, one study found that participating in adult education for 100 or more hours netted students an average income increase of \$6,635 (in 2007 dollars). A person with a high school diploma, or equivalent, earns an average of \$9,620 more per year than a non-graduate.

Title III Wagner-Peyser Employment Service Programs served more than 13 million U.S. workers and jobseekers—the equivalent of one of every twelve individuals in the labor force—during the most recent twelve month period for which we have data, providing critical job search, placement, and reemployment assistance that help connect skilled workers with local businesses. The President's budget calls for cutting funding for the program by approximately 40 percent, which will dramatically reduce the availability of these core services in communities across the country.

Apprenticeship. Despite the administration's rhetorical support for expanding apprenticeship, the proposed budget would actually scale back these efforts, cutting Federal investments by more than \$5 million relative to fiscal year 2017 levels and undermining the strong Congressional support for these valuable "earn-and-learn" models. While these cuts are less dramatic than those proposed for other Federal workforce and education programs, they send a clear signal about the administration's commitments to the kinds of job creation and training strategies that business leaders are seeking. We urge the subcommittee to reject these proposals and instead focus on strengthening these investments to develop and implement proven workforce models that will sustain US competitiveness in the years ahead.

Perkins CTE. The Perkins Act supports our Nation's high schools, technical centers and community colleges to provide the education necessary to develop a highly skilled workforce. Nationally, over 11 million students benefit from career technical education (CTE) and we know it's working: 93 percent of CTE concentrators graduate high school, approximately 10 percentage points higher than the national average. Not only do CTE students graduate high school, they're landing in college or a career at high rates—in Missouri, for example, 94 percent of CTE high school graduates placed into college or a career in 2013–2014. Furthermore, postsecondary CTE students are obtaining the knowledge and skills they need to succeed—for example, in Washington, 100 percent of postsecondary CTE students earned a credential, certificate or degree in 2013–2014. These are just a few examples of CTE's impact, but these outcomes cannot be achieved without an adequate Federal investment in Perkins to ensure that students and jobseekers can access high-quality edu-

cation and training that results in market-ready skills and credentials, and to support employers' engagement in aligning training with their skill requirements. We request that Congress reverse prior cuts to Perkins and fund Perkins Basic State Grants at a level at least equal to fiscal year 2010 levels, or approximately \$1.3 billion.

Pell Grants. The Pell Grant program remains an essential source of aid for millions of students seeking postsecondary training. Without the Pell Grant program, many of the more than 7 million individuals who receive these grants annually would find education completely out of financial reach. Yet the President's Budget proposes to rescind \$3.9 billion from the Pell Grant reserves. We urge the committee to reject this rescission and maintain the current Pell Grant discretionary baseline funding of \$22.5 billion to preserve fiscal stability for the program. Additionally, Congress should consider ways to reinvest current Pell Grant surplus funds into strengthening and modernizing the Pell Grant program, such as expanding access to Pell funds for students enrolled in short term training programs leading to industry-recognized credentials and employment in local in-demand industries.

Corporation for National Service (CNCS). CNCS promotes public-private partnerships with local organizations and governors, particularly through the AmeriCorps program to address critical community needs by engaging disconnected youth and veterans in high-quality, locally-driven, work-based service programs. Through those programs, students and veterans gain certifications and credentials and further education; receive education awards that can be used for training or school; and complete priority projects that are important to the community and States where they serve. Projects include disaster response, wildfire remediation, invasive species removal, infrastructure repair and development, education, construction, and community/economic development. We urge your support for funding CNCS, including the Social Innovation Fund, which was eliminated in fiscal year 2017.

Senior Community Service Employment Program (SCSEP). SCSEP is the only Federal employment program targeted at helping older Americans—unemployed veterans, individuals with disabilities, and other eligible jobseekers with significant barriers to employment—find jobs. Through the program, low-income jobseekers 55 years old or older train and earn minimum wage for 15–20 hours a week through community work experiences at local non-profits and government agencies such as libraries and senior centers. Through the on-the-job training, SCSEP participants learn skills, develop new work experiences, and gain confidence to reenter the changing workforce. Annual funding allows employment providers to assist about 67,000 older workers from nearly all 3,000 U.S. counties and territories. Of the thousands of older workers who secure unsubsidized employment because of SCSEP, more than 70 percent remained employed 1 year after exiting the program. We urge the subcommittee to fund SCSEP at the OAA authorized level in fiscal year 2018.

Community Services Block Grant (CSBG). It is essential to maintain or increase funding for the Community Services Block Grant (CSBG), which President Trump's fiscal year 2018 budget proposes to eliminate. The community action agencies (CAAs) funded by CSBG leverage enormous non-Federal resources: for each Federal dollar, CAA's leverage \$7.70, including \$2.34 of private resources, according to Community Action Partnership. Each year CSBG reaches 15.6 million Americans with services that are often what keeps families from choosing between food on the table and heat in the house. In this way CSBG reduces poverty, revitalizes low-income communities, and empowers low-income families and individuals on the road back to self-sufficiency.

Homeless Veterans' Reintegration Program (HVRP). Despite the significant decrease in veterans' homelessness since 2010, nearly 40,000 veterans remain homeless, including 13,000 who are living on the streets. Employment is critical to the prevention of and successful transition out of homelessness. Congress created HVRP to address the employment barriers and training needs of homeless veterans. DOL partners with community-based organizations on HVRP to provide and coordinate skills training, job placement and support services to help at-risk veterans reintegrate into the labor force and secure stable housing. About 17,000 veterans benefit annually from HVRP services HVRP exceeded its placement rate, placing 68.7 percent of all HVRP participants, including a 64 percent placement rate for female veterans (the fastest growing segment of our country's homeless population). An additional 5,000 homeless veterans could be served if Congress funded HVRP at its authorized level.

CONCLUSION

We must invest in education and workforce programs because the economy of the future requires it. Urban and rural areas both need trained employees. As of 2016,

there were 476 counties in the US 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.

We cannot depend on a robust economy alone to solve this problem. A stronger economy will bring people back into the workforce but it won't train them. Investments in America's workers' skills and education are critical to businesses, workers, and the economy. We are mindful of the constraints under which the Subcommittee must operate. Nevertheless, we urge you to invest in the future and fund these programs at least at their authorized level.

PREPARED STATEMENT OF THE CDC ARTHRITIS COALITION

On behalf of the 54 million adults and children living with doctor-diagnosed arthritis in the U.S., 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 2018.

We are concerned about the impact the President's budget would have on people with arthritis. The budget cuts more than \$1 billion from the Centers for Disease Control and Prevention (CDC), including over \$200 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. A block grant would disadvantage smaller programs like the Arthritis Program, and though it is the leading cause of disability in the US resulting in tens of billions of dollars in direct and indirect costs to States, we fear States would not prioritize arthritis funding and the functions of the program could cease to exist as we know them. To maintain the commitment to arthritis disease management, we respectfully request \$16 million as a line item for the CDC Arthritis Program for fiscal year 2018.

The CDC Arthritis Program is the only Federal program dedicated solely to arthritis, a chronic disease that affects 1 in 4 Americans and is the leading cause of disability in the U.S. The CDC Arthritis Program funds States, national partners and public health research with the goal of understanding the prevalence of the disease and targeting evidence-based interventions to improve the health outcomes of people living with the disease. 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. From 2013–14, efforts increased the number of new participants (5,067) by approximately 58 percent, compared to the previous year's reach (2,958). Coupled with this increase in new participation, there were over 600 additional participants from previous years.

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 The Community Health Network, which has increased the access of evidence-based self-management programs for providers and patients. We know that these programs are having a positive impact. One RI 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.

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. To date, the Y has served over 17,000 participants in 37 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 to be a cost saver with 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 patients 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 in a position to assess the impact of arthritis, to substantiate positions, and make decisions based on facts begins with having 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. It is cited by the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) in their budget justification to Congress. The current edition has been used by more than 60,000 people (38 percent researchers, 35 percent health policy and communications specialists, 27 percent by people seeking general information on bone and joint disorders).

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 40 percent of 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 lays out a clear need for expanded reach of 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 2018 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.

PREPARED STATEMENT OF THE CENTERS FOR DISEASE CONTROL
AND PREVENTION 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 at least \$7.8 billion for CDC’s programs in fiscal year 2018. We are deeply disappointed that the president’s proposed fiscal year 2018 budget proposes to cut CDC’s program level funding by nearly \$1.2 billion or nearly 17 percent below the fiscal year 2017 omnibus level. Many important programs at CDC would be impacted, including cuts to environmental health program, efforts that protect against infectious disease, protect the public against public health emergencies, assure occupational health, prevent spread of HIV, promote global health and address our Nation’s chronic disease epidemic. In addition, we are extremely concerned about efforts to repeal the Prevention and Public Health Fund through efforts to repeal the Affordable Care Act, and the impact the loss of this funding would have on CDC’s annual budget. The Prevention and Public Health Fund currently accounts for 12 percent of CDC’s budget and the committee and Congress must ensure that CDC’s budget remains whole in the face of efforts to repeal the ACA.

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 the recent multi-State measles outbreak to pandemic flu preparedness, 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. Unfortunately, the president's budget proposal would slash nearly \$140 million from CDC's public health preparedness and response activities. Additionally, the president's budget would cut more than \$70 million from the National Center for Emerging and Zoonotic Infectious Diseases.

Injuries are the leading causes of death for people ages 1–44. Unintentional and violence-related injuries, such as older adult falls, child maltreatment and sexual violence account for approximately 27 million emergency department visits each year. In 2013, injury and violence cost the U.S. approximately \$671 billion in direct and indirect medical costs. In 2015, opioids killed more than 33,000 individuals nationwide. CDC is working to provide 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. While we are pleased the National Center for Injury Prevention and Control maintains \$75 million, or level funding for addressing the opioid epidemic in the president's budget, the Center's budget is cut overall by \$19 million below fiscal year 2017 levels and funding for the Elderly Falls program and the Injury Control Research Centers are completely eliminated. We urge the committee to restore these cuts and adequately fund all efforts to prevent injuries and minimize their consequences.

According to CDC more than 117 million Americans are living with a chronic health condition and chronic disease such as heart disease and stroke, cancer, diabetes and arthritis cost the U.S. \$2 trillion in medical costs each year. We are disappointed that the president's budget proposes to cut \$222 million from CDC's chronic disease programs and we urge the Senate to maintain this important funding.

In 2015, over 633,000 people in the U.S. died from heart disease, the Nation's No. 1 killer, accounting for about 23 percent of all U.S. deaths. More males than females died of heart disease in 2015, 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 2015, over 140,000 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. We urge the Senate to maintain and adequately fund CDC's heart disease and stroke programs.

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. We urge the Senate to maintain and adequately fund CDC's cancer prevention and control programs.

Cigarette smoking causes more than 480,000 deaths each year. CDC's Office of Smoking and Health funds important programs and education campaigns such as the Tips From Former Smokers campaign, which has already helped more than 100,000 individuals quit smoking, and provides other resources to encourage smokers to quit. We must continue to support these vital programs to reduce the enormous health and economic costs of tobacco use in the U.S. We urge the Senate to maintain and adequately fund CDC's tobacco prevention and control programs.

Of the 29.1 million Americans who have diabetes, more than 8 million cases are undiagnosed. Each year, about 1.4 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 \$245 billion in 2012. We urge the Senate 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. While the obesity rates among children between the ages of 2-5 have significantly decreased over the past decade, more than one-third of adults are obese and 17 percent of children 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. We urge the Senate to maintain and adequately fund CDC's DNPAO.

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. We urge the Senate to maintain and adequately fund CDC's Arthritis 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. We urge the Senate to maintain and adequately fund CDC's HIV prevention programs.

The National Center for Health Statistics collects data on chronic disease prevalence, health disparities, emergency room use, teen pregnancy, infant mortality and causes of death. The health data collected through the Behavioral Risk Factor Surveillance System, Youth Risk Behavior Survey, Youth Tobacco Survey, National Vital Statistics System, and National Health and Nutrition Examination Survey must be adequately funded.

CDC's REACH program helps 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. The president's budget would eliminate all funding for the REACH program and we urge the Senate to reject the request and provide continued funding to this critical program.

CDC oversees immunization programs for children, adolescents and adults, and is a global partner in the ongoing effort to eradicate polio worldwide. Influenza vaccination levels remain low for adults. Levels are substantially lower for pneumococcal vaccination among adults as well, with significant racial and ethnic disparities in vaccination levels persisting among the elderly. 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. The president's budget would cut \$94 million from CDC's immunization and respiratory disease programs and we urge the Senate to reject these proposed cuts.

According to CDC, 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 nearly 57 million people 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. We are disappointed the president's budget proposes cutting NCBDDD by more than \$37 million and we urge the Senate to restore these cuts and adequately fund NCBDDD programs.

The National Center for Environmental Health works to protect public health by helping to control asthma, protect from threats associated with natural disasters and climate change, reduce, monitor and track exposure to lead and other hazards and ensure access to safe and clean water. We urge you to adequately support funding for the Climate and Health, Safe Water, Childhood Lead Poisoning Prevention, Environmental Health Laboratory and Asthma programs, the National Environmental and Public Health Tracking Network and to provide funding for the Built Environment and Health program which was eliminated in 2016. We urge the Senate to restore the \$25 million in proposed cuts, compared to the fiscal year 2016 funding level, to all NCEH programs, including the Climate and Health program which is proposed for elimination in the president's budget.

In order to meet the many ongoing public health challenges outlined above, we urge you reject the many troubling cut in the president's fiscal year 2018 budget proposal and instead to support our fiscal year 2018 request of at least \$7.8 billion for CDC's programs.

[This statement was submitted by Donald Hoppert, Director of Government Relations, American Public Health Association.]

PREPARED STATEMENT OF CHRISTOPHER & DANA REEVE FOUNDATION

Thank you for this opportunity to submit testimony to the Senate Appropriations subcommittee on Labor, Health and Human Services, Education, and Related Agencies in support of funding for the Paralysis Resource Center (PRC) within the Administration for Community Living (ACL).

My father Christopher Reeve's motto was "nothing is impossible". That's a mindset he instilled in us as a family, and it drives the continued work of the Christopher & Dana Reeve Foundation today. The Reeve Foundation believes in empowering those affected by paralysis with the best knowledge, resources and support they need to care for themselves and their families. The Paralysis Resource Center is an essential part of this important work.

The Paralysis Resource Center is a free, comprehensive, national source of informational support for people living with paralysis and their caregivers. Our primary goals are to promote health and independence, foster involvement in the community, and improve quality of life. Since its founding in 2002, the PRC has helped hundreds of thousands of people access information, receive direct mentoring and support, and participate in grant-funded programs that improve quality of life. 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.

For fiscal year 2018, the Foundation requests \$7,700,000. The Administration's budget recommends elimination of the PRC, saying "the activities carried out by (this program) are duplicative of other Federal efforts," and that "activities carried out by the Paralysis Resource Center . . . will be merged into the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)." In fact, there are no other Federal efforts targeted at paralyzed Americans that provide such focused benefits to so many. And attempting to replicate the Paralysis Resource Center's already successful programs within NIDILRR would not only take years, it would increase overall costs, exactly the opposite of what the Administration budget purports to do.

It's difficult to articulate how detrimental elimination of the PRC would be to the 5.4 million Americans currently living with paralysis. Providing information, resources, and support to these individuals and their families promotes independence and helps prevent adverse secondary health outcomes such as depression, infection, chronic pain issues and upper extremity problems that can increase medical costs, prevent individuals returning to the workplace, and seriously degrade quality of life and even hasten death. The PRC promotes the health, well-being and independence of people living with mobility impairments by providing comprehensive information, resources, and referral services in order to navigate the day-to-day challenges of living an independent and fulfilling life.

Below are descriptions of the many functions of the Paralysis Resource Center, reflecting how the PRC uses Federal dollars to leverage its efforts.

Information Specialists are a core feature of the PRC. Trained specialists, some living with paralysis themselves, provide personalized support to help individuals

and their families navigate the vast amount of information and services available for those living with paralysis.

- The PRC's five Information Specialists are full-time employees trained to answer any question related to paralysis, including Spanish language inquiries.

- Information Specialists are often the first port of call for individuals who are newly injured or diagnosed, as they and their families navigate the complex system of paralysis-related services and supports.

- Since 2002, the PRC's Information Specialists have provided direct counseling to over 80,000 people, and have distributed over 190,000 Paralysis Resource Guides, which is also downloadable online and a staple in hospitals and rehabilitation facilities across the country.

Quality of Life Grants administered by the PRC provide financial support to non-profit programs and projects that improve the quality of life for individuals with paralysis, foster community engagement while also promoting health and wellness.

- Since 1999, the PRC's Quality of Life Grants program has directed over \$22 million to 2,956 projects in all 50 States and territories.

- 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.

- 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. To date, 197 grants totaling \$1,543,126 have been awarded to projects serving military service members and veterans and their families.

- The successful launch of an additional program to support new, high-impact assistive technologies was completed in the 2016 grant year, with plans for expansion in 2017.

- Responding to feedback from ACL, the PRC has also awarded 65 grants related to caregiving. Caregivers actively connect and engage with PRC services and require the same level of education, guidance and support as the person living with paralysis.

- The PRC effectively leverages its position as a nationally-known funder of quality of life projects to create a valuable online resource map, where individuals living with paralysis can find services and resources in their areas.

- Grantees are able to leverage the grants they receive from the PRC to achieve an outsized fundraising effect, as applicants use the Reeve Foundation/PRC brand as a foundation for additional fundraising.

The Peer & Family Support Program, a cornerstone of the Reeve Foundation's Paralysis Resource Center, is a national peer-to-peer network. The program makes and supports person-to-person and community connections for people living with paralysis, their families and caregivers. The ultimate goal 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.

- The PRC's Peer & Family Support Program is a national network of peer mentors in 40 States that provides support to over 4,386 peers (people who are receiving mentoring) through a variety of means, including in-person, telephone, e-mail, and videoconferencing.

- Three of the four specialists that run this program live with paralysis themselves.

- In the past year, the PRC has increased its virtual trainings to increase and diversify its peer mentor pool, and recently made extensive revisions to its training curriculum.

- Since its inception in 2011, the Peer Program has also mentored 1,445 caregivers, providing an important peer support network for individuals who are often underserved.

A National Clearinghouse Lending Library of paralysis-related media, kept up-to-date with the very latest information and resources.

- The PRC's lending library has over 5,500 titles, including books, periodicals, videos, and other paralysis-related materials, which are utilized by staff and borrowed by clients at no cost to them.

- Resources cover cerebral palsy, MS, stroke, spinal cord injury, and lesser-known disorders such as Guillain-Barre syndrome and Transverse Myelitis.

- There is a separate online catalog for children.

The NeuroRecovery Network, a cooperative network of rehabilitation centers and local wellness facilities charged with developing and providing activity-based therapies to improve quality of life and health outcomes of those living with paralysis.

- The PRC’s NeuroRecovery Network coordinates the work of several leading rehabilitation centers and local community fitness facilities to provide effective, activity-based physical training to individuals living with paralysis, often in their home communities.
 - Facilities participating in the NeuroRecovery Network offer Locomotor Training and Neuromuscular Electrical Stimulation, two rehabilitation interventions that have been demonstrated to improve the independence and socio-emotional health of people with certain types of spinal cord injury.
 - In addition to significant functional motor improvements, participants in the NeuroRecovery Network report significant improvements to their quality of life, such as better circulation, fewer skin breakdowns, and better cardiovascular health that allow them to reduce medications, experience fewer hospital stays, and enjoy better health and independence.
 - The PRC has recently expanded the intervention to pediatric spinal cord injury, in association with the Children’s Hospital of Pittsburgh (CHOP) in Pittsburgh, PA and the Frazier Rehab Institute’s Department of Pediatric Rehabilitation in Louisville, KY.
 - Rehabilitation facilities currently participating in the NeuroRecovery Network are:
 - Craig Hospital (Englewood, CO)
 - Frazier Rehab Institute (Louisville, KY)
 - Kessler Institute for Rehabilitation (West Orange, NJ)
 - Magee Rehabilitation Hospital (Philadelphia, PA)
 - Ohio State University Medical Center (Columbus, OH)
 - The NeuroRecovery Network also includes Community Fitness and Wellness Centers that allow individuals to access affordable and effective activity-based exercise in their local communities. These centers make meaningful, specialized exercise available even multiple years after an injury, when insurance-covered therapy is typically no longer available. The PRC currently supports five such sites, in Minneapolis, MN; Louisville, KY; Lawndale, CA; Willow Springs, IL; and Canton, MA, with additional affiliates in South Jordan, UT; Houston, TX and Atlanta, GA. Plans are in place to open a facility in Indianapolis, IN.
- The Military & Veterans Program*, designed to support the unique needs of current service members and veterans affected by mobility impairments.
- The Christopher and Dana Reeve Foundation, via the PRC, helps servicemen and women whether they are paralyzed through combat-related, service-related, or non-service related events. It serves all veterans regardless of the era in which they served or how their injury was obtained.
 - The PRC’s specialized programming helps service members and veterans navigate their military benefits and combine them with civilian programs to foster high levels of health, well-being and independent living.
 - The Military and Veterans Program Advisory Council was formed with Reeve staff and volunteers who have ties to the military and veteran community. Goals of the Council include identifying and defining the needs of the military and veteran community and determining how the PRC can best reach and aid the community, 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.
- A Comprehensive Multicultural Outreach Program* dedicated to serving and promoting improved quality of life for members of minority and underserved communities. Populations targeted for outreach include: people with little to no proficiency in English, caregivers, military personnel and veterans, the LGBTQ community, people who live in rural areas, and people of various racial and ethnic backgrounds.
- The PRC’s Paralysis Resource Guide is available in hard copy or as an audiobook and has been translated into dozens of languages.
 - Many users discover the PRC via the Reeve Foundation website www.ChristopherReeve.org, which is revisited often by users to access resources that are hosted on the site. All of our materials can be translated in up to 170 languages.
 - Beginning in June 2015, the PRC began employing a broader cultural diversity outreach strategy, which now includes communities of color, ethnic minorities, people who have low incomes and limited proficiency in the English language, rural residents, 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.
- Thank you again for this opportunity to present testimony in support of the important work being undertaken by the Christopher and Dana Reeve Foundation’s Paralysis Resource Center. I am happy to answer any questions you may have.

[This statement was submitted by Alexandra Reeve Givens, Board Member, Christopher & Dana Reeve Foundation.]

PREPARED STATEMENT OF THE COALITION FOR HEALTH FUNDING

The Coalition for Health Funding is pleased to provide the House Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee with a statement for the record on fiscal year 2018 funding for the public health continuum. Since 1970, the Coalition has advocated for sufficient and sustained discretionary funding for the Public Health Service, including the agencies and programs that address the mounting and evolving public health challenges confronting the American people. Our 95 national, member organizations—representing the interests of more than 100 million patients and consumers, health providers, professionals, and researchers—are united in our belief that the Federal Government is an essential partner with State and local governments and the nonprofit and private sectors in improving our Nation's health. We are deeply concerned about the amount of funding that will be available in fiscal year 2018 for these core government functions.

Since 2010, efforts to reduce the Federal deficit have fallen largely on nondefense discretionary (NDD) programs, despite the fact that this funding accounts for only about 15 percent of all Federal spending—the lowest level on record as a share of our economy. Indeed, the Budget Control Act of 2011 reduced NDD spending by roughly \$1 trillion over 10 years by establishing austere budget caps and by roughly another \$1 trillion through sequestration of those caps due to Congress' failure to enact changes to revenue and mandatory spending. The Bipartisan Budget Acts of 2013 and 2015 granted partial and temporary relief from sequestration, but it is scheduled to return in fiscal year 2018, further shrinking the funding available for programs such as those provided by the Public Health Service.

As a result of these macro budget issues, Federal funding for public health and health research represents a small and shrinking share of the budget. In fiscal year 2016, discretionary health funding was only \$57 billion, or 1.5 percent of all Federal spending. Of this, about half supports medical research at the National Institutes of Health (NIH), and the remainder supports all other public health activities across the Public Health Service agencies and programs—disease prevention & response, health safety & security, workforce development, and access to primary and preventive care.

Still, President Trump in his fiscal year 2018 budget has proposed further decimating public health, health research, and other NDD programs by cutting \$54 billion to offset increased spending at the Department of Defense. Application of this cut across the Federal budget resulted in a more than 20 percent cut to the Department of Health and Human Services overall and unprecedented, draconian cuts to health research, public health and prevention, health workforce development, and social services that help our Nation's most vulnerable. In short, this budget proposal would compromise America's health security and the infrastructure that protects it.

The President's budget is not the only threat. Continued cuts to discretionary health programs have already forced agencies to do less with less under the BCA's austere budget caps. In our 2014 report, *Faces of Austerity: How Budget Cuts Hurt America's Health*, the Coalition compiled stories from individuals across the country on the impact of budget cuts. This report highlighted stories of Americans who no longer are able to access the care they need and the preventive services that keep them healthy where they live. It told the story of our declining ability to monitor and contain disease outbreaks as cuts force States and cities to reduce the number of public health officials they employ to meet these austere budgets. On the ground, cuts also reduced the ability for our Nation to train the medical professionals that are sorely needed in rural and urban communities and delayed progress on life saving treatments by shortchanging the medical research enterprise. These are just some examples of the impacts that Americans are seeing on the ground due to austerity.

Public health and health research programs are critical to Americans' health and do not contribute to the debt. In fact, when adequately funded, they help reduce healthcare costs in mandatory programs such as Medicare and Medicaid. Yet, the threats to discretionary health programs continue to grow. In addition to budget caps, the return of sequestration, and proposed cuts to the NDD budget, the potential repeal of the Affordable Care Act (ACA) further threatens the funding available for key public health activities. Specifically, the ACA's Prevention and Public Health Fund now represents 12 percent of the CDC's budget. Addressing the shortfall cre-

ated by ACA repeal will require cuts to other programs within the subcommittee's jurisdiction, further reducing our ability to protect Americans' health.

The first and foremost responsibility of the Federal Government is to protect and defend the American people against threats, both foreign and domestic. Short-changing public health and health research programs leaves Americans vulnerable to health threats already on or approaching our shores. As demonstrated time and time again, public health hazards such as Zika virus, opioid abuse, antibiotic resistance, diabetes, obesity, cancer, foodborne illness, lead poisoning, and others demonstrate the need for increased investment by the Federal Government in America's health, not the opposite.

[This statement was submitted by Emily Holubowich, Executive Director, Coalition for Health Funding.]

PREPARED STATEMENT OF THE COALITION ON ADULT BASIC EDUCATION

As Executive Director of the Coalition on Adult Basic Education (COABE), I appreciate the opportunity to submit testimony for the Record about the funding level for Adult Education programs. The Coalition on Adult Basic Education submits this testimony to the Senate Subcommittee on Labor, Health and Human Services, Education, and related agencies to address fiscal year 2018 funding levels in the Department of Education for Adult Education and Family Literacy.

The Department is the Education Department and the program and account is Adult Education and Family Literacy.

COABE is a membership organization comprised of more than 20,000 educators, administrators, mentors, and guides working to improve educational outcomes for adults and to build strong communities. We advance national and international adult education and literacy opportunities for all people. The purpose of COABE is to promote adult education and literacy programs and other State, Federal, and private programs that assist undereducated and/or disadvantaged adults to function effectively, unify the profession, develop human resources, encourage teachers and students, use research for 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. COABE conducts and sponsors professional development conferences, webinars, and other activities to advance adult education and literacy. COABE members 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 supports funding adult education in fiscal year 2018 at \$649.3 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. WIOA 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. However, WIOA cannot succeed unless Congress supports it adequately.

Federally funded adult education programs serve only a small fraction of adults in the United States with limited English, math, or reading skills. Federal funding and enrollment have declined from over 2.8 million students and \$700 million in 2001 to 1.5 million learners and \$582 million in 2016. Adult education State grants have been essentially flat-funded since fiscal year 2002, a reduction of more than 25 percent in real terms, while enrollment has declined by 44 percent, most sharply among those who most need adult education and workforce skills services. Demand for services across the country far exceeds supply.

Some adults enrolled in adult education programs are seeking their high school diploma or equivalent, but many American adults who have earned a high school diploma still struggle with basic skills. The problem is large and growing:

- More than 36 million Americans can't read or write at the most basic level.
- More than 60 million Americans lack the basic math skills necessary to operate a cash register or understand a bus schedule.
- 60 million Americans lack the credentials and skills necessary to succeed in postsecondary education.
- Every year, one in three young adults drops out of high school.

According to PIAAC (OECD's Program of International Assessment of Adult Competencies), Americans lag behind the international average for basic skills in literacy, numeracy, and problem-solving in technology-rich environments. Other na-

tions show consistent progress in enhancing the education levels of their adult populations. The Federal investment in adult education is important to our economy because the U.S. is increasingly losing the skills race to many of its economic competitors. The international Survey of Adult Skills (OECD, 2013) found that our average performance in literacy and numeracy was significantly lower than the international average. Proportionately, the U.S. has more working-age adults with low literacy skills than seven other industrialized nations.

We must invest in adult education because the jobs of the future will require postsecondary education. According to 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.

We cannot depend on a robust economy to solve this problem. A stronger economy will bring people back into the workforce but it won't train them. According to Alan Daley's "Overcoming the Skills Shortage," "More than 75 percent of manufacturers report moderate to severe skills shortages and up to 11 percent revenue losses from increased production costs and sales losses due to those shortages. Service industries are hardest hit. 33 percent of all small businesses say they cannot identify candidates qualified for job openings, and 43 percent of small business owners say unfilled jobs are impeding their growth or expansion."

Significant underinvestment in adult education and workforce skills development is eroding America's global competitiveness and our economic growth. 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 invest in adult education.

High schools alone cannot provide business and industry the workers they need. Most of America's workforce of tomorrow is already in today's workforce. They are beyond the reach of high schools and postsecondary education. Adult education is the best way to re-engage them.

There are also generational impacts on not investing in adult education. By neglecting the adults who need services, we affect their children, too. Education levels have more of an effect on earnings over a 40-year span in the workforce than any other demographic factor. Almost 60 percent of children whose parents don't have a college education live in low-income families, and are less likely themselves to get a good education and qualify for family-sustaining jobs. Mothers and fathers who learn basic skills are better equipped to help their children succeed. 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 premiums grow with more intensive participation. Finally, children whose parents are involved with them in family literacy activities score 10 points higher on standardized reading tests.

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 even more the demand for adult English-language programs for adults.

Adult education is a good investment. 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 investment in adult education is cost-effective. 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.

Data from the Longitudinal Study of Adult Learning (LSAL), which recorded the educational and workforce experiences of a random sample of high school dropouts between 1998 and 2007, shows that sustained participation in adult education increases the earnings of students. Using propensity score matching to observe differences between individuals who enrolled in adult education and those who did not, one study found that participating in adult education for 100 or more hours netted students an average income increase of \$6,635 (in 2007 dollars), nearly one half of standard deviation of students' 2007 incomes.

According to "The Return on Investment from Adult Education and Training," a 2011 policy paper issued by the McGraw-Hill Research Foundation in conjunction with NCSDAE, "A preemptive focus on adult education actually saves governments money by reducing societal healthcare, public assistance, and incarceration costs. Adult education also . . . expands the Nation's available pool of human capital . . . and at a far lower cost per learner when compared to either K-12 or higher education."

Low literacy levels 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 be living in poverty than high school graduates. They are three times more likely to be unemployed than adults with college degrees. Experts estimate that low literacy costs the U.S. more than \$225 billion in lost tax revenue, reduced productivity, crime, and poor health. Investing in adult education can improve health outcomes, reduce poverty, and reduce recidivism.

Fiscal Year 2018 Funding Request

Other nations are boosting the educational levels of their young and working age adults at a faster rate than the U.S. They are showing consistent progress while the U.S. is losing ground. Adult education is a gateway to a job and a career. It is a hand up, not a hand out. Its impact can last for generations. Properly funding the adult education system would yield substantial economic benefits, adding to GDP growth, personal incomes, and increased tax revenue.

In summary, we ask the subcommittee to remember that adult education is a path from low-income jobs and dead-end futures to family sustaining jobs and post-secondary education. In an increasingly competitive world we must empower individuals, families, and communities with the educational opportunities they need. We cannot afford to waste the talents of millions of Americans who cannot read, perform basic math, use a computer, or solve problems creatively.

- Low education and skill levels are fundamental barriers to almost every major challenge facing the U.S., including the need for early childhood education, educational reform, international competitiveness, improving the health and well-being of our Nation's families, reducing crime, and restoring the American dream.
- Adult education works. The number of adults without a high school diploma or equivalent declined by 20 percent from 2000 to 2015.
- A person with a high school diploma, or equivalent, earns an average of \$9,620 more per year than a non-graduate.
- Adult education funding must be increased if WIOA is to succeed.
- COABE urges you to fund Title II of WIOA at the fiscal year 2018 authorized level.

We understand the committee faces a challenging budgetary environment. Nevertheless, we urge you to fund adult education at the level authorized in WIOA so that the ambitious goals of that law may be realized. We must invest adequately in our adult education system to remain economically competitive.

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. Recognizing that so many health research issues are inter-related, we request that the subcommittee provide at least \$2 billion above fiscal year 2017 for the National Institutes of Health, and within that amount a proportionate increase for the National Institute on Drug Abuse, in your fiscal year 2018 Labor-HHS Appropriations bill. We also respectfully request the inclusion of the following NIDA specific report language.

Opioid Misuse and Addiction. The Committee continues to be extremely concerned about the epidemic of prescription opioids, heroin, and synthetic opioid use, addiction and overdose in the U.S. Approximately 144 people die each day in this country from opioid overdose, 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 fentanyl and its analogs into 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, 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 abuse and addiction within affected populations.

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.

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.

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.

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/criminal justice 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, early evidence suggests 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. Early 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. Placing dollar figures on the problem; smoking, alcohol and illegal drug use results in an exorbitant economic cost on our Nation, estimated at over \$600 billion annually. 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—significant declines in a wide array of youth drug use—over the past several years that we think are due, at least in part, to NIDA’s public education and awareness efforts. However, areas of significant concern include the recent increase in lethalties 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 2018 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. We look forward to working with you to make this a reality. Thank you for your support for the National Institute on Drug Abuse.

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 the official record. For fiscal year 2018, COSSA requests an increase of at least \$2 billion above the fiscal year 2017 appropriated level for the National Institutes of Health (NIH), in addition to funds included in the 21st Century Cures Act for targeted initiatives. We further urge the Subcommittee to appropriate \$7.8 billion for the Centers for Disease Control and Prevention (CDC), \$170 million for the National Center for Health Statistics (NCHS), \$364 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.

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 that leads to discoveries that benefit all. It represents the collective interests of all fields of social and behavioral science research, including but not limited to sociology, anthropology, political science, psychology, economics, statistics, language and linguistics, population studies, law, communications, educational research, criminology and criminal justice research, geography, history, and child development. COSSA appreciates the Subcommittee’s continued support for NIH, CDC, NCHS, AHRQ, IES, and International Education programs. Strong, sustained funding for these agencies and activities is essential to our national priorities of better health and economic competitiveness.

NATIONAL INSTITUTES OF HEALTH,
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Since 2003, NIH funding has declined by 23 percent after adjusting for biomedical inflation, despite recent budget increases provided by the Congress over the past 2 fiscal years. The agency’s budget remains lower than it was in fiscal year 2012 in actual dollars. 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 necessitates a funding level for the

NIH of at least \$2 billion above fiscal year 2017, in addition to the funds included in the 21st Century Cures Act for targeted initiatives. This funding level would enable real growth over biomedical inflation, an important step toward ensuring stability in U.S. research capacity over the long term.

As this Committee knows, the NIH supports scientifically rigorous, peer/merit-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.” However, we remain extremely concerned about continued criticism of some of the NIH’s funding decisions and mischaracterizations of NIH-supported projects, primarily in the behavioral and social sciences. Such criticisms are unsupported when one looks at the important contributions the behavioral and social sciences have made to the well-being of this Nation.

Due in large part to behavioral and social science research sponsored by the NIH, we are now aware of the enormous role behavior plays in health. At a time when genetic control over disease is tantalizingly close but not yet possible, knowledge of 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.

Thanks to strong Congressional commitment to the NIH in years past, our knowledge of the social and behavioral factors surrounding chronic disease health outcomes is steadily increasing. This support has allowed the NIH’s behavioral and social science portfolio to emphasize the development of effective and sustainable interventions and prevention programs targeting those very illnesses that are the greatest threats to our health, but the work is just beginning.

CENTERS FOR DISEASE CONTROL AND PREVENTION,
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

COSSA urges the Subcommittee to appropriate \$7.8 billion for the Centers for Disease Control and Prevention (CDC), including \$170 million for CDC’s National Center for Health Statistics. 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. These scientists play a key role in the CDC’s surveillance and monitoring efforts, which collect and analyze data to better target public health prevention efforts, and in identifying and understanding health disparities. The social and behavioral sciences also play an important role in the evaluation of CDC programs, helping policymakers make informed, evidence-based decisions on how to prioritize in a resource-scarce environment.

COSSA requests \$170 million for the National Center for Health Statistics (NCHS), the Nation’s principal health statistics agency. 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 like the National Health Interview Survey (NHIS), the National Health and Nutrition Examination Survey (NHANES), and the National Vital Statistics System (NVSS) 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,
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

COSSA urges the Subcommittee to appropriate \$364 million for the Agency for Healthcare Research and Quality (AHRQ) and reject the proposal from the Administration to transfer AHRQ to the NIH. AHRQ funds research on improving the qual-

ity, 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. For example, AHRQ-funded research has been instrumental in reducing hospital-acquired conditions by 17 percent in 5 years, translating to 87,000 lives and nearly \$20 billion in healthcare costs saved; identifying strategies to help primary care practices cope with the challenges of the opioid epidemic; and helping doctors make better decisions and improve patients' health by taking advantage of electronic health records and other IT advances. Without AHRQ, important research on topics like reducing waste and unnecessary costs, improving access to healthcare, and getting the best treatments into the hands of providers would fall through the cracks.

Further, AHRQ reports and data give us vital information about the state of the U.S. healthcare system and identify areas we can improve. For example, the Congressionally-mandated National Healthcare Quality & Disparities Report is the only comprehensive source of information on healthcare quality and healthcare disparities among racial and ethnic minorities, women, children, and low-income populations. 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.

INSTITUTE FOR EDUCATION SCIENCES,
U.S. DEPARTMENT OF EDUCATION

COSSA requests a funding level of \$670 million for IES in fiscal year 2018, which would build on the fiscal year 2016 allocation, accounting for inflation over the past 2 years plus a 4 percent increase. As the research arm of the Department of Education, IES supports research and produces statistics and data to improve our understanding of education at all levels, from early childhood to elementary and secondary education, through higher education. Research examining special education, rural education, teacher effectiveness, education technology, student achievement, reading and math interventions, and many other areas is also supported by IES.

Findings from IES-supported research have 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 (which highlights interventions that work and identifies those that do not). With increasing demands 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. Further, adequate funding will allow IES to continue to support this important research, data collection and statistical analysis, and dissemination. A strong fiscal year 2018 investment in the Institute will allow IES to build upon existing findings and to conduct much-needed new research.

INTERNATIONAL EDUCATION AND FOREIGN LANGUAGE PROGRAMS,
U.S. DEPARTMENT OF EDUCATION

The Department of Education's International Education and Foreign Language programs play a significant 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. This sum represents a modest increase in funding, which would broaden opportunities for students in international and foreign language studies. It would also allow us to strategically strengthen our human resource capabilities in the areas of the world that most 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. Please do not hesitate to contact me should you require additional information.

[This statement was submitted by Wendy A. Naus, Executive Director, Consortium of Social Science Associations.]

PREPARED STATEMENT OF THE CORPORATE COMMITTEE FOR LIBRARY INVESTMENT

The more than 90-member Corporate Committee for Library Investment (fundlibraries.com), including three multi-sector national trade associations, was launched on May 17, 2017 expressly to promote robust Federal library funding in fiscal year 2018 and beyond. We write today in support of two modest but critical library programs. Specifically, CCLI asks that you appropriate \$186.6 million for the essential programs funded under the Library Services and Technology Act (LSTA) and \$27 million for the Innovative Approaches to Literacy (IAL) program. LSTA funding goes almost entirely to a population-based matching grant program that puts States in charge of how funds are spent. IAL allows school libraries to buy books and educational materials for the Nation's neediest children.

We make this request as businesses operating in every State in the Nation and which collectively generate several billion dollars in annual revenue, employ thousands of people and financially enable scores of other firms in our supply and service chains to hire thousands more. We support LSTA and IAL for clear business and other economic reasons:

- Libraries build strong workforces and strong economies in communities of every size in every State in the Nation. For example, an fiscal year 2017 study in Texas just documented “ROP” of \$4.64 for every dollar invested in public libraries and that result is not anomalous;
- State libraries dramatically leverage taxpayer dollars by using LSTA funds to purchase or contract for electronic materials that they make available to every individual library in their States, thus realizing enormous efficiencies and economies of scale. Consequently, every library user enjoys access to authoritative information that would cost many fold more or simply be unavailable due to cost factors if otherwise had to be purchased by individual libraries, schools and universities; and
- Public universities garner billions in private industry grants for R & D research to which such LSTA-funded electronic online resources are vital. Those grants, in turn, offset taxpayer-funded education costs and contribute substantially to keeping American companies competitive.

By these measures, library funding may be among the very best yielding and most leverageable investment that Congress makes across the entire Federal budget. Libraries are thus very much critical national infrastructure: ubiquitous, indispensable, and economically essential. Consider:

- There are 25 percent more public libraries in the United States than Starbucks;
- Each year, America's more than 120,000 libraries of all kinds are visited 1.4 billion times nationwide (that averages to about 4 million visits per day or 2,663/minute);
- Those many millions of visitors come to modern libraries to borrow books, but also because libraries do (and have for decades been doing) so much more:
 - 100% of libraries offer free access to the Internet;
 - 97% help patrons, including veterans, complete government forms online;
 - 90% train children and adults in computer literacy and other online skills;
 - 73% aid patrons with job applications and interviewing skills;
 - 68% help users use databases to find job openings; and
 - 48% provide entrepreneurs and small business owners with online resources.

The bottom line, literally and figuratively, is that the health of our businesses, our workers and all of our communities is inextricably linked to the health of libraries and their continued Federal funding. Accordingly, we urge you to:

- Fully fund the Library Services and Technology Act at \$186.6 million and the tiny but vital Innovative Approaches to Literacy program at \$27 million; and
- Ensure sufficient funding for the Institute of Museum and Library Services, which has efficiently administered the LSTA to bipartisan praise for many years.

Thank you for supporting America's businesses by supporting America's libraries.

Al Manhal
 Albert Whitman & Company
 Bang Printing
 Barefoot Books
 Bedrock Solid, LLC
 Berrett-Koehler Publishers
 bibliobibli
 Blackstone Audio, Inc.
 Bloomsbury Children's Books
 Bookmobile

Books of Aurora, Inc.
 Boydell & Brewer, Inc
 Boyds Mills Press
 ByWater Solutions
 Childress Ink LLC
 Cohen Strategy Group, LLC
 Continental Sales Inc.
 Credo Reference
 Dawn Publications
 Equinox Open Library Initiative

Favorable Impressions	Prestwick House
Firebrand Technologies	Publishers Weekly
Free Spirit Publishing	ReferenceUSA
Gallopade International, Inc	Rowman & Littlefield
Independent Publishers Group	SAGE Publishing
Information Library & Information Solutions	SEBCO BOOKS
Ingenta Connect	Soc. of Children's Book Writers & Illustrators
Jump!	Sourcebooks
Knapp Made Products Inc	South Shore Computer Repair
Learning ZoneXpress	ST Imaging
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Lectorum Publications, Inc.	Talking Leaves Books on the Web
Lerner Publishing Group	Tanglewood Publishing, Inc.
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LibraryWorld, Inc.	Tuttle Publishing
Media Source, Inc.	Who's On My WiFi
MEP Schoenhof's	Workman Publishing
Mitchell Lane Publishers	World Book, Inc.
NBM Graphic Novels/Papercutz	Writerspace
NetGalley LLC	Yewno
OCLC	ZRJavelin, LLC

PREPARED STATEMENT OF THE CORPORATION FOR NATIONAL AND
COMMUNITY SERVICE

Chairman Blunt, Ranking Member Murray, and distinguished Subcommittee Members, I encourage you to do all that you can to protect vital funding for the Corporation for National and Community Service (CNCS) as you consider your appropriations requests for fiscal year 2018. The Federal agency CNCS creates jobs, strengthens communities, and bolsters the civic health of our nation through invaluable national service programs including AmeriCorps, Senior Corps, the Social Innovation Fund, and the Volunteer Generation Fund.

I begin this testimony by highlighting the impact that AmeriCorps had on my life and the community in which I served. Like many other college graduates, I had the tall order of wanting my first job to be one with responsibility and meaning. After months of Internet searches, phone interviews, and sweaty handshakes I knew I struck gold when I got the position as a Highland Street AmeriCorps Ambassadors of Mentoring (AOM) within a human service agency in Cambridge, Massachusetts. Like the other 21 energetic young professionals in my corps, I was tasked with strengthening a mentoring program. Having an AOM afforded my agency the capacity to implement an innovative mentoring program for children living with a family member with a mental illness. Through my work at the agency I recruited participants, trained mentors, and supported 7 matches. The work of the 7 volunteer mentors totaled 1,000 hours at the end of my service year.

My AOM experience not only supported youth in need, it allowed me to nurture my own professional development skills. During my service year I was exposed to the benefits of mentoring, the field of mental health, and the fight for social justice. My career path trajectory would not have been the same without my AOM experience. I'm not sure I would have been able to procure a job at a public health think tank in Massachusetts. I'm not sure I would have decided to become a volunteer mentor myself. I'm not sure I would be at Columbia University today getting graduate degrees in social work and public administration.

Since 2008, the funding from CNCS has touched the lives of 174 AOMs like myself. Since 2008, the funding from CNCS has allowed AOMs to serve in 64 mentoring agencies in Massachusetts, create an average of 379 matches a year, and reach more than 10,000 youth through nearly 35,000 hours of service.¹ The AOM program in Massachusetts is just one seed in the garden of AmeriCorps service programs that would be destroyed without CNCS funding.

CNCS programs are cost-effective, force multipliers for strengthening communities. Specifically, economists found that their social benefits— including the value of output produced and the longer-term gains from greater human and social cap-

¹“Highland Street AmeriCorps Ambassadors of Mentoring.” Mass Mentoring Partnership. Web. 27 Apr. 2017. Accessed at <http://massmentors.org/ambassadors>.

ital—exceed their costs by a factor of 3.95.² Given the efficiency of CNCS programs, it's no surprise that American citizens strongly support them. According to a 2016 poll of over 1,300 registered voters across the country, 80 percent of voters agree that we should continue Federal investment in the programs. That support is bipartisan. When voters were asked specifically if they would support a robust National Service program proposed by President Trump, an overpowering 87 percent of Republicans and 88 percent of Trump supporters support this program.³

Many of us have seen National Service programs at work in our schools, senior centers, and health facilities. Many of us have met people who have been served by National Service programs. Now is the time to ensure that the fiscal year 18 budget keeps CNCS and provides the same amount of funding (1.1 billion) for CNCS as was provided in fiscal year 17. National Service unifies our country, remains bipartisan, and irrefutably benefits our country.

[This statement was submitted by Rachel Lee, M.S.W., M.P.A, Columbia University Candidate.]

PREPARED STATEMENT OF THE CORPS NETWORK

Dear Chairman Blunt and Ranking Member Murray,

On behalf of The Corps Network, our 135+ Corps, and the 25,000 participants, or Corpsmembers, they enroll, I write to respectfully request that you support strong funding for the Corporation for National and Community Service (CNCS) in fiscal year 2018 Appropriations and that you oppose the elimination of, or cuts to, the Corporation or its programs. I applaud the hard-work of this subcommittee and your dedication to national service and AmeriCorps funding over the past 2 fiscal years, and I urge your continued support of funding at the current levels: \$386 million for AmeriCorps State and National; \$30 million for the NCCC; \$92.4 million for VISTA; \$220 million for the National Service Trust (Education Awards); and \$16 million for State Commissions. We also support continuation of the Social Innovation Fund.

While there are many critical priorities under your jurisdiction, CNCS programs like AmeriCorps meet some of the most vital public needs in rural and urban communities around the country, leverage significant additional private funding and resources through locally-based organizations, and save the government money in the long run. A recent study put the return on investment in AmeriCorps at 4:1. Especially in a difficult fiscal environment, an investment of taxpayer resources in a proven, accountable, and local partnership-based effort makes sense.

AmeriCorps invests in local, cost-effective, public-private partnerships like Corps that generate significant private matching funds. In fact, AmeriCorps programs generate more private resources than the Federal investment, making this an important partnership to attract additional support for important local needs and more effectively using taxpayer resources. Corps utilize AmeriCorps to help make local, state, and Federal Government more efficient and effective by “putting service to work” on a variety of cross-jurisdictional projects and leveraging limited government funds, not to mention providing an opportunity to learn the value and dignity of hard work and civic duty to thousands of young Americans.

Corps provide young adults and veterans (Corpsmembers) the opportunity to serve their country, advance their education, and obtain in-demand skills. Serving in crews and individual placements, Corpsmembers perform important conservation, recreation, infrastructure, wildfire, disaster response, and community development projects on public lands and in rural and urban communities. Corps enroll over 25,000 diverse youth and veterans annually in all 50 states and DC, Puerto Rico, and American Samoa. Over 60 percent of whom were living below the poverty line, unemployed, not in school but without a High School Diploma/GED, or were formerly incarcerated or court-involved, prior to their enrollment in the Corps.

As a result of CNCS' AmeriCorps State and National, AmeriCorps VISTA, and AmeriCorps NCCC, Corps accomplish critical projects and engage thousands of veterans and youth to respond to disasters, improve public lands, increase access to outdoor recreation, promote economic development in rural and urban communities, provide Corpsmembers in-demand skills and help them and their families afford continued education or skills development.

²Belfield, Clive. *The Economic Value of National Service*. Voices for National Service and Civic Enterprises for the Franklin Project at The Aspen Institute, 2013.

³TargetPoint Consulting. *National Service Strategy Memo*. Michael Meyers, 16 Dec. 2016. Web. Accessed at <http://voicesforservice.org/wp-content/uploads/2017/02/VNS-Polling-Summary-Memo.pdf>.

For example, Corps have been on the frontlines of all recent major disasters, including tornadoes in Missouri and Oklahoma; Hurricanes Katrina, Sandy, and Matthew; flooding in Missouri, Louisiana, West Virginia, Colorado, and Texas; wildfires in Tennessee, Colorado, and California; mudslides in Washington; and the recent California dam disaster. Corps send crews to all major disasters in coordination with AmeriCorps. When fires, storms, and floods occur, Corps help communities recover by managing volunteers, removing debris, mucking and gutting houses, and conducting site remediation.

Corps also work on infrastructure projects like transportation and water systems. Further, they specifically engage veterans in conservation and fire fighting, remediation, and recovery, and Native youth in conservation and restoration projects on tribal lands like in Acoma Pueblo and the Navajo Nation. Some Corps improve and preserve our public lands, recreation assets, and national parks while others provide energy conservation services, including weatherization and alternative energy installation. Corps also create urban parks and gardens.

We are pleased to be able to participate in several new public-private partnerships through CNCS' National Service Task Force, and urge your continued support for those partnerships as well. For example, with funding provided by CNCS and the Department of Justice, The Corps Network has been able to get court-involved youth back on track and be seen as an asset to their community, not a liability.

Additionally, we've worked with CNCS and the Departments of Agriculture and Interior to enroll AmeriCorps members in a 21st Century Conservation Service Corps to accomplish important work on public lands and help address the millions of dollars in backlogged maintenance and meet wildfire suppression and fighting needs. Recently, we have implemented high-quality summer programming at several of our Corps, allowing hundreds of high school aged youth to learn in-demand skills that make them more attractive to employers, stay on track to graduate, and earn an education award in order to transition to postsecondary education or career development.

As you can see, CNCS supports many important initiatives that engage a diverse population of youth serving in Corps including veterans, Native youth and individuals with disabilities. With increasing strains on public support systems and Federal resources, it is more important than ever to support this type of public-private partnership that engages local organizations for locally-based solutions. Through your support, we can provide more service opportunities for our youth and veterans to reengage in education, hard work, and their communities and get on a productive path for America's continued growth and prosperity.

Thank you for the opportunity to provide written testimony for the record. We again respectfully urge your support for CNCS fiscal year 2018 and continued funding for these critical programs for thousands of communities and every state around the country. Thank you for your time and consideration of this testimony.

Sincerely,

[This statement was submitted by Mary Ellen Sprenkel, President & CEO, The Corps Network.]

PREPARED STATEMENT OF THE COUNCIL OF ACADEMIC FAMILY MEDICINE

The member organizations of the Council of Academic Family Medicine (CAFM) are pleased to submit testimony on behalf of programs under the jurisdiction of the Health Resources and Services Administration (HRSA) and the Agency for Healthcare Research and Quality (AHRQ). The CAFM collectively includes family medicine medical school and residency faculty, community preceptors, residency program directors, medical school and health system department chairs, research scientists, and others involved in family medicine education.

We urge the Committee to appropriate at least \$59 million for the health professions program, Primary Care Training and Enhancement, authorized under Title VII, Section 747 of the Public Health Service Act under the jurisdiction of the Health Resources and Services Administration (HRSA.) In addition, we recommend the Committee fund the Agency for Healthcare Research and Quality (AHRQ) at no less than \$364 million in base discretionary funding, consistent with the agency's fiscal year 2015 funding level.

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. (Petterson, et al Mar/Apr 2015) The Primary Care Training and Enhancement program and AHRQ primary care research will help build our Nation's workforce and health infrastructure. Both improve primary care services that will produce better health outcomes and reduce the increasing costs of healthcare.

The President's fiscal year 2018 budget harms the primary care infrastructure of the United States—particularly the two funding lines mentioned above. We reject the statement included in the Administration's "2018 Major Savings and Reforms" document that the Title VII health professions programs "lack evidence of significantly improving the Nation's health workforce." We show, below, the value of the Primary Care Training and Enhancement program to this country. In addition, the Budget cherry-picks parts of AHRQ's mission, eliminating the statutory basis for primary care research in the newly proposed "National Institute for Research on Safety and Quality (NIRSQ,)" harming the primary care research currently supported by AHRQ and cutting primary care funding needlessly. More, not less, primary care research supported by Federal funding is needed to address the overall health of the Nation.

PRIMARY CARE TRAINING AND ENHANCEMENT

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. The most recent Congressional reauthorization modified the Title VII health professions programs to direct HRSA to prioritize training in the new competencies relevant to providing care in the patient-centered medical home model. It also calls for the development of infrastructure within primary care departments for the improvement of clinical care and research, as well as innovations in team management of chronic disease, integrated models of care, and healthcare transitions. Its purpose is not only, as the President's budget contends, to increase workforce numbers, but to also increase value. These programs accomplish both aims; increased funding, rather than elimination, would strengthen the primary care workforce in number and quality.

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 to transform practice delivery. Future training needs include: training in environments that include integrated care with other health professionals (e.g. behavioral health, care coordination, nursing, oral health); development and implementation of curricula to build inter-professional teams; and development and implementation of curricula to develop leaders and teachers in practice transformation. New competencies are required for our developing health system.

Multiple studies have recognized the value of this program.¹ In addition, decreased resources for the program over time have had a detrimental impact. The Advisory Committee on Training in Primary Care Medicine and Dentistry December 2014 reports 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."² The Advisory Committee recommended that Congress increase funding levels for training under the primary care training health professions program, starting in fiscal year 2017 and for the next 5 years. The current funding of \$38.9 million does not allow for 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, and no new awards have been granted thus far in fiscal year 2017. Family medicine alone has over 100 departments in medical schools and over 450 residencies.

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 are gravely concerned about the Administration's proposal to zero out this program. We urge your continued support for this program and an increase in funding from fiscal year 2017 levels to \$59 million in fiscal year 2018 to allow for a robust competitive funding cycle. This funding level will help continue important Title VII programs such as the University of South Alabama's curricular innovation that incorporated multimedia education, standardized patients, and point of care evidence-based teaching and patient-based

¹ <http://www.jgme.org/doi/full/10.4300/JGME-D-14-00329.1>.

Fryer GE Jr, et al. The association of Title VII funding to departments of family medicine with choice of physician specialty and practice location. *Fam Med*. 2002;34(6):436–440.

Politzer RM, et al. The impact of Title VII departmental and predoctoral support on the production of generalist physicians in private medical schools. *ArchFam Med*. 1997;6(6):531–535.

Rittenhouse DR, et al. Impact of Title VII training programs on community health center staffing and national health service corps participation. *Ann FamMed*. 2008;6(5):397–405.

² <http://www.hrsa.gov/advisorycommittees/bhpradvisory/actpcmd/Reports/eleventhreport.pdf>.

evaluation of medical students in their first and second years—making better doctors.

AGENCY FOR HEALTH CARE RESEARCH AND QUALITY

AHRQ (Agency for Health Care Research and Quality) supports primary care research around the country. Most other research funding in the United States supports research of one specific disease, organ system, cellular, or chemical process—not for the person as a whole, not for primary care—even though the overall health of a population is directly linked to its primary healthcare system. Primary care research includes: translating science into patient care, organizing healthcare to meet patient and population needs, evaluating innovations to provide the best health for patients, and engaging patients, communities, and practices to improve their own health. AHRQ is uniquely positioned to support best practice research and to help disseminate the research nationwide.

There are six areas AHRQ highlights that are not emphasized elsewhere in the biomedical research infrastructure:

1. Practice-based Research Networks (PBRNs)
2. Practice transformation
3. Patient quality and safety outside of the hospital
4. Multi-morbidity research
5. Mental and behavioral health in primary care practices
6. Training future primary care investigators.

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 Oklahoma Primary Healthcare Improvement Center to serve as a resource to the emerging Oklahoma Primary Healthcare Extensions System. Part of the Evidence Now Initiative, this grant will support the dissemination of patient-centered outcomes research findings into practices, support 300 primary care practices in risk management around smoking cessation, blood pressure control, statins, and low-dose aspirin, and evaluate the intervention's impact on practice performance.

AHRQ funds research into multiple chronic conditions—a hallmark of primary care practice—and not found elsewhere. How care is delivered, such as whether care and outcomes are different in team based practices, compared to traditional practices is another unique role of AHRQ. Highlighting the success of AHRQ's patient safety initiatives, a 2014³ 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. Now more needs to be done in the outpatient arena. AHRQ supports the research that delivers higher quality of care and better health while reducing the rising cost of care. We need to understand how patients can best decide how and when to seek care, how to introduce and disseminate new discoveries into real life practice, and maximize appropriate care.

Past budgets have reduced funding for AHRQ and disproportionately reduced critical research efforts within AHRQ such as those related to care for persons with multiple chronic conditions. For this reason, we support increased funding for AHRQ at least at the level of \$364 million for fiscal year 2018.

The Administration also proposed moving AHRQ to become an institute within the National Institutes of Health (NIH). CAFM supports this effort with several caveats:

- First, we request that AHRQ clearly retain its current purposes. We hope this proposal will enable AHRQ's unique work to continue and be enhanced as part of the complementary schema of NIH. As part of this potential transition, we ask that the statutory support for the work of AHRQ in serving as “the principle source of funding for primary care practice research . . . [which] focuses on first contact when illness or health concerns arise, the diagnosis, treatment or referral to specialty care, preventive care, and the relationship between the clinician and patient in the context of the family and community” (Healthcare Research and Quality Act of 1999) continue in any new NIH Institute.
- Second, we ask that the new Institute be called the Institute for Primary Care and Health Services Research. Basic science and disease-specific research is the historic and current focus of the NIH. Primary care research has been grossly underfunded. Less than 0.5 percent of NIH funding goes to family medicine researchers. This small amount is concentrated among a limited number of de-

³Publication # 15-0011-EF.

partments with little funding for new investigators. A new Institute must emphasize primary care from the top down.

—Third, we request a National Academy of Medicine (NAM) study to articulate a blueprint of the future vision of the Institute within NIH, including gaps in primary care research that should be addressed, and the opportunities and challenges of being within NIH. Support for a non-partisan study by NAM to identify a future vision for a primary care and health services NIH institute would advance the state of primary care and consequently the health of the public.

CAFM looks forward to working with the Subcommittee to protect HRSA primary care programs and the future of AHRQ—both entities protect and enhance our Nation’s primary care workforce and health infrastructure.

[This statement was submitted by Mary N. Hall, MD, Chair, Council of Academic Family Medicine.]

PREPARED STATEMENT OF THE CROHN’S AND COLITIS FOUNDATION

SUMMARY OF FISCAL YEAR 2018 RECOMMENDATIONS

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- \$36 billion for the National Institutes of Health (NIH). \$2.165 billion for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).
 - Continued Focus on Digestive Disease Research and Education at NIH, and Support for the Inflammatory Bowel Disease (IBD) Portfolio.
 - \$1,000,000 for the Centers for Disease Control and Prevention’s (CDC) IBD Epidemiology Activities.

Chairman Blunt and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities on behalf of the Crohn’s and Colitis Foundation. The Foundation has remained committed to its mission of finding a cure for Crohn’s disease and ulcerative colitis and improving the quality of life of children and adults affected by these diseases for nearly 50 years.

Inflammatory Bowel Diseases (IBD) are chronic disorders of the gastrointestinal tract which cause abdominal pain, fever, and intestinal bleeding. IBD represents a major cause of morbidity from digestive illness and has a devastating impact on both patients and their families. A recent CDC study indicated that the prevalence of IBD has nearly doubled in the past 15 years from affecting 1.6 million Americans to 3.3 million, demonstrating an inherent need for investment in this area.

The social and economic impact of digestive disease is enormous and difficult to grasp. Digestive disorders afflict approximately 65 million Americans. This results in 50 million visits to physicians, over 10 million hospitalizations, collectively 230 million days of restricted activity. The total cost associated with digestive diseases has been conservatively estimated at \$60 billion a year.

NATIONAL INSTITUTES OF HEALTH

For NIH (National Institutes of Health), the Foundation recommends:

- \$36 billion for NIH
- \$2.165 billion for the National Institute of Diabetes and Digestive and Kidney Disease (NIDDK)

We at the Foundation respectfully request that any increase for NIH does not come at the expense of other Public Health Service agencies. With the competing and the challenging budgetary constraints the Subcommittee currently operates under, the Foundation would like to highlight the research being accomplished by NIDDK which warrants the increase for NIH.

In recent years, researchers have made significant progress in the fight against IBD. The Foundation commends NIH for continuing to support cross-cutting research at multiple institutes and centers through the Human Microbiome Project supported through the Common Fund. Specifically, the Foundation is excited about the NIH-funded research being done characterizing the gut microbial ecosystem for diagnosis and therapy in IBD.

The Foundation applauds NIDDK for its strong commitment to IBD research through the Inflammatory Bowel Disease Genetics Research Consortium which has contributed to furthering our understanding of how these diseases operate on a molecular and biological level. The Foundation urges NIDDK to continue efforts to identify the etiology of the disease in order to inform the development of cures for inflammatory bowel disease.

Recently, IBD has seen a dramatic increase in prevalence in the United States which has led to a number of new questions related to onset of IBD that require

significant resources. Specifically, there is little scientific documentation on the connection between environmental triggers and the onset of IBD. Environmental triggers have been linked to the onset of many autoimmune conditions but the specific connection in relation to IBD still needs to be investigated. Additionally, the emerging field of epigenetics has shown great promise for data regarding disease pathogenesis of IBD. Further investment in this area is needed to realize this research areas full potential as it relates to IBD.

CENTERS FOR DISEASE CONTROL AND PREVENTION

The Foundation commends CDC for implementing a robust IBD epidemiology study and asks the Subcommittee to provide additional funding for the program so that CDC can expand the study to incorporate additional populations. In this regard, a recent Morbidity and Mortality Weekly Report (MMWR) from CDC indicated that incidence of IBD has nearly doubled over a 15-year period, from 1.6 million to 3.3 million, with increased prevalence in minority populations. Not enough is known about the impact of IBD among minority populations. As the incidence of IBD rises in minority populations, investment in this area becomes increasingly important.

CDC, in collaboration with a nationwide, geographically diverse network of large managed healthcare delivery systems, has led an epidemiological study of IBD to understand incidence, prevalence, demographics, and healthcare utilization. The group, comprised of investigators at the Massachusetts General Hospital in Boston, Rhode Island Hospital, the Foundation, and CDC, has piloted the Ocean State Crohn's and Colitis Registry (OSCAR), which includes both pediatric and adult patients. Since 2008, OSCAR investigators have recruited 22 private-practice groups and hospital based physicians in Rhode Island and are that enrolling newly diagnosed patients into the registry. This study found an average annual incidence rate of 8.4 per 100,000 people for Crohn's disease and 12.4 per 100,000 for Ulcerative Colitis; published in *Inflammatory Bowel Disease Journal*, April 2007.

The Foundation encourages CDC to continue to support a nationwide IBD surveillance and epidemiological program at \$1 million in fiscal year 2018 to expand current efforts to identify the impact of IBD, specifically in minority populations.

CONCLUSION

The Foundation asks the Subcommittee to support \$36 billion for NIH and \$1,000,000 for the IBD Program at CDC. The Foundation hopes you will carefully consider the tremendous benefits to be gained by supporting a strong research and education program at NIH and CDC. Millions of Americans are pinning their hopes for a better life on digestive disease research conducted through NIH and surveillance at CDC. On behalf of our patients, we appreciate your consideration of our views. We look forward to working with you and your staff.

[This statement was submitted by Laura Wingate, Vice President, Education, Support & Advocacy, Crohn's and Colitis Foundation.]

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 through the National Institutes of Health (NIH), and to submit this written testimony to request at least an additional \$400 million in fiscal year 2018 above the final enacted amount for fiscal year 2017 for Alzheimer's disease research at NIH.

Cure Alzheimer's Fund is a national nonprofit, based in Massachusetts, that funds research throughout the United States and Internationally, starting with the genetic 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.

Although this request is focused on fiscal year 2018, I would be remiss in not thanking you for your work in finalizing a full appropriation for NIH fiscal year 2017 that included a recommended increase of \$400 million for Alzheimer's disease research at the NIH.

Science and research explore and illuminate the unknown. But to do this, there needs to be a level of certainty in the funding. By completing work on the fiscal year 2017 appropriations package for NIH, and having it for the balance of the fiscal year, you have helped researchers by allowing them to know what funding will be available this year.

This Subcommittee has been a constant supporter of increased funding for the NIH in general and Alzheimer's disease research specifically. It has shown that it recognizes the need for appropriating as much funding as possible within budgetary constraints. Because of this commitment, funding for Alzheimer's disease research will, for the first time ever, surpass \$1 billion.

This steady increase is necessary to fight both devastating budgetary and societal impacts of Alzheimer's disease. A report authored by Dr. Amy Kelly of the Icahn School of Medicine at Mount Sinai Hospital, and published in the *Annals of Internal Medicine*, found that the overall costs for the public and private healthcare systems for dementia patients in the last 5 years of life were 57 percent higher than patients without dementia. Additionally, average out-of-pocket expenses for patients with dementia were 81 percent higher than those without dementia. And these costs are even higher for African-Americans, unmarried people, or those with less than a high school education.

Currently, approximately 20 percent of Medicare spending is on patients with dementia. This is expected to increase to a third by 2050. This is an unsustainable path. And the way to get off this path is to invest in research and find a cure.

Alzheimer's disease is the only condition in the top ten leading causes of death with mortality rates that are increasing. It is the only top ten cause of death without a therapeutic intervention. I stated this last year in my written testimony, and unfortunately it is still true today. We must change this. And we can.

We can change this through a continued commitment to research and determining the pathology of Alzheimer's disease. And this is happening. There is good news.

We are learning more about Alzheimer's disease and how and when it develops. It is a very complex genetic disease, but there is emerging consensus around its pathology. The consensus is that for Alzheimer's disease to develop three things must happen: an accumulation of A β in the brain, the presence of Tau neurofibrillary tangles, and inflammation. If one of these can be impacted, then the onset of Alzheimer's disease can be delayed and possibly stopped.

Cure Alzheimer's Fund has embarked on two major research efforts to build upon this consensus. The Genes to Therapy program will take what we have learned from our funded genome sequencing to focus on the most important causal and protective genes for Alzheimer's disease. Our CIRCUITS (Collaboration to Infer Regulatory Circuits and to Uncover Innovative Therapeutic Strategies) is a 2-year, \$4 million, first-of-its-kind investigation and will aim to establish entirely new methods for translating genetic findings into new therapeutics.

These research initiatives will be supported by Cure Alzheimer's Fund, but the results will lead to further research that will be funded by NIH. This is the model of collaboration and leverage that Cure Alzheimer's Fund has been following since its founding in 2004.

Cure Alzheimer's Fund has a venture philanthropy model which invests in proven talent and empowers them to succeed; invests in ideas early for the biggest possible impact; evaluates potential projects rigorously, but funds them quickly; takes smart risks for the biggest rewards; and has a focused strategy, but is nimble to react to, and take advantage of, new developments. Cure Alzheimer's Fund takes no intellectual property interest in the research it supports.

Since its founding in 2004, Cure Alzheimer's Fund has invested more than \$50 million in Alzheimer's research. Often, this investment has been on projects that are considered too early for NIH investment. But because Cure Alzheimer's Fund has provided the vital initial philanthropic investment, researchers are able to prove their concept and compile the necessary data to secure NIH investment. The \$50 million invested by Cure Alzheimer's Fund has led to more than \$59 million in NIH grants for a total of more than \$109 million invested in Alzheimer's disease research as a result of Cure Alzheimer's Fund's willingness to fund basic research.

Cure Alzheimer's Fund realizes that there is an important and vital role for each organization to play in the fight against Alzheimer's disease. We must work collaboratively while focusing on what we can do best. Cure Alzheimer's Fund is able to quickly fund basic research that gives the field new ways of looking at the pathology of Alzheimer's disease and new targets for interventions. NIH is able to take these discoveries and provide scale and funding to move the research into trials and ultimately to market.

Cure Alzheimer's Fund recently had a webinar with NIH discussing the role of each organization along the research continuum. This webinar can be accessed at: <https://livestream.com/accounts/1570581/events/6724311/videos/143547953>.

Collaboration is vital to Alzheimer's disease research. It is too complex a disease to be understood through a singular focus. Researchers must collaborate. Institutions must collaborate. Organizations must collaborate. Cure Alzheimer's Fund works closely with others in the Alzheimer's disease community to ensure that re-

search findings are distributed and that we are working together toward the goal of the National Alzheimer's Project Act of effectively treating or preventing Alzheimer's disease by 2025.

This goal can be reached if the research community continues to have the necessary resources. Cure Alzheimer's Fund is committed to providing funding for basic research and we have more than tripled our research funding since 2013 to more than \$15 million in 2017. This is a tiny fraction of the NIH budget, but if NIH does not have adequate resources, discoveries made by Cure Alzheimer's Fund will not be able to be pursued.

The cure for Alzheimer's disease should be limited only by the science, not by the budget. An increase of at least \$400 million above the final enacted fiscal year 2017 level will help discoveries move from the laboratory to the development of therapeutic interventions to reduce the burden of Alzheimer's disease on society.

Cure Alzheimer's Fund applauds the Subcommittee for its commitment to increasing funding for Alzheimer's disease, especially during times of ongoing budget constraints. But as real progress is being made, it is not the time to step backwards and slow, if not stop, this progress.

Thank you for the opportunity to submit this written testimony and to respectfully request at least an additional \$400 million above the final enacted level in fiscal year 2017 for fiscal year 2018 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 CURE SMA

OVERVIEW OF REQUESTS

Cure SMA, the largest organization in the United States dedicated to the treatment and cure of spinal muscular atrophy (SMA), is grateful for the opportunity to submit written testimony to the Subcommittee on the critical importance of providing sufficient fiscal year 2018 funding for newborn screening (NBS) programs administered by HHS through the Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC). In addition, we thank the Subcommittee for the opportunity to support requests for much-needed biomedical research funding for SMA at the National Institutes of Health (NIH) and its sub-agencies.

In the United States there are approximately four million infants born each year. According to the CDC, birth defects affect one in every 33 infants born and are the leading cause of death in infants, accounting for 20 percent of all infant deaths. For many of these infants, like those affected by SMA, the defect is unapparent at birth. Anxious new parents are put at ease with the birth of their seemingly happy and healthy baby, and none the wiser they are sent home with no reason to suspect their child has an underlying condition that could cause severe disabilities or even death.

NBS is the only method available to identify conditions which are hidden at birth and affect the long-term health and survival of infants. The success of treating these conditions is most often determined by the early detection, diagnosis, and ability to begin treatment before the onset of symptoms. Though tests do not yet exist for a number of conditions, in instances where a valid and reliable test exists and there is an FDA approved treatment for a specified condition, there should be no delays in making the NBS available for infants born in each of the 50 States, so that all infants born in the U.S. may have uniform and equal access to treatment.

For these reasons, we believe it is of the utmost importance that members of the Subcommittee continue their historically strong support for NBS programs and provide robust funding to support HRSA and CDC. Specifically, we are requesting Congress appropriate \$19.9 million in fiscal year 2018 to HRSA's Heritable Disorders program and \$29.8 million to the CDC's Newborn Screening Quality Assurance Program (NSQAP). These investments will ensure States have the technical assistance and resources necessary to uniformly and rapidly add safe and effective testing of new conditions to their respective State NBS panels. It is the role of these Federal

programs, as authorized by Congress,¹ to ensure infants born with a serious and possibly fatal disease have the swiftest possible access to FDA-approved treatments, ultimately preventing unnecessary suffering and saving lives.

Given this public health imperative, we have concerns regarding the President's fiscal year 2018 budget proposal, which proposes to eliminate entirely HRSA's Heritable Disorders program and to reduce funding for CDC's NSQAP. Our Nation's infants need and deserve access to NBS in order to maximize their health and wellbeing. As such, we wholly oppose these budget proposals and urge the committee to do the same.

In addition, we join with our colleagues in the patient advocacy and biomedical research communities in opposing the significant cuts to the National Institutes of Health (NIH) included in the President's fiscal year 2018 budget proposal. We urge you to similarly reject these proposals and to provide robust funding for the agency as well as for the National Institute of Neurological Disorders and Stroke, the National Institute of Child Health and Human Development (NICHD) and the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS); the NIH and these institutes provide vital support for the research and development of new SMA therapies, and also have contributed to the implementation of NBS pilot studies for SMA, which are a vital component of establishing the validity, reliability, and viability of NBS and its suitability for implementation across all States.

Given the recent FDA approval of the first-ever treatment for SMA and the availability of valid NBS for SMA, we are hopeful that with continued and sufficient funding of these agencies, NBS for SMA will soon be implemented as a viable tool for identifying infants affected by the disease in every State, ending the threat of death that is otherwise posed to 60 percent of infants born with SMA.

SMA OVERVIEW

SMA is the leading genetic cause of death for infants under 2 years of age. It is an autosomal recessive neuromuscular disease that affects approximately 1 in 11,000 live births in the U.S., and an estimated 1 in 50 Americans is a genetic carrier. SMA is caused by a mutation in the gene Survival Motor Neuron 1 (SMN1). In a healthy person, this gene produces a protein that is critical to the function of the nerves that control muscles. Without this protein, those nerve cells cannot properly function and eventually die, leading to debilitating and often fatal muscle weakness robbing patients of their ability to walk, eat, or even breathe. However, SMA does not affect a person's ability to think, learn, and build relationships with others.

Cure SMA, in its efforts to fund research activities for SMA and support families affected by the disease, works with 12,000 households in the SMA community, as well as with researchers and healthcare providers, and with a network of more than 115,000 additional supporters. These stakeholders represent all 50 States as well as dozens of countries. In addition, Cure SMA has funded approximately \$65 million in research. This type of private sector investment coupled with a robust Federal investment at NIH, CDC, and HRSA helps to facilitate important breakthroughs in screening, diagnosis, treatment, and care.

On February 28, 2017, Cure SMA, in partnership with members of the SMA Newborn Screening Coalition, submitted an application nominating SMA to be added as a condition on the Recommended Uniform Screening Panel (RUSP), a list of disorders that are screened at birth and recommended by the Secretary for States to screen as part of their State universal NBS programs. Administered by HHS's Heritable Disorders Program, the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) reviews and adds conditions to the RUSP in accordance with the Newborn Screening Saves Lives Act of 2008 (Public Law 110-204), and its reauthorization in 2014 (Public Law 113-240). However, due to the lack of sufficient funding, not all States currently are able to implement testing for the full slate of RUSP conditions.

On May 11, 2017, the SACHDNC voted unanimously in favor of moving the SMA nomination forward to consideration by its evidence review workgroup. The workgroup will conduct a nine month intensive review as defined by statute in order to make a determination of whether or not it believes SMA should be added to the RUSP.

The submission of SMA for consideration to be added to the RUSP follows the December 23, 2016 approval of SPINRAZA™, the first-ever FDA-approved treatment for the disease. The swift progression of the FDA approval of SPINRAZA™ and the subsequent immediate submission of SMA to the SACHDNC signifies how critical

¹ See Public Law 113-240; HOUSE REPORTS: No. 113-478 (Comm. on Energy and Commerce). CONGRESSIONAL RECORD, Vol. 160 (2014).

each day is in the life of an SMA patient. Time has a clear and profound adverse effect on the outcome for SMA patients. Just a few weeks can mean the difference between life and death for an infant with SMA type I, where the median survival is between eight and 11 months in recent natural history studies. Furthermore, research in both human and animal models suggests that treatment for SMA is most effective when it can begin before symptoms appear, making NBS a vital predicate for the most successful treatment of SMA. For this reason, it is crucial Congress provide increased funding to ensure testing for additional conditions can be appropriately included on the RUSP and quickly adopted and implemented without delay across all States. Ideally, there would be little delay between SACHDNC's addition of a new condition to the RUSP and the subsequent testing for that condition in newborns across all fifty States.

Federal Funding for NBS Programs and Coordination with States

Unfortunately, for infants born with SMA and many other conditions, State NBS programs are often slow to add new conditions to their NBS panels because they lack the necessary funding and other resources. As such, the number of conditions an infant is screened for at birth still varies between States, creating a vast disparity in the quality of life and survival for children born in some States as compared to others.

In 2008, Congress enacted the Newborn Screening Saves Lives Act of 2007 (Public Law 110–204), to reauthorize and expand the role of HRSA's Heritable Disorders program² in developing national NBS guidelines, and to assist States in facilitating the implementation of comprehensive screening. Prior to the law's passage, the number and quality of NBS tests varied greatly from State to State; some States were screening for as little as four conditions, while others were screening for up to 36. Additionally, there was little to no guidance for States on the quality and validity of tests adopted for the screening of particular conditions. As a result, there was a vast disparity in the quality of life and survival rate for children born in some States as compared to others. A child diagnosed and successfully treated in one State was likely to have suffered irreversible damage had they been born in another State.

Congress recognized the important role of the Federal Government in supporting States in this critical work: providing resources and technical support to eliminate the disparities among States' NBS programs and continuing to make improvements in the quality and timeliness of adopting new conditions across States. As a result, the Republican-led Congress in 2014, with strong bipartisan support, passed a 5 year reauthorization bill to continue the Heritable Disorders program and to set timelines and other requirements to improve the speed at which the committee recommends—and States adopt—new conditions for NBS.

In addition to improving the SACHDNC's timing of review of conditions to be added to the RUSP, the technical assistance required and provided by CDC helps to facilitate and speed the addition of new conditions to State NBS programs. Still, Federal funding for CDC's NSQAP has been significantly short of the amount required to support States and keep pace with the addition of new conditions. Few States currently screen for all 34 conditions on the RUSP. Without an increase in funding for CDC, it is unlikely States will be able to quickly adopt the current conditions on the RUSP, and importantly for those born with SMA, it likely means States will be unprepared for the adoption of NBS for SMA if it is added to the RUSP in early 2018.

Summary of fiscal year 2018 Funding Requests for NBS

For the reasons expressed above, Cure SMA reiterates our requests for Congress to provide robust funding for the HRSA and CDC programs as follows:

HRSA: Heritable Disorders Program. We ask Congress to provide \$19.9 million in fiscal year 2018 to HRSA's Heritable Disorders program to ensure infants born in every State receive equal access to rapid identification, early intervention, and potentially life-saving treatment. A condition may only be added to the RUSP once an FDA-approved treatment exists and a test has been validated that can successfully screen for the disease in the American population. Congress outlined the Federal role for HRSA and the SACHDNC beginning in 2000 (Public Law 106–310) and recognized that the agency should continue to play a fundamental role in coordinating and supporting a large number of complex activities including the in-depth scientific

²The U.S. Department of Health and Human Services originally chartered the SACHDNC in 2003, following the enactment of the Children's Health Act of 2000, which included the establishment of a Federal advisory committee to make recommendations to the Secretary that would standardize NBS programs in the U.S.

review of conditions nominated for the RUSP (Public Law 110–204 and Public Law 113–240). These roles and responsibilities cannot be replaced by programs at the State level. Further, the agency plays an essential and unique role in coordinating many stakeholders, including clinicians, hospitals, parents, laboratories, and public health professionals.

CDC: Newborn Screening Quality Assurance Program. We ask Congress to provide \$29.8 million to CDC's NSQAP to support States in adopting and implementing testing for new conditions. Following the 2010 addition of severe combined immunodeficiency (SCID) to the RUSP, Congress determined specially appropriated funds were needed to enable more States to quickly adopt technologies to test for SCID. These activities include funding for laboratory equipment, supplies, and staffing as well as expert analysis and unique technical experience regarding which tests are the most effective and efficient for State laboratories to adopt for their populations. Once determined, NSQAP provides State laboratories with hands-on laboratory based training. Additionally, NSQAP also develops quality assurance materials to ensure tests can detect both rare and common markers for a disease. This scientific expertise is crucial to ensuring the quality and accuracy of testing for NBS programs. CDC is the only Federal agency that works alongside State laboratories to implement new tests and conduct ongoing laboratory testing for NBS, which saves lives.

CONCLUSION

As the development of new technologies continues to progress more rapidly year over year, we are seeing more and more first-ever treatments for rare and deadly conditions and the discovery of new tests to detect and identify these diseases. These innovations and the speed at which they become a reality underscores the need for continued and robust funding of these Federal programs to ensure timely, effective and unvarying adoption of NBS across States. The fate of any child born in the U.S. most certainly should not be contingent upon the State where an infant is born.

Cure SMA feels strongly that additional fiscal year 2018 funding to support NBS activities at HRSA and CDC—along with increased funding for NIH, NINDS, NICHD, and NIAMS—is critical to making much-needed progress in SMA screening, diagnosis, treatment, and care, for affected individuals and families. With these additional investments States will have the resources they need to help expand their NBS programs and, in turn, the lives of individuals with SMA will be improved. We thank you for your leadership and past support of NBS programs and appreciate the opportunity to share our views in this testimony.

PREPARED STATEMENT OF THE CYSTIC FIBROSIS FOUNDATION

On behalf of the Cystic Fibrosis Foundation and the 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 2018. The Foundation requests funding levels of at least \$36.1 billion for the National Institutes of Health (NIH) for the coming year. We encourage special consideration and support for the National Center for Advancing Translational Sciences (NCATS) and programs under its jurisdiction, including the Cures Acceleration Network (CAN) and the Clinical and Translational Science Awards (CTSA) as well as the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the National Institute of General Medical Sciences (NIGMS), and the National Heart, Lung, and Blood Institute (NHLBI), all of which play a vital role in CF research.

We also recommend that the Committee provide robust resources to the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA), particularly their work to support nationwide newborn screening programs. Further, we urge the Committee to provide ample funding for the Agency for Healthcare Research and Quality (AHRQ) to continue their important work regarding healthcare quality improvement.

NATIONAL INSTITUTES OF HEALTH

Consistent, Robust Funding for NIH is Critical for American Research

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. As the Committee considers its funding priorities for the coming fiscal year, we urge consider-

ation of the critical role that NIH plays in the development of treatments for cystic fibrosis and other rare diseases.

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 in treatment for cystic fibrosis would not have been possible without the research being done at the NIH. The NIH devoted \$83 million to cystic fibrosis research in fiscal year 2016, and a strong funding partnership between NIH and the Cystic Fibrosis Foundation has funded additional groundbreaking research and advances. At a recent hearing of the LHHS Appropriations Subcommittee in the House of Representatives, Dr. Francis Collins, Director of the NIH, discussed recent advances in cystic fibrosis research and touted NIH scientists who are currently using new technologies to better understand the underlying mechanisms that cause CF symptoms.

More broadly, NIH-funded basic science research fuels discoveries that enable the entry of new and more effective drugs into the market. Over the past 40 years, NIH-supported research has contributed to the discovery of 153 new FDA-approved drugs, vaccines, and new indications for current drugs. For example, NIH-funded advances in genetics and the development of high-throughput screening techniques were essential for creating the groundbreaking therapies that are changing the lives of many people with cystic fibrosis.

We are grateful to the Committee for the \$2 billion funding increase provided to the NIH in fiscal year 2017. However, we are concerned that the President's Budget for fiscal year 2018 suggests severe cuts to NIH funding, proposing a total budget of \$25.9 billion, which is a \$5.7 billion decrease and nearly a 20 percent reduction from fiscal year 2017 CR levels. These cuts are even more severe in relation to the appropriated increases provided to the NIH for fiscal year 2017.

Researchers need consistent, reliable funding to run successful laboratories and plan long-term projects, and we urge the Committee to reject this proposal. The 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 the field. Additional cuts would have devastating effects on US research and medical progress. They will result in the loss more than 1,000 promising programs and jeopardize our standing as a world leader in biomedical research. Moreover, once these research programs end, they are unlikely to ever be restarted, resulting in decades of lost opportunities.

Further, NIH is an important driver of the US economy, providing nearly 380,000 jobs and \$65 billion of economic output. Increased investment in biomedical research can provide even greater economic payoff and support for the scientific progress that makes the United States the worldwide leader in biomedical research.

Research at NIH Supports Advances in CF Therapeutics

Cuts to funding at the NIH have been detrimental to those seeking support for cystic fibrosis research. Grants for CF Research and Translation Centers, awarded by the NIDDK, support shared resources and facilities for use by multiple investigators and provide much needed funding for clinical and basic research at cystic fibrosis research centers. The funding increase in fiscal years 2016 and 2017 has provided critical support to these programs, but if this momentum does not continue, large centers may be at risk of losing research programs and infrastructure. This would be detrimental to the individual centers and causes immense interruption and uncertainty in CF research overall.

Further, NIH-funded advances in fundamental cellular and molecular processes, such as the mapping of the human genome, and the development of high-throughput screening were essential for the creation of two therapies that have been approved to treat the underlying cause of CF in many of those with the disease. The development of these breakthrough drugs, ivacaftor (Kalydeco) and ivacaftor/lumacaftor (Orkambi) would not have been possible without basic research discoveries funded by the NIH. Robust funding for the NIH is critical to maintain innovation in basic research and ensure a full pipeline of therapies for those with CF.

NIH also funds translational research tools that support the development of new therapies for rare diseases like cystic fibrosis. For example, animal models that have the same genetic mutation and express the similar symptoms to a genetic disease are critical tools for understanding disease progression and identifying potential new treatments. 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 Collaboration Promotes Cost-Efficient Research

Research supported by the NIH takes place at thousands of institutions across the country, and support of funding for the NIH is an effective way to foster collaboration among public and private stakeholders and allows for an efficient, well-funded research process. The CF Foundation collaborates with the NIH to fund and organize a number of research initiatives. For example, 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. NIH and the CF Foundation also jointly fund a research program at the University of Iowa to study the effects of CF in a pig model. The program is yielding fundamental new insights to help advance developments in the search for a cure. Additionally, the University of Alabama has developed a CF rat model using joint funding from NIH and the Foundation to examine methods for studying basic mechanisms and treatment of the disease.

The CF Foundation also urges the Committee to support collaborative efforts by the FDA and NIH, such as the creation of joint workshops to promote pediatric drug development and novel methodologies to streamline the research and development process.

Advancing Translational Science at the NIH

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. 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.

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's Therapeutics Development Network (TDN) as a model for TRND's innovative therapeutics development model.

The Foundation also urges consideration of 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.

Supporting the Next Generation of Researchers

We strongly urge the Committee to provide robust resources for the NIH to address critical challenges in recruiting and retaining a strong scientific workforce. It is challenging to recruit scientists into rare disease research, especially in pediatric subspecialties. Robust funding for programs like the K awards, which support researchers who are starting their careers, are critical to attracting and retaining a strong scientific workforce. Supporting new researchers, especially those who specialize in rare diseases and pediatric subspecialties is critical in the fight to find a cure for CF and countless other diseases for which there are not adequate treatment options.

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

The CF Care Center Network is a model of quality, coordinated care that can be used as an example by policymakers and the rare disease community. Over the last several decades, the CF Foundation has collected data on people with CF who are seen at one the Foundation's accredited CF care centers. Today, the CF Patient Registry collects information from more than 28,000 people each year, and this information is used to create CF care guidelines, assist care teams providing care to individuals with CF and guide quality improvement initiatives at care centers. The work being done at the Agency for Healthcare Research and Quality (AHRQ) provides guidance and support to further quality improvement in CF care and for many other

diseases. We encourage additional support for AHRQ to continue its work to promote research in healthcare quality improvement and identification of best practices as well as clinical effectiveness and patient reported outcomes.

Health Resources and Services Administration and Centers for Disease Control and Prevention

In 2015, 59.6 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. Support for newborn screening programs from the Federal Government has done a tremendous amount to bring these State based programs into alignment, but more can and should be done to improve this critical public health function.

In particular, the Foundation urges the Committee to provide adequate funding to the CDC, 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. We also encourage the Committee to provide ample funding for HRSA, 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.

* * *

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 \$36.1 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 Chief Executive Officer, Cystic Fibrosis Foundation.]

PREPARED STATEMENT OF DINE GRANT SCHOOLS ASSOCIATION

The Dine Grant Schools Association (DGSA) is comprised of the school boards of six Bureau of Indian Education (BIE)-funded schools which are operated pursuant to the Tribally Controlled Schools Act (PL 100-297) and located on the Navajo Nation in Arizona and New Mexico. These schools are: Dzilth-Na-O-Dith-Hle Community Grant School; Kinteel Residential Campus, Inc.; To'hajilee Day School; Na' Neelzhiin Ji'Olta (Torreon Day School); Hunters Point Boarding School; and Chilchinbeto Community School.

As tribal school boards, we have both the greater freedom and the tremendous responsibility to ensure that our students receive the kind of world-class, culturally relevant education that will help them reach their fullest potential. We take this responsibility seriously and we consider Congress a partner in this endeavor.

In order to keep the lights on, our doors open and our teachers' salaries paid, we rely on both core funding from the BIE paired with pass through funding from the Department of Education for certain specific programs which are authorized by the Elementary and Secondary Education Act and the Individuals with Disabilities Act. We were alarmed to see that the Administration's fiscal year 2018 budget request proposes zero out one of these critical Department of Education programs on which our students rely: the 21st Century Community Learning Centers program. This program allows us to provide critical after-school and summer tutorial services to struggling students. If students do not first grasp foundational concepts, it imperils their path to acquiring the kind of complex skills and knowledge needed to succeed as an adult. Because of the 21st Century Community Learning Centers program we

are able to identify struggling students, engage with them and their parents and offer both after-school and summer tutoring opportunities to help them reach proficiency with foundational concepts. Being able to intervene early and offer appropriate services and counseling means that they are less likely to become disengaged from the broader educational system or to need to repeat a grade.

At To'hajiilee Day School, where I serve on the school board, and at other Dine Grant Schools Association member schools, we are seeing real, measurable results because of the 21st Century Community Learning Centers program.

Our students would be harmed if this program were zeroed out.

Thank you for the opportunity to provide testimony on this critical program.

[This statement was submitted by Jerry Chavez, President, Dine Grant Schools Association.]

PREPARED STATEMENT OF THE DYSTONIA MEDICAL RESEARCH FOUNDATION

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2018

- Provide \$36 billion for the National Institutes of Health (NIH) and proportional increases across its Institutes and Centers
 - Expand 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 Advocacy Network (DAN) 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, Congress should support NINDS, NIDCD, and NEI in conducting and expanding critical research on dystonia.

Currently, dystonia research at NIH (National Institutes of Health) 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 have recently met with the leadership of NINDS to discuss the current science and research into dystonia. A State of the Science conference was also discussed to bring together researchers from across the country to discuss emerging and ongoing science opportunities and ways for possible collaborations.

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 is dedicated to robust funding at NIH through the proposed \$2 billion increase in fiscal year 2017 and the \$4.8 billion over the next 10 years through the 21st Century Cures Act. We support the full implementation of the Cures funding and the increases through the regular appropriations process as complements to one another helping further NIH's ability to fund meaningful research that benefits our patients.

In summary, the DMRF recommends the following for fiscal year 2018:

- Provide \$36 billion for NIH and a proportional increase for its Institutes and Centers
- Expand the dystonia research portfolio at NIH through NINDS, NIDCD, and NEI.

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 well being 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 EASTERSEALS

Chairman Blunt, Ranking Member Murray and Members of the Subcommittee:

Thank you for the opportunity to share Easterseals' strong support for restoring funding to the U.S. Department of Labor's (DOL) Senior Community Service Employment Program (SCSEP). Easterseals is a leading non-profit organization committed to helping individuals with disabilities, veterans, and older adults reach their potential by accessing employment services and other community supports through our national network of 75 affiliates.

Referred to in your bill as Community Service Employment for Older Americans, SCSEP is the only Federal employment program targeted at helping older Americans find jobs. Through the program, low-income jobseekers, 55 years old or older, train and earn minimum wage for 15–20 hours a week through work-based training assignments at local non-profits and government agencies, such as libraries and senior centers. More than 65,000 older workers from nearly all 3,000 U.S. counties and territories receive SCSEP employment services as a result of funding provided by this subcommittee.¹ Easterseals is a national SCSEP provider with local older worker programs in nine States.

SCSEP is best described through the experiences of older Americans who receive work-based training and employment supports through the program—older workers like Daphne, Alan, Gwen and Bob. While they entered SCSEP for different reasons and from diverse backgrounds and employment barriers, they share the common goals of improving their economic self-sufficiency and competitiveness in today's marketplace.

Daphne (Alabama): A few years into retirement, Daphne found herself needing to return to the workforce for extra income. She applied the same dedication and determination she demonstrated in her successful working career into her post-retirement job hunt. But no one would hire her. She suspected her age (69) was partly to blame for her unsuccessful job search. Luckily, she found SCSEP and Easterseals in Alabama. Through the program, Daphne trained at a charitable pharmacy, senior center and career center. Her training assignment at the career center was particularly rewarding as she was able to share her own job search experience and resume training with other jobseekers. The assignment also allowed her to stay current on job openings that matched her customer service and healthcare industry interests. She found a perfect match when a concierge position at a nearby senior living facility opened. She applied and was later hired! She regularly interacts with and provides support to the senior residents—a job that perfectly fits Daphne's skill set and personality.

¹ Fiscal year 17 DOL Budget: <https://www.dol.gov/sites/default/files/documents/general/budget/CBJ-2017-V1-06.pdf>.

Alan (Connecticut): Alan, a 58-year-old resident from Connecticut, worked for several years as an emergency medical technician (EMT), including within an emergency room. The high-stress work environment took a heavy toll on Alan. He switched careers and, eventually, found a greater calling in caring for his elderly parents and aunt. His full-time caregiving responsibilities ended upon his father's death, a difficult time in Alan's life. His depression made it hard to even get out of bed some days. On top of that, the job market had changed significantly since he last applied for employment. Through a friend, Alan was connected to Easterseals SCSEP in Connecticut. Easterseals employment specialists provided Alan with individualized assistance with his resume, job search, interviewing, and computer literacy. He trained at an area host agency and participated in Easterseals' Participant Advisory Council, a group made up of his SCSEP peers who work with staff to improve SCSEP training and the participant experience. In the spring of 2016, Alan secured a regional connector position at a local mental health provider where he links individuals facing mental health or addiction challenges with health and treatment services. He continues to work with the agency on a contract basis. Alan said SCSEP taught him how to network, present himself and, most of all, "not to give up."

Gwen (Arizona): Gwen was 60 years old when she enrolled in SCSEP for help in finding employment. Shortly after moving to Arizona from another State, Gwen became unemployed and homeless, living in a transitional housing shelter for women. She enrolled in SCSEP and began her on-the-job training at a local nonprofit where she displayed a great work ethic, determination and an eagerness to find permanent employment. She attended and was an active participant in the program's Job Club, where SCSEP participants learn tips for improving their job hunt, resume building and interviewing skills. Gwen had been a hairdresser for many years in another State and her license was current but not recognized in Arizona. Through money she earned during her training assignment and with financial assistance available through SCSEP, Gwen secured her Arizona hairdresser license. Within 9 months of entering SCSEP, Gwen turned her SCSEP training and experiences into a full-time job as a hairdresser. Gwen said, "because of the SCSEP program I now have a job and an apartment. I am very grateful for you all. I couldn't have done it without you. You are my angels."

Bob (Utah): Bob served in the military (Navy), graduated from college, and enjoyed a successful work career—even owning and running his own marketing company—before retiring. During retirement, Bob's wife became sick and, after an extended illness, she passed away—leaving Bob in debt due to the high cost to treat her chronic condition. He needed a job. But he had been out of the job market for several years and required assistance. Bob connected to Easterseals' Senior Community Service Employment Program in Utah where he began his on-the-job training at a community agency. Through SCSEP's regular engagement with the local business community, Easterseals was aware of Pep Boys' commitment to hiring veterans. With the help of an Easterseals employment specialist, Bob applied for an position at his local Pep Boys store and was interviewed the same day. Shortly afterwards, Bob was hired to stock inventory and to deliver automotive parts. He earns \$10 per hour and works full time. Bob credits SCSEP—in particular its job training and referral—for his current employment.

Daphne, Alan, Gwen and Bob greatly benefited from the work-based training best practice that is the foundation of SCSEP's success. The on-the-job training allows SCSEP participants to develop relevant skills, add new work history for their resume, and gain confidence. Work-based learning models like SCSEP prepare workers for the workforce and benefit employers by providing a skilled pool of job candidates, according to the recent *What Works In Job Training: A Synthesis of the Evidence* report.² Congress recently endorsed on-the-job training and work-based learning models in its passage of the Workforce Innovation and Opportunity Act (Public Law 113–128) and the Older Americans Act Reauthorization Act (Public Law 114–144). In addition, Congress reaffirmed SCSEP's dual purpose of community service and work-based training through last year's OAA reauthorization.

Easterseals SCSEP programs also leverage employment best practices developed from Easterseals' decades of experience in helping individuals with disabilities and other underserved populations secure employment. Easterseals requires each of its local SCSEP programs to strongly engage the business community through the development of a Business Advisory Council (BAC). Easterseals recognizes that the program's success depends on employers who are willing to hire older workers trained through SCSEP. For example, Easterseals in Montgomery, Alabama has an active BAC with representatives from Regions Bank, Big Lots Distribution Center,

²What Works in Job Training Report: <https://www.dol.gov/asp/evaluation/jdt/jdt.pdf>.

Sam's Club, and Compass Bank. Alabama BAC members assist SCSEP participants through mock interviews and resume development. In addition, BAC members inform SCSEP staff about current training needs of the businesses community.

In Oregon, Easterseals has forged a strategic partnership with Enterprise Rent-A-Car, a major regional employer who regularly needs reliable workers with strong customer service and computer skills. Easterseals focuses its SCSEP training to help boost participants computer and customer service experience. In turn, Enterprise representatives works with SCSEP participants on resume building and mock interviews. Most importantly, Enterprise regularly hires SCSEP participants, especially veterans, following their training. "Without SCSEP the people we hired would probably not have had the tools necessary to seek and secure stable employment," said Doug Rice, Talent Acquisition Manager for Enterprise Holdings of Oregon. "The training, coaching and mentoring of SCSEP allowed these people to bridge the gap between their skills and getting a job." By tailoring the skills training and community work experiences to the needs of SCSEP participants and the business community, Easterseals has been successful in helping more than 5,000 older workers find permanent jobs with community employers since 2003.

Easterseals was pleased that Congress rejected the Trump Administration's last-minute supplemental budget request for fiscal year 2017 that called for the elimination of SCSEP. However, the \$34 million or 8 percent reduction that SCSEP received in the Consolidated Appropriations Act of 2017 will result in thousands of older Americans losing access to SCSEP's specialized on-the-job training and employment supports. The President's fiscal year 2018 budget highlights SCSEP's record of finding jobs for one in every two long-term unemployed participants in the program.³ Congress designed SCSEP to prioritize employment services to the most-in-need or individuals with the most significant barriers to employment. And the program is fulfilling Congress' mandate by serving the most-in-need, including female (65 percent), homeless or at-risk of homelessness (53 percent), minority (49 percent), individuals with disabilities (20 percent), veterans (13 percent), or rural residents (28 percent). And for SCSEP participants like Daphne, Alan, Gwen and Bob who transition into unsubsidized employment as a result of the SCSEP training, more than 70 percent remain on the job 1 year after exiting the program. SCSEP also exceeded its entered employment rate and earnings targets during its most recent program year.⁴

Easterseals urges this subcommittee to build off the bipartisan support for and expansion of SCSEP in the Older Americans Act Reauthorization Act by restoring SCSEP funding to its fiscal year 2016 level of \$434,371,000. By comparison, Public Law 114-144 recommended that SCSEP be funded at \$454,499,494. Less than 1 percent of eligible older workers are served through current SCSEP funding levels. The U.S. Government Accountability Office—which found SCSEP had done a "reasonably good job" in accomplishing key employment goals—said "increased funding could help meet the employment needs of a very disadvantaged and underserved population that many employers are unlikely to employ in the absence of severe labor shortages."⁵

Easterseals focused its fiscal year 2018 testimony on SCSEP given the recent cut and current threats to the program. However, Easterseals has several funding priorities within the subcommittee's jurisdiction that help individuals and families access early intervention services, job training, and educational supports. We were especially pleased that the Consolidated Appropriations Act included funding increases for the Homeless Veterans' Reintegration Program and Vocational Rehabilitation program and retained funding for Early Intervention Grants for Infants and Families program (IDEA Part C) and Preschool Grants for Infants and Families Program (IDEA Part B). We know that these investments would not have been possible without your strong leadership and advocacy for these programs. We urge you to robustly fund these programs, along with SCSEP, in your fiscal year 2018 bill.

Thank you again for the opportunity to share Easterseals' support for specialized job training and employment services through the Department of Labor's Senior Community Service Employment Program.

[This statement was submitted by Maynard Friesz, Assistant Vice President, Government Relations, Easterseals.]

³Fiscal year 2018 President Budget: https://www.whitehouse.gov/sites/whitehouse.gov/files/omb/budget/fy2018/2018_blueprint.pdf.

⁴Fiscal year 2018 DOL Budget Justification: <https://www.dol.gov/sites/default/files/BJ-2018-V1-05.pdf>.

⁵GAO Study (12-445); <http://www.gao.gov/assets/600/590408.pdf>.

PREPARED STATEMENT OF THE ELDERCARE WORKFORCE ALLIANCE

Mr. Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee:

We write on behalf of the Eldercare Workforce Alliance (EWA), a coalition of 31 national organizations—representing healthcare professionals, family caregivers, consumers, direct care workers, and providers—joined together to address the healthcare workforce needs in caring for an aging America. As the Subcommittee begins consideration of funding for programs in fiscal year 2018, the Alliance urges you to provide adequate funding for programs designed to increase the number of healthcare professionals prepared to care for America’s growing population of older adults and to support family caregivers in the essential role they play in this regard. We urge you to support a total \$51 million in funding for geriatrics programs in Title VII and Title VIII of the Public Health Service Act administered by the Health Resources and Services Administration (HRSA); \$187.5 million in funding for programs administered by the Administration for Community Living (ACL) that support the vital role of family caregivers in providing care for older adults; and \$1.7 billion to support the research efforts of the National Institute on Aging (NIA).

The number of Americans over age 65 is expected to double between 2000 and 2030, totaling more than 70 million people and accounting for almost 20 percent of the American population by the end of the next decade. Today’s healthcare workforce is inadequate to meet the special needs of older Americans, many of whom have multiple chronic physical and mental health conditions and cognitive impairments. Of equal importance is supporting the legions of family caregivers who annually provide billions of hours of uncompensated care that allows older adults to remain in their homes and communities. Without a national commitment to expand training and educational opportunities, the workforce will continue to grow even more constrained and care for our Nation’s older adults will be compromised. This is why the Title VII and VIII geriatrics programs, ACL programs that support family caregivers, and the research efforts of the National Institute on Aging are so critical to ensuring there are skilled eldercare workers and well-supported family caregivers available to meet the complex and unique needs of older adults.

EWA specifically requests the following levels of funding:

*Title VII and VIII Geriatrics Workforce Enhancement Program:*¹ Request: \$51 Million

The Title VII and VIII Geriatrics Workforce Enhancement Program (GWEP) is the only Federal program that aims to develop a healthcare workforce that maximizes patient and family engagement while improving health outcomes for older adults. It equips the primary care workforce with the knowledge and skills to care for older adults and builds community networks to address gaps in healthcare through individual, system, community, and population level change. In July 2015, HRSA announced 44 three-year grant funded programs located in 29 States. Specifically, the program:

- Integrates geriatrics and primary care to transform clinical training environments to provide more coordinated and comprehensive care
- Develops providers who can assess and address the needs of older adults and their families/caregivers
- Creates and delivers community-based programs that provide patients, families, and caregivers with the knowledge and skills to improve health outcomes and the quality of care for older adults
- Provides Alzheimer’s disease and related dementia education to families, caregivers, direct care workers, and health professions students, faculty, and providers

In academic year 2015–16, GWEP grantees provided training for nearly 18,500 students and fellows. In addition, more than 104,000 faculty and practicing professionals participated in 1,173 unique continuing education courses offered by GWEP grantees.

EWA is particularly concerned that President Trump’s fiscal year 2018 budget proposal calls for elimination of this program, along with the other Title VII and VIII health professions and nursing health workforce training programs. As the baby boomers reach retirement age and life expectancy increases, now is a critical

¹In December 2014, HRSA combined the existing 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 Geriatrics Workforce Enhancement Program. The fiscal year 2016 Omnibus also consolidated these programs, citing HRSA’s combined competition for the program.

time to expand, not limit, investments in the primary care workforce and family caregivers that we rely on to provide high quality care to older Americans.

To that end, for fiscal year 2018, the first year of the new grant cycle, EWA requests increased funding to close current geographic and demographic gaps in geriatrics workforce training. Specifically, the increased funding could launch at least eight new GWEP centers, targeted to underserved and rural communities, and provide \$100,000 to each GWEP site to reestablish the Geriatrics Academic Career Award program.

Administration for Community Living Family Caregiver Support Programs: Appropriations Request: \$187.5 million

These programs support caregivers, elders, and people with disabilities by providing critical respite care and other support services for family caregivers, training and recruitment of care workers and volunteers, information and outreach, counseling, and other supplemental services.

—*Family Caregiver Support Services: EWA Requests \$158.5.* This program provides a range of support services for family and other unpaid caregivers including counseling, respite care, training, and assistance with locating the services that help family caregivers care for their loved ones at home for as long as possible. In fiscal year 2015, the program provided more 116,000 caregivers with counseling and training services, provided 67,000 family caregivers with 6.2 million hours of respite care, and provided nearly 1.2 million contacts to caregivers assisting them in locating services from a variety of public and private agencies. However, in fiscal year 2014, more than 1 in 3 family caregivers still experienced trouble accessing services so additional funding would go a long way in ensuring families can access the support they need.

—*Native American Caregiver Support: EWA Requests \$8 million.* This program provides grants to eligible tribal organizations to provide support for family and informal caregivers of Native American, Alaskan Native, and Native Hawaiian elders. It offers information and outreach, access assistance, individual counseling, support groups and training, respite care and other supplemental services. In fiscal year 2015, more 750,000 caregivers were served through this program.

—*Alzheimer's Disease Support Services and Specialized Supportive Services: EWA Requests \$5 million for the Alzheimer's Disease Support Services Program and \$11 million for the Alzheimer's Disease Initiative—Specialized Supportive Services.* A critical focus of these programs is to support the family caregivers who provide countless hours of unpaid care, thereby enabling their family members with dementia to continue living in the community. Funds will go to evidence-based interventions and expanding the dementia-capable home and community-based services, enabling additional older adults to live in their residence of choice. The programs provided direct services to more than 61,000 individuals with Alzheimer's disease and their family caregivers in fiscal year 2016.

—*Lifespan Respite Care: EWA Requests \$5 million.* This program funds grants to improve the quality of and access to respite care for family caregivers of children or adults of any age with special needs. In fiscal year 2016, 36 States participated in the program.

National Institute on Aging: EWA Request: \$1.7 billion

The National Institute on Aging, one of the 27 Institutes and Centers of the National Institutes of Health, leads a broad scientific effort to understand the nature of aging in order to promote the health and well-being of older adults. Funding will aid in researching training initiatives for the workforce that cares for older adults and research on physician-family communication during end-of-life and critical care. In addition, the NIA coordinates the Older Americans Independence Centers Program, which aims to increase scientific knowledge leading to better ways to maintain or restore independence in older persons. The NIA also supports on-going projects that improve patient-level health outcomes for individuals with three or more chronic health conditions.

The Eldercare Workforce Alliance commends you on your past support for geriatrics workforce programs and asks that you join us in supporting the eldercare workforce at this critical time—for all older Americans deserve quality care, now and in the future. Thank you for your consideration.

[This statement was submitted by Nancy Lundebjerg, MPA, Alliance Co-Convener, and Michèle Saunders, DMD, MS, MPH, Alliance Co-Convener.]

PREPARED STATEMENT OF THE ENDOCRINE SOCIETY

The Endocrine Society thanks the Subcommittee for the opportunity to submit the following testimony regarding fiscal year 2018 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 NIH to fund endocrine-related research focusing on, among other challenges, diabetes, cancer, fertility, aging, obesity and bone disease. Our membership also includes clinicians who depend on new scientific advances to better treat and cure their patients' diseases. To support necessary advances in biomedical research to improve health, the Endocrine Society asks that the NIH receive at least \$36.1 billion in fiscal year 2018, representing an increase of at least \$2 billion above the fiscal year 2017 final appropriated amount.

ENDOCRINE RESEARCH IMPROVES PUBLIC HEALTH AND REDUCES HEALTHCARE COSTS

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 the biomedical research enterprise and 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 have a unique approach to and 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 study glands such as the adrenal glands, pancreas, thyroid, and specific sections of the brain, such as the hypothalamus, that control these glands. Endocrinologists also study interrelated systems, for example how hormones produced by fat can influence the development of bone disease.

In addition to the improvements in public health, quality of life, and longevity that medical research delivers, substantial cost savings may be realized by the translation of breakthrough research into applied therapies. As NIH Director Francis Collins, MD, PhD, mentioned in testimony to Congress, the development of the artificial pancreas could result in substantial cost savings for the treatment of patients with diabetes. Enabling coverage for this breakthrough technology early in the course of the disease could result in savings to Medicare of nearly \$1 billion over 25 years due to a reduction in life-threatening diabetes-related complications.¹

NIH REQUIRES STEADY, SUSTAINABLE FUNDING INCREASES

The Endocrine Society was encouraged by the \$2 billion increase for NIH in the fiscal year 2016 Omnibus Appropriations bill and further \$2 billion increase in fiscal year 2017. These much-needed increases will help the NIH address critical research gaps to improve public health; however, the biomedical research community requires steady, sustainable increases in funding to ensure that the promise of scientific discovery can efficiently be translated into new cures. Equally important, consistent increases must be provided to the NIH's base appropriation, so that the NIH has the flexibility to support emerging research areas and can empower scientists to pursue innovative projects. Despite recent increases, 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 underinvest-

¹Michael J. O'Grady, et. AL., "Substantial Medicare Savings May Result If Insurers Cover 'Artificial Pancreas' Sooner For Diabetes Patients." *HealthAffairs*. August, 2012 31:8; 1822–29.

ment in research. We do know however, that when “laboratories lose financing; they lose people, ideas, innovations and patient treatments.”² 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.³

Many endocrine researchers are also physician-scientists who treat patients and conduct research. A restricted funding environment exacerbates many of the unique challenges facing this important group of scientists, who make critical contributions in the translation of basic research to applied clinical practice, given their understanding of both the complicated research and practice landscape. As detailed in the NIH Physician-Scientist Workforce Working Group Report, without steady, sustainable increases in funding, endocrine physician-scientists will increasingly be driven out of the research pipeline, and the Nation will lose a valuable component of the research enterprise.⁴

PREVENTION RESEARCH REQUIRES SUPPORT

Without adequate support, meritorious programs struggle to complete objectives that would have significant public health impact. Prevention of disease remains one of the most important strategies for reducing healthcare costs and improving public health worldwide. New research is shedding light on how environmental exposures to common chemicals may raise the risk of thyroid cancer and contribute to the increased incidence of thyroid cancer in the United States. Meanwhile, more research is needed to develop strategies to reduce the risk of developing endocrine and hormone-sensitive cancers, such as breast, thyroid, and pancreatic cancer, in addition to research that will result in better treatments and therapies.^{5,6}

One example of the NIH’s critical role in efforts to prevent disease is the Cancer Monographs program of the International Agency for Research on Cancer (IARC). Through this program, the National Cancer Institute and the National Institute for Environmental Health Sciences jointly support a rigorous and robust scientific review process evaluates environmental factors, including manufactured chemicals, for their ability to increase the risk of cancer in humans. By identifying carcinogenic chemicals, NIH contributes to public health efforts and improvements in medical practice that directly impact everyone in the United States and worldwide.

TYPE-1 DIABETES RESEARCH IS THREATENED IN FISCAL YEAR 2018

The Endocrine Society is particularly concerned about the future of the Special Diabetes Program (SDP). The SDP was created in 1997 to advance research for type 1 diabetes and to address the disproportionate burden of type 2 diabetes on American Indians and Alaska Natives. Research funded by the SDP has made outstanding contributions to our understanding of, and ability to treat diabetes in the United States. The SDP has advanced research in islet cell transplantation, beta cell therapy, treatment for diabetic retinopathy, and the development of an artificial pancreas.⁷ Without reauthorization, the SDP is set to expire in 2017. We urge the congress to continue to support this valuable program and renew the SDP for an additional 2 years.

FISCAL YEAR 2018 NIH FUNDING REQUEST

The Endocrine Society recommends that the Subcommittee provide at least \$36.1 billion for NIH in the fiscal year 2018 Labor-HHS-Education Appropriations bill, representing a \$2 billion increase in funding over the fiscal year 2017 amount. This funding recommendation is the minimum investment necessary to avoid further loss of promising research and at the same time allows the NIH’s budget to keep pace

² Teresa K. Woodruff “Budget Woes and Research.” The New York Times. September 10, 2013.

³ 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.

⁴ The Physician-Scientist Workforce Working Group Report. https://acd.od.nih.gov/documents/reports/PSW_Report_ACD_06042014.pdf Accessed May 24, 2017.

⁵ Sosa, JA, et al., “Exposure to Flame Retardant Chemicals and the Occurrence and Severity of Papillary Thyroid Cancer: A Case-Control Study” Presented at: ENDO 2017, the Endocrine Society’s Annual Meeting; 2017, April 1—April 4; Orlando FL.

⁶ Glenda Fauntleroy “Cautiously Optimistic: The Future of Pancreatic Cancer Treatments.” Endocrine News October 2016. <http://endocrinenews.endocrine.org/cautiously-optimistic-the-future-of-pancreatic-cancer-treatments/> Accessed May 24, 2017.

⁷ “Special Diabetes Program Reauthorization” Endocrine News <http://endocrinenews.endocrine.org/special-diabetes-program-reauthorization/>. Accessed February 27, 2017.

with biomedical inflation. We fully understand that the Appropriations Committee faces challenging decisions in fiscal year 2018; however, we assert that additional cuts to the NIH and other non-defense discretionary programs is not the way to solve the budgetary issues facing the United States.

The Endocrine Society remains deeply concerned about the future of biomedical research in the United States without sustained support from the Federal Government. Flat funding levels in 2018 and beyond would imperil the Nation's world-class scientific enterprise. The Society strongly supports increased Federal funding for biomedical research to provide the additional resources needed to enable American scientists to address scientific opportunities and maintain the country's status as the world's preeminent research engine.

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).

ESA requests a robust fiscal year 2018 appropriation for the National Institutes of Health (NIH) at \$2 billion above the final fiscal year 2017 enacted levels. 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.

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 their arachnid relatives (including ticks and mites) serve as vectors of a diversity of infectious diseases that threaten the health and well-being of people across the globe, including populations in every State and territory of the United States and U.S. military personnel serving 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. The exponential rise of the Zika virus in the Americas is an example of the astonishing rapidity with which an insect-borne disease can become pandemic. Entomological research aimed at elucidating the relationships between arthropod vectors and the diseases they transmit—including, in the case of mosquitoes, dengue, Zika virus, and chikungunya, and, in the case of ticks, Lyme disease, human anaplasmosis and ehrlichiosis—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 together (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 support of research on basic human and pathogen biology and by development of 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.

One example of NIAID-funded research on infectious diseases is a study examining the mechanism by which DEET, a widely used synthetic mosquito repellent discovered more than 60 years ago, is perceived by the southern house mosquito, a vector of St. Louis encephalitis and West Nile virus. DEET was shown to bind to and activate a specific odorant receptor on the antennae of female mosquitoes; moreover, inactivating the gene that codes for the receptor protein dramatically reduced the repellency of DEET. These investigators also showed that methyl jasmonate, a plant-derived mosquito repellent, activates the same receptor, opening

up the possibility that this specific odorant receptor may be a useful target for developing new, safe and affordable repellents.¹

Another example of infectious disease research supported by NIAID is an ongoing study aimed at understanding the molecular mechanisms underlying the feeding behavior of the black-legged tick and the lone star tick; these two species are principal vectors for multiple human tick-borne diseases in the United States, including Lyme disease and human ehrlichiosis, respectively. These ticks, which must feed for several days, remain attached to their hosts by producing an adhesive secretion known as tick cement. In this study, investigators are working to identify the proteins in tick cement that are injected first into the feeding site, before transmission of disease-causing pathogens, including the Lyme disease agent. Identifying these proteins and disabling them can provide an entirely new strategy for disrupting the transmission cycle of Lyme disease and other tick-borne human illnesses.²

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.

CDC, serving as the Nation's leading health protection agency, conducts science 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.

Among the activities supported by DVBD are the ArboNET surveillance system for mosquito-borne diseases and the TickNET system for tick-borne diseases. ArboNET is a nationwide network managed by CDC and State health departments that monitors West Nile virus, Zika virus and other arthropod-borne diseases through a variety of activities, including the collection and testing of mosquitoes. TickNET is a partnership between State and local health departments and the CDC's Division of Vector-Borne Diseases and Division of Parasitic Diseases that tracks tick-borne diseases such as Lyme disease and funds applied research aimed at prevention and pathogen discovery. As well, a 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. Founded in 1889, ESA has over 6,500 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 Susan Weller, PhD, President, Entomological Society of America.]

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 \$35 billion in fiscal year 2018 for the National Institutes of Health (NIH) within the Department of Health and Human Services.

FASEB, a federation of 30 scientific societies, represents over 125,000 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.

¹Xu, P et al. 2014. Mosquito odorant receptor for DEET and methyl jasmonate. *Proc. Natl. Acad. Sci. USA* 111: 16593–16597 (NIAID NIH Award R01AI095514).

²Mulenga, A. 2016. *Ixodes scapularis* and *Amblyomma americanum* tick cement proteome. (NIAID NIH Award 1R21AI119873–01A1).

The National Institutes of Health (NIH) is the Nation's largest funder of biomedical research. It provides competitive grants to more than 300,000 scientists at universities, medical schools, independent research institutions, and biotechnology companies located in nearly every congressional district. Since 1939, NIH has supported 149 Nobel Laureates over the course of their careers, including one of the 2016 winners of the Nobel Prize in Chemistry.

A century of advances based on NIH-funded research has improved our health, fostered economic growth, and expanded our scientific knowledge. Increased longevity, a reduction in the number of deaths from heart disease and stroke, the development of the first vaccines for hepatitis A and Ebola, and research that led to the approval of innovative treatments for rare autoinflammatory diseases are part of NIH's outstanding legacy. Research funded by NIH on detection and treatment of prostate cancer helped establish a 5-year survival rate of nearly 99 percent. Greatly improved understanding of how the brain functions and new insights about risk factors for Alzheimer's disease came from NIH-supported studies. In addition, NIH research helped reduce preterm births and contributed to substantial improvements in the survival rates of babies born early.¹ A new class of drugs developed by NIH-funded scientists studying soil led to critical progress in responding to antibiotic resistance. The agency has also been at the forefront of research on spinal cord stimulation that allowed a small group of paralyzed individuals to regain some voluntary leg movement.

Many of these advances were made by scientists investigating fundamental molecular, cellular, immunological, and physiological mechanisms and systems. NIH's focus on investigator-initiated research identified the underlying causes of many diseases and fostered the translation of scientific discoveries into effective clinical interventions. The investment in basic research also made it possible for NIH to respond rapidly to urgent public health crises. Basic science also transformed the field of genomics, capitalized on advances in big data and technology to accelerate the pace of research, and created innovative new industries.

Emerging scientific opportunities that hold the promise of improving the lives of millions of people are on the horizon. Further investment in basic science could revolutionize techniques to image various body parts, improve understanding of how brain circuits function, complete the development of a universal flu vaccine, harness the immune system to fight cancer, and create an artificial pancreas, leading to better management of diabetes. Basic research also holds the key to develop treatments for rare diseases for which no therapies are currently available.

Research funded by NIH produces critical new findings every year across a broad spectrum of basic, translational, and clinical research studies. Recent accomplishments include:

Understanding Chemotherapy Resistance in Breast Cancer Cells: Two proteins, BRCA1 and BRCA2, play important roles in stabilizing DNA in human cells. Patients who carry mutant forms of these proteins are at higher risk of developing breast cancer. Though these patients can be treated with chemotherapy, tumors can develop resistance to drugs, making treatment less effective. By studying this chemoresistance in cell culture, researchers at the National Cancer Institute have now discovered how protein molecules in cancer cells allow tumors to resist chemotherapy drugs. This discovery not only opens up the possibility for monitoring patients' responses to cancer therapies in the clinic, but also may lead to the development of new, more effective pharmaceuticals for the treatment of cancer.²

Vaccination and the Evolution of Virulence: Vaccines have been invaluable in the fight against communicable diseases and have prevented illness in hundreds of millions of people. In a world where infectious microbes rapidly spread to new populations, it is critical to develop new vaccines and also understand the dynamics of disease transmission. By studying a disease in chickens, researchers at the Pennsylvania State University have discovered how specific conditions can lead to the emergence of more virulent pathogen strains that attack unvaccinated individuals. This work sheds light on how disease agents evolve in a population of hosts and is laying the foundation for how we might manage treatments to prevent the emergence of new, dangerous infections.³

Laboratory-based strategy for predicting the emergence of different flu strains: Each year, an updated flu vaccine has to be produced to match the most common flu variants. Scientists must monitor flu strains around the world in order to predict which types will emerge during a given flu season. However, sometimes an unex-

¹ <https://www.nichd.nih.gov/health/topics/preterm/researchinfo/Pages/activities.aspx>.

² <https://www.nih.gov/news-events/nih-research-matters/how-breast-cancers-resist-chemotherapy>.

³ <http://www.thereadgroup.net/wp-content/uploads/Read-et-al-PLoS-2015.pdf>.

pected strain emerges for which the vaccine doesn't offer sufficient protection. In order to address this problem, researchers at the University of Wisconsin-Madison have developed an experimental method to better understand how different flu strains emerge. This deeper understanding of which mutations are likely to occur should lead to more reliable vaccine development in the future.⁴

Stem-Cell Derived Pancreatic Beta-Cells and a Possible Treatment for Diabetes: Type-1 diabetes is a disease in which cells in the pancreas, called beta-cells, are destroyed, thus compromising the patient's ability to properly regulate blood-sugar levels. In their search for new diabetes treatments, researchers at Harvard University have for the first time produced adult stem-cell-derived functional beta cells. These engineered cells have enormous potential as a treatment, or possibly even a cure, for diabetes. Clinical trials are already underway.⁵

Increased Funding for Biomedical Research Is Critical to Sustain Progress

Discoveries made by NIH-supported researchers have provided the foundation for thousands of recent medical advances. The fundamental insights that made progress possible were often the result of decades of basic research supported by the government in collaboration with the private and public sectors, other science agencies, philanthropic foundations, and industry partners.

To facilitate long-term planning and support the best science, NIH needs stable, predictable budget increases. A multi-year strategy of sustained increases in Federal funding for biological and biomedical research will ensure the most efficient use of resources and maximize the return on investment for taxpayers.

At the request of Congress, NIH submitted a 5-year agency-wide strategic plan in late 2015 that identified new challenges for human health that could be addressed through scientific exploration. As the plan states, "By maintaining and strengthening its already impressive foundation of fundamental science, biomedical research will be poised to identify and capitalize upon potential opportunities for revolutionary breakthroughs with the potential for preventing, treating, and curing disease." The fiscal year 2018 appropriation for NIH must build on and expand the agency's capacity to fund the basic research. Stable funding is also needed to attract and retain talent to the U.S. biomedical research workforce. Physician-scientists, who possess research and clinical skills that allow them to facilitate the translation of new discoveries are in short supply. A base budget of \$35.0 billion in fiscal year 2018 would allow NIH to accelerate progress in all areas of research with the potential to transform our understanding of human health and disease. This funding level could support approximately 2,000 new R01 grants for investigator-initiated research, a major step in reversing the 22 percent loss of research capacity NIH experienced from fiscal year 2003 to 2015 due to budget cuts, sequestration, and the failure to keep pace with rising costs.

These funds could also enable NIH to accelerate clinical trials for new therapies and take advantage of improvements in technology to further develop novel research methods and techniques. The \$500 million already authorized through the 21st Century Cures Act would provide additional support in fiscal year 2018 for research in four areas: cancer, precision medicine, neuroscience, and regenerative medicine. But there are other areas in urgent need of additional resources.

The funding level of \$35.0 billion reflects the growth recommended in the bipartisan fiscal year 2017 Senate Labor, Health and Human Services appropriations bill. We encourage Congress to continue the effort to establish a pattern of increases for NIH as there are excellent proposals for outstanding research that cannot be funded under current budget levels.

To enhance the Nation's capacity for biomedical research, and to build on the momentum from the funding increases provided in fiscal year 2016 and through the 21st Century Cures Act, FASEB recommends at least \$35.0 billion for NIH in fiscal year 2018.

[This statement was submitted by Jennifer Zeitzer, Director of Legislative Relations, Federation of American Societies for Experimental Biology.]

PREPARED STATEMENT OF THE FOGARTY INTERNATIONAL CENTER

Dear Honorable Members:

We the undersigned include researchers, educators, and bioethicists who are involved with educational initiatives with our colleagues in low- and middle-income

⁴ <https://www.nih.gov/news-events/nih-research-matters/strategy-may-improve-seasonal-flu-vaccines>.

⁵ <http://www.nature.com/articles/ncomms11463>.

countries (LMICs) through the Fogarty International Center (FIC) at the National Institutes of Health (NIH). The Trump Administration has proposed a 20 percent reduction to the NIH budget and the complete elimination of the NIH's Fogarty International Center. We urge Congress to reject these budget proposals, which will put at risk the health of Americans and the rest of the global community and will undermine the U.S. as a leader in global health.

For nearly 50 years, the FIC has supported research and training within and outside the U.S. With an operating budget of \$69.1 million, representing just 0.02 percent of the total \$32 billion NIH budget, it currently provides grants at more than 100 American universities. Beyond its support for international engagement by the NIH, it undertakes work critical to the health and security of U.S. citizens.

Through its programs, the FIC facilitates global health research and trains the next generation of scientists to address global health needs. Reducing funding to public entities with a global focus like the FIC reduces our ability to build relationships with well-trained and trusted international collaborators; it enhances America's exposure to the threat of serious diseases. The ever present threat of swine and bird flu and the emergence of yet unidentified infectious diseases is surely a reason to strengthen, not weaken (let alone eliminate) the FIC.

Strong science and strong ethics are two sides of the same coin. The FIC has long understood that the success of global research depends on the observance of ethical standards and on institutions that ensure the validity of research results and the responsible conduct of research.

Without assurances of strong ethical standards, we will lose the public confidence that researchers will protect the rights and welfare of research participants whose poverty, limited access to healthcare, and low literacy leave them vulnerable. An important aim of the FIC includes the establishment of programs that enhance skills in research ethics among researchers to ensure that research everywhere is conducted ethically. Such programs are especially important now in an era when research sponsored and conducted by private entities, such as pharmaceutical companies, are rapidly growing in LMICs. As FIC Director Dr. Roger Glass explained, "As clinical research and trials increase in LMICs, the need for skilled local experts to independently assess and address thorny ethical issues will remain key."

The Fogarty Center supports training to enhance the professional development of local leaders who can strengthen their national research ethics guidelines, build functioning review boards that evaluate the ethical aspects of research, develop ethics education programs at their own institutions, publish original research on ethical issues, and guide the development of policies that promote the human rights of research participants and their communities. A key focus of the FIC is the establishment of sustainable degree programs in research ethics at foreign institutions to ensure that ethics safeguards persist.

Currently, Fogarty supports 23 research ethics programs around the world and has a presence in Botswana, Democratic Republic of the Congo, Kenya, Madagascar, Mozambique, Nigeria, Rwanda, South Africa, Tanzania, Uganda, Zambia; Egypt, Jordan, Morocco, Sudan; China, Myanmar, Thailand, Vietnam, India; Argentina, Brazil, Grenada, Guatemala, Mexico; Albania, Bosnia-Herzegovina, Bulgaria, Macedonia, Montenegro, Romania, Lithuania, Serbia; Turkey; Azerbaijan, Tajikistan, Kazakhstan, Kyrgyz Republic, and Uzbekistan.

Last year, Fogarty awarded grants to four institutions totaling up to \$5.3 million for 5 years of support. Such grants support programs in places where medical research occurs at an increasing rate: the Americas, the Middle East, North Africa and sub-Saharan Africa. These recent grants will enable Harvard Medical School to build capacity for a self-sustaining national system of ethics review of research in Rwanda; support Dartmouth College to enable Muhimbili University of Health and Allied Sciences to train scientists and healthcare providers in Tanzania and throughout East Africa; help the Latin American University of Social Sciences in Argentina to expand its training of researchers and ethics committee members; and enable the University of Maryland, Baltimore to develop degree programs in research ethics with their colleagues in Egypt, Sudan and Morocco.

FIC support for the development of capacity in research ethics promotes the bilateral exchange of knowledge and expertise between U.S. faculty and their foreign counterparts, which is instrumental in building ethically sound and culturally appropriate research in these countries.

The Fogarty International Center is a national treasure and should be regarded as such. Its elimination will seriously weaken the U.S. as a leader in global health, diminish public confidence in research, threaten the rights and welfare of participants in international research, and undermine both domestic and global health security, as Americans will become more vulnerable to diseases that have been increasingly global in its spread. Moreover, elimination of the Fogarty Center will un-

dermine current and future U.S. university programs and threaten the employment of U.S. faculty, as 80 percent of Fogarty grants awarded in fiscal year 2016 were made to U.S. institutions and 100 percent of Fogarty grants awarded in fiscal year 2016 involved U.S. researchers.

We strongly urge the U.S. Congress to defend against the anticipated elimination of the Fogarty International Center at the NIH in the President's fiscal year 2018 budget proposal. We would be glad to meet with members of this committee to explain further our concerns.

Respectfully submitted,

Henry Silverman, MD, USA	Myaing Myaing Nyunt, Institute for Global Health Myanmar, University of Maryland, USA
Bebe Loff, Monash University, Australia	Nancy Kass, Professor of Bioethics and Public Health, Johns Hopkins University, USA
Jon F. Merz, PA, USA	Nelson Sewankambo, Uganda
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Bernard Friedland, MA, USA	Richard D. Waddell, Associate Professor of Medicine, Dartmouth College, Hanover, NH, USA
Cheryl Macpherson, St George's University, Grenada	Robert Hall, U.S.A., Mexico
Clement Adebamowo, Nigeria/USA	Rosamond Rhodes, Icahn School of Medicine at Mount Sinai, NY, USA
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Muhsin Aboud, Tanzania	

PREPARED STATEMENT OF THE FOND DU LAC BAND OF LAKE SUPERIOR CHIPPEWA

I am Kevin R. Dupuis, Sr., Chairman of the Fond du Lac Band of Lake Superior Chippewa. Thank you for the opportunity to submit testimony on fiscal year 2018 Appropriations for programs that aid Indian country funded through the Departments of Education, Health and Human Services, and Labor. In separate testimony submitted to the Senate Appropriations Subcommittee on Interior, Environment, and Related Agencies, we addressed fiscal year 2018 appropriations for the Interior Department's Bureau of Indian Education and Indian Health Service. Because of the important role that programs administered by the Departments of Education, Health and Human Services, and Labor also have on our ability to meet the needs of our community, we address those here.

The Fond du Lac Band occupies a reservation in northeastern Minnesota. It was established by Treaty in 1854 and is a small part of our aboriginal homeland. We have approximately 4,200 members and provide health, education, social services, housing, public safety and other governmental services to more than 7,300 Indian people who live on and near our Reservation. With the assistance of the Federal Government, as well as other public and private partners, we have been working to find effective solutions to end the legacy of poverty that has plagued our community, so that we are able to provide good jobs, grow the local economy, educate our children, prevent crime, and care for our elders and infirm. We are proud of what we have accomplished, but much still needs to be done. Federal funding is essential to these efforts.

DEPARTMENT OF EDUCATION

We operate the Fond du Lac Ojibwe School which serves an average of 340 children from pre-K through 12th grade. Our students come from very low-income households; more than 90 percent of our students qualify for free or reduced rate

lunches. We rely on Federal funds from both the Interior Department and Education Department to run this school. We are making progress in improving the outcomes for our students. For example, high school graduation rates for American Indians in Minnesota have improved from 37.9 percent in 2003 to 52.6 percent in 2016, but are still well-below state-wide graduation rates. We have always been handicapped by limited resources. Past Federal funding for education has never kept pace with need. As shown by data compiled by Minnesota in 2016, there remain significant disparities between American Indians and the population statewide on education:

	Living below poverty	3rd Grade students at 3rd grade reading level	8th Grade students at 8th grade math level	High school graduation rates
Statewide	10.2%	57.3%	58%	82.2%
MN Indian	25.1%	35.8%	30.3%	52.6%

From: Minnesota Compass, <http://www.mncompass.org/education/overview>.

We are very concerned about the President’s proposed budget as it relates to education funding. In addition to proposing a cut of \$105 million to BIE funding, the President proposes a substantial 12 percent cut to funding for the Department of Education. Such cuts would only compound the problem we face. Among other things, the President would eliminate funding for after school programs (which are important to Indian students) as well as funding for teacher support and instruction, which are essential to maintaining quality programs. In addition, the proposed cuts to programs that help college students, like Pell grants and Perkins student loans, will disproportionately hurt our youth who seek a college education, but most often lack the financial resources. We urge Congress to increase, not reduce, funding for these programs.

Because education, including pre-school and after-school programs, opens the door for our children to move past poverty and achieve, we urge Congress to increase Federal funding for several other key programs that serve BIE and tribally-operated schools, as follows:

- Every Student Succeeds Act (ESSA) Title I, Part A: Local Education Agency Grants.* We urge Congress to provide \$20 billion for Title I, Part A. This is an important source of our school’s funding, as over 90 percent of our children come from low income families. An increase in funding for these grants will help offset the adverse impacts of inflation and sequestration.
- ESSA Title VI Part A.* Congress, in fiscal year 2017, enacted a much-needed increase to the funding for Grants to Local Educational Agencies-Indian Education from \$144 million to \$165 million. The President’s proposed budget would keep funding at only fiscal year 2016 levels, but the program should be at least maintained at the fiscal year 2017 level.
- Individuals with Disabilities Education Act (IDEA), Part B.* Here too, we urge Congress to increase funding for this important program which meets the special education needs of children with disabilities.
- Education for Homeless Children and Youth.* While Congress increased the funding for this program to \$77 million in fiscal year 2017, the President’s proposal would keep it at prior years’ levels. Funding for this program should be increased, or at least remain at fiscal year 2017 levels.

Finally, we are deeply troubled by the President’s proposal to increase funding for school choice, including a proposal to make \$1 billion of funding from Title I of the ESSA “portable.” Title I funds are targeted to help schools that have a high percentage of low income students. Title I funds should not be made “portable,” as that will only divert critical resources from those who have the greatest need, and will further tax schools that are already chronically underfunded.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

We are striving to improve the health of our members and the Indian people that we serve. But because of the legacy of poverty and the problems that poverty creates, much still needs to be done. Our people have disproportionately higher mortality rates than the non-Indian population in our region,¹ and face disparities in health across a range of indicators. For example, in 2015 the rate of diabetes among American Indians in Minnesota was 18.4%—more than double the rate of the popu-

¹Great Lakes Inter-Tribal Epidemiology Center, American Indian and Alaska Native Health in Michigan, Minnesota and Wisconsin 2016, at 37–38; Indian Health Service, Indian Health Disparities (April 2017).

lation statewide.² Heart disease, cancer, obesity, chemical dependency and mental and behavioral health problems are prevalent among our people. We are on the front lines of combatting an opioid epidemic. At our outpatient treatment centers alone, we see several hundred each year who are assessed for opiate addiction (439 in 2015, 380 in 2016, and 184 in 2017 to date). Some are as young as 12 years old and range to age 62. We are able to have more than half of those (an average of 250 each year) enter treatment, but the need for care exceeds existing resources. The Federal Government's promise to provide us with healthcare dates back to our Treaties with the United States and has been reaffirmed in many Federal statutes. Yet, funding for Indian healthcare continues to lag far behind all other federally-funded healthcare services. Studies show that, for example, in 2015 IHS spending for medical care per user was \$3,136, while the national average spending per user was \$8,517.³ We serve over 7,300 Indian people at our clinics, but the current Federal funding meets less than our needs.

Despite the longstanding unmet need, the President's proposed fiscal year 2018 budget would reduce funding for the Indian Health Service by \$300 million below the fiscal year 2017 enacted level. The harm that this would do to Indian healthcare would be compounded by the President's proposals to cut other DHHS grants on which Indian healthcare also depends, as well as the proposals to radically cut and change Medicaid. The importance of these to Indian healthcare cannot be understated.

CMS—Medicaid. We urge Congress not to enact legislation that cuts or changes the way in which Medicaid is paid to IHS-funded healthcare providers. Because IHS funding has never been sufficient to meet the healthcare needs in Indian country, Congress, 40 years ago amended the Social Security Act to authorize Medicare and Medicaid reimbursement for services provided in IHS- and Tribally-operated facilities. Medicaid has since become a key source of funding for our healthcare programs; it helps fill the shortfalls in IHS funding whenever we serve Medicaid-eligible Indian people. Medicaid covers over one-third of our budget. Preserving Medicaid is one of the best ways to address the opioid epidemic. If Medicaid dollars are cut, or block-granted to the States, or allocated per capita, then substantially larger increases will be needed in IHS funding.

National Institute of Health. We use a combination of resources to address behavioral health issues. Grant funds from NIH's Native American Research Centers for Health (NARCH) allowed us to partner with the Mayo Clinic to find alternative ways to treat chronic pain rather than prescribe opioids. While our NARCH grant has expired, and we are looking for other sources to continue this work, the resources provided through the NIH plays a key role in Indian healthcare. We urge Congress to maintain funding for NIH.

SAMHSA also plays an important role in addressing mental and behavioral health services. We receive, through Minnesota, a portion of its Substance Abuse Prevention and Treatment Block Grant, as well as a portion of its Mental Health Services Block Grant. While we were encouraged to see that the President's proposed budget identifies combating the opioid epidemic as a priority, the proposal to simply keep funding for Substance Abuse Treatment Grants at existing levels will not effectively address this serious problem. Moreover, the President's proposal to cut funding for Community Mental Health Services Block Grants (from \$541 million in fiscal year 2017 to \$416 million in fiscal year 2018) should be rejected. Mental healthcare is not adequately funded by IHS. The MHBG funds that we receive allow us to employ therapists who provide child and family counseling. This work is also provided at local schools and serves approximately 100 Indian children and their families. Funding should be increased for both of these important block grants.

Centers for Disease Control and Prevention. Grants awarded through the CDC have helped us implement preventive care programs that are not funded through IHS. With CDC funds, we implemented a cancer prevention program. With the CDC's Public Health Block grant, we provide educational and supportive services to new mothers on maternal and child health needs. Investing in preventive care reduces the risks and higher costs of more serious health problems.

Administration for Children and Families (ACF)

—*Head Start.* While the President proposes to keep Head Start funding at fiscal year 2016 levels, we urge Congress to, at a minimum, provide a cost-of-living increase to Head Start. Head Start has a proven track record of success for

²See Minnesota Compass, <http://www.mncompass.org/health/overview>.

³National Tribal Budget Formulation Workgroup's Recommendations on the Indian Health Service fiscal year 2018 Budget.

early childhood development and education and should continue to be funded at levels consistent with increases in cost-of-living.

—*Child Care Block Grant*. Here too, the President proposes to keep the Child Care block grants at fiscal year 2016 levels. Congress recognized the need for an increase to this important grant in fiscal year 2017 and a similar increase should be made in fiscal year 2018. These funds allow us to help subsidize the cost of child care needed by parents who are working or enrolled in school. Parents in the program pay a small co-pay for this assistance. In an area where we face disproportionately high unemployment, aid to parents with the cost of child care allows our members to work or attend classes or training that would allow them to find work.

—*Low Income Home Energy Assistance Program and Community Services Block Grants*. We urge Congress to reject the President's proposal to completely eliminate these two programs. We receive funding from both. Although the funds we receive are modest, they help fill important gaps. In the harsh winters of northern Minnesota, LIHEAP assistance to cover home heating costs can make a life-or-death difference for our poorest tribal members.

—*Administration for Native Americans (ANA)*. We urge Congress to increase, or at least maintain funding for, ANA grants. Over the years, the Band has secured modest ANA grants which we have used for a variety of very successful purposes, such as for our language program and for planning and zoning. These grants are often seed money which allow a program to begin and, as it evolves, to secure other sources of funding. An example is an ANA grant to the Indian Land Tenure Foundation which established a successful estate planning program for Indians. They have since secured other funding sources and continue to aid Indian people in preparing wills and probate matters, which help reduce the problems of fractionated trust lands.

Special Diabetes Program for Indians (SDPI). This program plays a critical role in our effort to reduce the high rate of diabetes in our community. SDPI allows us to provide our patients with supplies, education and exercise classes which helps them manage this disease. We are urging Congress to reauthorize SDPI and hope that in doing so, annual funding will be increased from the 2004 \$150 million level.

DEPARTMENT OF LABOR

Workforce Innovation and Opportunities Act—Native American Program. This program provides a modest amount of funding to aid tribes in providing job training to adults and summer job opportunities to youth. Congress appropriated \$50 million in fiscal year 2017, as it did in fiscal year 2016. Given the importance of jobs to the welfare of our communities, we urge that funding for this program be increased. Miigwech. Thank you.

[This statement was submitted by Kevin R. Dupuis, Sr., Chairman, Fond du Lac Band of Lake Superior Chippewa.]

PREPARED STATEMENT OF THE FRIENDS OF THE HEALTH RESOURCES
AND SERVICES ADMINISTRATION

Friends of HRSA is a nonpartisan coalition of 195 national organizations representing 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. For fiscal year 2018, we recommend restoring HRSA's discretionary budget authority to the fiscal year 2010 level of \$7.48 billion. HRSA is the primary Federal agency responsible for increasing access to healthcare for people who are medically underserved through access to quality services, a skilled health workforce and innovative programs. HRSA's discretionary budget authority is far too low to fully address the Nation's current health needs. HRSA's fiscal year 2017 discretionary budget authority is nearly 17 percent below the fiscal year 2010 level. We also are deeply concerned that the president's proposed fiscal year 2018 budget would cut HRSA's discretionary budget authority by \$674.5 million below fiscal year 2017 levels. Many important programs at HRSA would be significantly impacted by this proposal.

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. Additionally, like the people they serve, the Nation's health workforce is also aging and approaching retirement, which will put additional stress on the healthcare system as they exit the workforce. 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. Restoring HRSA's discretionary budget to fiscal year 2010 levels will allow the agency to take on the many health challenges our Nation faces and more effectively fill preventive and primary healthcare gaps. 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 who have complex health, behavioral and social needs and 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 in collaboration across the Federal Government to enhance health outcomes. For example, HRSA's HIV/AIDS Bureau partners with the Office of the Assistant Secretary for Health, the Centers for Disease Control and Preventions, the Substance Abuse and Mental Health Services Administration, the Centers for Medicare and Medicaid Services, the Indian Health Services, the National Institutes of Health, the Agency for Healthcare Research and Quality, the Department of House and Urban Development, the Department of Veterans Affairs and the Department of Justice to ensure an effective use of resources, and a coordinated and focused public health response. This Federal response has contributed to the number of annual HIV infections dropping 18 percent between 2008 and 2014 with HRSA's Ryan White HIV/AIDS Program serving as the foundation for delivering healthcare and support services to reach the public health goal of ending the HIV epidemic.

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 at risk for or infected with the Zika virus in Puerto Rico and affected territories. However, much of this work required additional funding through the fiscal year 2016 Zika supplemental 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 24.2 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. While it has been well documented that increasing diversity among health professionals is associated with improved access to care for minority patients, greater patient satisfaction, better patient-

clinician communication, among many other benefits, and evidence suggests that minority health professionals are more likely to serve in areas with a high proportion of uninsured and underrepresented racial and ethnic groups, the president's budget proposes to eliminate all programs designed to increase diversity in health professions. Unfortunately, the president's budget also proposes to cut all Interdisciplinary, Community-based Linkages programs, Public Health Workforce Development and four of the five nursing workforce development programs. We urge the Senate to reject the proposed eliminations and continue to provide funding for these important workforce programs.

—*Maternal and child health programs* support initiatives designed to promote optimal health, reduce disparities, combat infant mortality, prevent chronic conditions and improve access to quality healthcare. Through its maternal and child health programs, HRSA has played a major role in decreasing the U.S. infant mortality rate, which is a widely used indicator of the Nation's health. MCH programs help assure that nearly all babies born in the U.S. are screened for a range of serious genetic or metabolic diseases and that coordinated long-term follow-up is available for babies with a positive screen. They also help improve early identification and coordination of care for children with sensory disorders, autism and other developmental disabilities. The president's budget proposes to eliminate multiple MCH programs, including Autism and Other Developmental Disorders, Sickle Cell Service Demonstrations, Universal Newborn Hearing Screening, Emergency Medical Services for Children and Heritable Disorders. We urge the Senate to reject the proposed eliminations and continue to provide funding for these important MCH programs.

—*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 over 533,000 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. The president's budget proposes to eliminate the AIDS Education and Training Centers and the Special Projects of National Significance, which supports the development, evaluation and dissemination of innovative models of care to increase the retention rate and improve health outcomes of RWHAP clients. We urge the Senate to reject the proposed eliminations and continue to provide funding for these important HIV/AIDS programs.

—*Title X family planning* 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. In 2015, Title X family planning resources helped prevent over 901,000 unintended pregnancies.

—*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. The president's budget proposed significant funding cuts to Rural Health Policy Development, Rural Health Outreach Grants and Telehealth, and proposed elimination of Rural Hospital Flexibility Grants and State Offices of Rural Health. There are over 46 million people living in rural America who face ongoing challenges in accessing healthcare. People living in rural areas have higher rates of age-adjusted mortality, disability and chronic disease compared with people living in urban communities. We need to invest more in rural health, not less and we thank the subcommittee for recognizing this need and providing an increase in funding for HRSA's rural health programs in fiscal year 2017.

—*Healthcare system programs* include the Organ Procurement and Transplantation Network, the National Marrow Donor Program, the C.W. Bill Young Cell

Transplantation Program and National Cord Blood Inventory. These programs maintain and facilitate organ marrow and cord blood donation, transplantation and research, along with efforts to promote awareness and increase organ donation rates. Healthcare System 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. PCCs also play an important role in addressing the opioid epidemic by helping to define and trace the problem, and responding to calls from healthcare providers seeking treatment advice for the patient. However, given the rise of emergency room visits due to opioid overdoses, it is expected to become increasingly difficult to maintain inbound call volume with level funding.

We urge you to consider HRSA's central role in strengthening the Nation's health and advise you to adopt our fiscal year 2018 request of \$7.48 billion for HRSA's discretionary budget authority.

Thank you for the opportunity to submit our recommendation to the subcommittee.

PREPARED STATEMENT OF THE FRIENDS OF THE NATIONAL INSTITUTE OF CHILD
HEALTH AND HUMAN DEVELOPMENT

On behalf of the Friends of NICHD (National Institute of Child Health and Human Development), I urge the Labor, Health and Human Services, Education, and Related Agencies Appropriations Subcommittee to support an additional \$2 billion for the National Institutes of Health (NIH) over fiscal year 2017, including a proportionate amount for NICHD in fiscal year 2018. The Friends of NICHD includes over 100 organizations representing scientists, physicians, healthcare providers, patients, and parents concerned with the health and welfare of women, children, families, and people with disabilities. We are pleased to support the extraordinary work of NICHD.

NICHD has achieved great success in meeting the objectives of its biomedical, social, and behavioral research mission, including research on child development before and after birth; women's health throughout the life cycle; maternal, child, and family health; learning and language development; reproductive biology; population health; and medical rehabilitation. With sufficient resources, NICHD can build upon the initiatives listed below to produce new insights and solutions to benefit the women, children, and families in your districts and States.

Zika Virus: NICHD plays a crucial role in research on the Zika virus. Due in part to NICHD research, we know that the Zika virus has a direct link to the development of congenital microcephaly and other birth defects; however, there is still much we don't know about risks to reproductive, maternal and infant health. NICHD is uniquely positioned to investigate mechanisms that lead to Zika-related birth defects during pregnancy and to help uncover medical breakthroughs to mitigate harmful long-term effects of Zika virus (e.g., vision and hearing problems, abnormal reflexes, epilepsy, and respiratory infections). We urge Congress to maintain a sustained focus.

Preterm Birth: NICHD supports a comprehensive research program on the causes, prevention, and treatment of preterm birth, the leading cause of infant mortality and intellectual and physical disabilities. Research shows the survival rate and neurological outcomes may be improving for very early preterm infants, but continued prioritization is needed through extramural preterm birth prevention research, the Maternal-Fetal Medicine Units Network, the Neonatal Research Network, and intramural research program. Robust funding is needed for research to determine the complex interaction of behavioral, social, environmental, genetic, and biological influences on preterm birth with the goal of developing the interventions necessary to decrease prematurity.

Environmental Influences on Child Health Outcomes (ECHO) Program: The ECHO program has the potential to be an important tool for assessing the impact of a child's environment on health outcomes. We encourage the NIH to ensure that the cohorts selected to participate in this program collect prospective data during pregnancy to determine the impact of in utero exposures. NIH should develop a mechanism to provide for peer review of this program.

Intellectual and Developmental Disabilities Research Centers (IDDRC): The IDDRCs are a national resource for basic research into the genetic and biological basis of human brain development, greatly improving our understanding of the causes of developmental disabilities and promoting the development of effective

treatments. We urge NICHD to provide additional resources to the IDDRCs for research infrastructure and expansion of cores to conduct basic and translational research to develop effective prevention, treatment, and intervention strategies for children and adults with developmental disabilities.

Population Research: The NICHD Population Dynamics Branch supports research on how population change affects the health, development, and wellbeing of children and their families, including through the National Longitudinal Study of Adolescent to Adult Health that has demonstrated how social relationships affect physical health, including chronic disease and longevity; and the Fragile Families and Child Wellbeing Study that has demonstrated the role that family stability (e.g., chronic stress) and parental involvement (e.g., paternal engagement) play in the long-term health and development of children.

PregSource: The PregSource crowd-sourcing project will allow pregnant women to track their health data from gestation to early infancy and access evidence-based information about healthy pregnancies. Unique to this project, will be the ability for researchers to connect with NICHD staff to access aggregate data and potentially recruit participants for clinical trials in order to eliminate knowledge gaps and improve care for pregnant and post-partum women.

Data on Pediatric Enrollment in NIH Trials: The 21st Century Cures Act requires that NIH begin collecting and reporting on study enrollment by age, including for pediatric subgroups. The law also requires that NIH hold a workshop within 6 months of enactment to discuss these issues. We urge the NIH to quickly move forward with plans to begin to collecting and reporting on age-related data to ensure that all populations, including children, benefit from research.

Best Pharmaceuticals for Children Act (BPCA): NICHD funds, through the BCPA, the study of old, off-patent drugs important to children but inadequately studied in pediatric populations. We urge continued funding for this research and for training the next generation of pediatric clinical investigators.

Contraceptive Research: NICHD's Contraception Research Branch supports basic, applied and clinical research on contraceptive methods, including behavioral issues related to fertility and contraceptive use, evaluation of the safety and effectiveness of hormonal contraceptives for women who are overweight, and the development of new contraceptive modalities that are more effective, affordable, acceptable, and easier to deliver. Opportunities in this area include the need for non-hormonal contraception, pericoital contraception, and multipurpose prevention technologies that would prevent both pregnancy and sexually transmitted infections.

Reproductive Sciences: NICHD researches innovative medical therapies and technologies and improving existing treatment options for gynecological conditions affecting health and fertility. This research focuses on serious conditions that have been overlooked and underfunded although they impact many women. Future work could focus on infertility and the need for treatments for disorders such as endometriosis, polycystic ovarian syndrome (PCOS) and uterine fibroids.

Pelvic Floor Disorders Network (PFDN): Female pelvic floor disorders represent a major public health burden with high prevalence, impaired quality of life, and substantial economic costs. The PFDN conducts research on improving female urinary incontinence outcome measures and ensuring high quality patient-centered outcomes for these painful conditions.

Mother-Infant Relationships: NICHD supports research on mother-infant attachment and its impact on development. Early life experiences can have profound impacts later in life, but require specific experimental controls to pinpoint various factors. We urge NICHD to support intramural and extramural research in this areas to understand the complex interaction of behavioral, social, environmental, genetic and biological factors on health outcomes to improve interventions for mental disorders such as depression, addiction, and autism.

Development of the Research Workforce: There is a large gap between number of women's reproductive health researchers being trained and the immense need for research. NICHD's Women's Reproductive Health Research (WRHR) Program and Reproductive Scientist Development Program (RSDP), provide hundreds of training grants aimed at obstetrician-gynecologists to further their education and experience in basic, translational, and clinical research. Continued investment in these and other training programs is critical.

Implementation of Task Force on Research in Pregnant Women and Lactating Women: We urge Congress to continue its strong support for implementing the Task Force on Research in Pregnant Women and Breastfeeding Women, passed as part of the 21st Century Cures Act. NICHD is leading the Task Force's efforts, we look forward to supporting its work so that lifesaving treatments that pregnant women may take are known as safe and effective.

Down Syndrome: NICHD continues to do critical work to expand our understanding of Down syndrome: identifying treatments to reverse or ameliorate associated cognitive impairment; understanding the development of Alzheimer's disease and other conditions (e.g., through the Biomarkers of Alzheimer's Disease in Down Syndrome initiative); working with the Down syndrome research community on developing outcome measures for cognitive, behavioral, and physical measures for clinical trials; and coordinating with the NIH Down Syndrome Working Group to launch DS-Connect, the Down syndrome registry.

Cerebral Palsy: In collaboration with other NIH Institutes, NICHD conducts and supports research relevant to cerebral palsy (CP). We urge NICHD to support research into the positive outcomes of neuroplasticity in infants, toddlers, children, teens and adults with CP.

National Pediatric Research Network: We urge support to enable NICHD to leverage their funding in part through innovative partnerships with other NIH Institutes and Centers, by supporting implementation of the National Pediatric Research Network (PL 113-55), which was strengthened further through the 21st Century Cures Act, as well as to support the institute's career development and research training and fellowship needs.

Human-Animal Interaction Research: NICHD plays an essential role in human-animal interaction research, including showing the benefits of animal-assisted therapy for children with autism spectrum disorder (ASD) and other neurological conditions. A strong pipeline of high-quality, multidisciplinary, peer-reviewed science in this area is critical.

Thank you for your consideration. We look forward to working with you on these critical issues.

PREPARED STATEMENT OF THE FRIENDS OF NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES

In fiscal year 2018, the Friends of NIDDK encourages the Senate Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies to increase funding for research programs and activities at the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) that focus on preventing acute and chronic disease and other conditions in adults as well as youth, and reducing health disparities. In particular, the Friends of NIDDK is requesting a funding level of \$2.165 billion in fiscal year 2018 for NIDDK. This is an increase of approximately 10 percent over fiscal year 2016 funding. Given the large burden that acute and chronic diseases place on the U.S. healthcare system, economy, and quality of life years, the Friends of NIDDK believe that increased funding for these efforts in fiscal year 2018 will help reduce this burden.

The Friends of NIDDK is a coalition of professional societies and patient advocacy groups with a vested interest in promoting and sustaining the vital research activities of the NIDDK. The coalition was established in 2013 with the vision of uniting organizations to speak with one voice about the important research being conducted by the NIDDK and to ensure that the investment is deepened in future years. The Friends of NIDDK educates members of Congress and other stakeholders on the prolific scientific advances made through NIDDK's ongoing research and the critical importance of funding for future scientific initiatives.

ABOUT NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES

NIDDK is the fifth largest institute at the National Institutes of Health and coordinates research on many of the most serious diseases affecting public health. The mission of NIDDK is to "conduct and support medical research and research training and to disseminate science-based information on diabetes and other endocrine and metabolic diseases; digestive diseases, nutritional disorders, and obesity; and kidney, urologic, and hematologic diseases, to improve people's health and quality of life."

The NIDDK supports a wide range of medical research through grants to universities and other medical research institutions across the country, and supports scientists who conduct basic, translational, and clinical research across a broad spectrum of research topics and serious chronic diseases and conditions. In addition, the NIDDK supports research training for students and scientists at various stages of their careers and a range of education and outreach programs, including the National Diabetes Education Program, the National Kidney Disease Education Program, and the Weight-control Information Network, to bring science-based information to patients and their families, healthcare professionals, and the public.

U.S. DISEASE BURDEN

The diseases that are included within the NIDDK research portfolio are some of the most common, yet costly, diseases impacting Americans and demand increased research funding in fiscal year 2018. Chronic diseases are the Nation's leading causes of morbidity and mortality and account for 86 cents of every dollar spent on healthcare in the U.S.¹ For example, nearly 30 million Americans have diabetes and 86 million have prediabetes. Diagnosed and undiagnosed diabetes, prediabetes, and gestational diabetes cost the Nation \$322 billion a year in 2012 (\$244 billion alone in medical costs), an increase of 48 percent in just 5 years. About 26 million American adults have chronic kidney disease (CKD) and millions of others are at increased risk, although NIH investments in kidney research are less than 1 percent of Medicare costs for kidney care. Recent Centers for Disease Control and Prevention (CDC) data indicates that the prevalence of Crohn's disease and ulcerative colitis, collectively known as inflammatory bowel disease (IBD), has nearly doubled over the past 15 years from 1.6 million to 3.3 million. These diseases cost more than \$2.2 billion in direct and indirect costs annually. Urologic diseases affect people of all ages, result in significant healthcare expenditures, and may lead to substantial disability and impaired quality of life. Patients with cystic fibrosis, an inherited disease that primarily affects the lungs and digestive system, continue to face much lower life expectancy compared to healthy adults, despite dramatic advances in treatment. These diseases represent only a portion of the NIDDK research portfolio, but nonetheless underscore the need for continued investment.

National Institute of Diabetes and Digestive and Kidney Diseases Successes

The researchers at NIDDK are collaborating and using innovative technologies to discover cross-cutting solutions that will ultimately reduce healthcare costs and improve quality of life for millions of Americans. NIDDK releases an annual report to illustrate their scientific advances, and incorporates personal stories of individuals that participate in NIDDK-sponsored clinical research. Funding of \$2.165 billion in fiscal year 2018 would allow NIDDK to move forward on the following recent innovations outlined in the report:

- NIDDK's Kidney Precision Medicine Project would incorporate the systematic collection, storage, and preservation of kidney tissue, combined with advances in genetics and precision medicine, in order to define the subgroups of CKD and Acute Kidney Injury (AKI) to better facilitate the identification of specific drugs and enable individualized care.
- Together with the National Cancer Institute, NIDDK plans to expand the Consortium for the Study of Pancreatitis, Diabetes, and Pancreatic Cancer. This could work hand in hand with a proposed Cancer Moonshot Initiative project on diabetes and pancreatic cancer.
- Discovery of gut microbial communities that are shaped by human genetic factors. These findings indicate that microbial communities are important contributors to the human metabolism. Additionally, the findings show that their presence, or absence, is strongly affected by one's genes.
- Building upon the success of an FDA-approved hybrid closed loop system artificial pancreas in September 2016. NIDDK will continue to support research toward safe, portable artificial pancreas technologies.
- Research areas for treatment of liver disease including experimental cell based approaches for liver cell regeneration.

Thank you for this opportunity to present our views and we urge the Subcommittee to make fiscal year 2018 appropriations decisions that reflect the need to address the broad spectrum of diseases in NIDDK's research portfolio.

We look forward to working with you to prevent chronic illness, improve the quality of lives, and save billions of dollars in healthcare spending through an increased investment in the NIDDK.

[This statement was submitted by Jim Twaddell, Staff Consultant, Friends of National Institute of Diabetes and Digestive and Kidney Diseases.]

PREPARED STATEMENT OF THE FRIENDS OF THE NATIONAL INSTITUTE ON AGING

Chairman Blunt, Ranking Member Murray, and members of the Committee, this testimony is being submitted on behalf of the Friends of the National Institute on Aging (FoNIA), www.friendsofnia.org, a coalition of more than 50 academic, patient-centered and non-profit organizations that supports the research and training mis-

¹Centers for Disease Control and Prevention, Chronic Disease Prevention and Health Promotion, November 14, 2016, <https://www.cdc.gov/chronicdisease/>.

sions of the National Institute on Aging (NIA) by promoting and advocating for the NIA and its initiatives as public policies in health and research take shape. We appreciate the opportunity to provide testimony in support of the NIA and to comment on the need for sustained, long-term growth in aging research funding. Considering the resources the Federal Government spends on healthcare costs associated with age-related diseases, we feel it makes sound economic sense to increase Federal resources for aging research. Specifically, given the unique challenges created by an aging population and the range of promising scientific opportunities in the field of aging research, the FoNIA recommends an additional \$500 million in the fiscal year 2018 National Institutes of Health (NIH) budget to support biomedical, behavioral and social sciences aging research efforts at the NIH. We believe that this funding is the minimum essential to sustain research needed to make progress in attacking the chronic diseases that are driving significant increases in our national healthcare costs. In addition, given the exceptional challenges presented by Alzheimer's Disease and Related Disorders (ADRD), FoNIA endorses a minimum increase of an additional \$400 million for ADRD research across NIH in fiscal year 2018 to ensure that overall NIH research progress continues.

NIA's mission is urgent. The number of Americans aged 65 and older is growing at an unprecedented rate. By 2030, there will be 72 million Americans in this age group; more than double the number from 2000. The number of "oldest old"—people age 85 or older—is expected to more than triple between 2010 and 2050. Age is a primary risk factor for many disabling diseases and conditions—most notably, ADRD. The NIA is the primary Federal agency responsible for ADRD research. We know that over 5 million Americans aged 65 years and older may have Alzheimer's Disease (AD) with a predicted increase to ~14 million by 2050. NIA's comprehensive ADRD research program spans the spectrum of discovery, from basic neuroscience through translational research and clinical application. The National Alzheimer's Plan (<https://aspe.hhs.gov/report/national-plan-address-alzheimers-disease-2016-update>), 2012 and 2015 Research Summits, and allocation of additional funds over the past several years have accelerated momentum in this field. Recommendations from the Research Summits have been incorporated into new Funding Opportunity Announcements (FOAs) that cover virtually every aspect of AD research including health disparities, caregiving, epidemiology, diagnosis and prediction, molecular and cellular mechanisms, brain aging and clinical trials.

Efforts in ADRD research have been bolstered by the advent of new technologies to generate and analyze enormous data sets. These new technologies have been particularly effective in identifying risk and protective genes for ADRD. Researchers can now access genome sequence data from the Alzheimer's Disease Sequencing Project (ADSP), a collaboration between the NIA and the National Human Genome Research Institute to facilitate identification of risk and protective genes. The opening of a new data sharing and analysis resource developed under AMP (Accelerating Medicines Partnership), the AMP-AD Knowledge Portal, and the release of the first wave of data will enable large and complex biomedical datasets to be shared and analyzed. Researchers believe this approach will ultimately lead to selecting novel disease targets.

Because aging is the single biggest risk factor for the development of many chronic diseases, a better understanding of the basic biology of aging may open up new avenues for prevention and cures. Therefore investing in research on the basic biology of aging is a major priority for NIA. The establishment of the trans-NIH GeroScience Interest Group (GSIG) to facilitate discovery on the common risks and mechanisms behind age-related diseases and conditions has invigorated the field of basic geroscience. Recommendations from the 2013 GSIG Summit entitled "Advances in Geroscience: Impact on Healthspan and Chronic Disease" continue to energize researchers in this field.

Understanding that up to half of premature deaths in the United States are due to behavioral and social factors, NIA is committed to supporting basic behavioral and social research in aging. The NIA-supported Health and Retirement Study remains the world's premier multidisciplinary source of data on the health and well-being of older Americans, linking objective and subjective measures of health with information about retirement, economic status, family structure, personality, as well as health behaviors and service utilization. Funds from the American Recovery and Reinvestment Act facilitated expansion of the study, including genotyping DNA samples from participants. Research will be ongoing to take advantage of the available genetic data to advance understanding of how genetic, behavioral and psychosocial factors affect health and well-being. NIA remains an active participant in the trans-NIH Science of Behavior Change initiative and the Basic Behavioral and Social Science Opportunity Network.

Personalized medicine is closer than ever to being realized for many aging-related diseases and conditions. One example involves AD—approaches to systems biology identifying complex genetic and molecular networks, such as AMP, will enable identification of molecular signatures and networks underlying the various disease processes that lead to symptoms associated with AD. NIA is also partnering with the Patient-Centered Outcomes Research Institute (PCORI) to test an individually-tailored injurious falls prevention strategy that includes a “fall care manager” in community healthcare systems. Falls are a key cause of disability in older people. Multiple chronic health conditions are common among older adults and another NIA initiative supports research to identify behavioral interventions, targeted at older adults with multiple chronic conditions, with high potential impact on health outcomes.

NIA also supports several innovative programs dedicated to training the next generation of aging researchers. These include the Paul Beeson Career Development Awards in Aging Research for outstanding clinician-scientists and the Butler-Williams Scholars Program, a “boot camp” for emerging investigators in aging research to prepare them to compete successfully for grant funding.

Despite the recent infusion of money targeted at ADRD research, which we greatly appreciate, NIA’s current budget does not reflect the tremendous responsibility it has to meet the health research needs of a growing U.S. aging population. According to National Health Expenditure Data, in 2010 out of each healthcare dollar spent, 34 cents was spent on adults age 65 and older. Yet only 3.6 cents out of every dollar appropriated to NIH in 2010 went to support the work of NIA (NIH Almanac).

NIA is poised to accelerate the scientific discoveries that we as a Nation are counting on. With millions of Americans facing the loss of their functional abilities, their independence and their lives to chronic diseases of aging, there is a pressing need for robust and sustained investment in the work of the NIA. In every community in America, healthcare providers depend upon NIA-funded discoveries to help their patients and caregivers lead healthier and more independent lives. In these same communities, parents are hoping NIA-funded discoveries will ensure that their children have a brighter future, free from the diseases and conditions of aging that plague our Nation today. We do not yet have the knowledge needed to predict, preempt and prevent the broad spectrum of diseases and conditions associated with aging. We do not yet have sufficient knowledge about disease processes to fully understand how best to prevent, diagnose and treat diseases and conditions of aging, nor do we have the knowledge needed about the complex relationships among biology, genetics, and behavioral and social factors related to aging. Bold, visionary and sustainable investments in the NIA will make it possible to achieve substantial and measurable gains in these areas sooner rather than later, and perhaps too late.

We recognize the tremendous fiscal challenges facing our Nation and that there are many worthy, pressing priorities to support. However, we believe a commitment to the Nation’s aging population by making bold, wise investments in programs will benefit them and future generations. Investing in NIA is one of the smartest investments Congress can make.

[This statement was submitted by Kathryn Jedrzewski, PhD, Chair, Friends of the National Institute on Aging and Deputy Director, University of Pennsylvania Institute on Aging.]

PREPARED STATEMENT OF THE FRIENDS OF THE NATIONAL INSTITUTE ON
DRUG ABUSE

Thank you for the opportunity to submit testimony in support of the National Institute on Drug Abuse (NIDA). The Friends of the National Institute on Drug Abuse is a coalition 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. Recognizing that so many health research issues are inter-related, we request that the subcommittee provide at least \$2 billion above fiscal year 2017 for the National Institutes of Health, and within that amount a proportionate increase for the National Institute on Drug Abuse, in your fiscal year 2018 Labor-HHS Appropriations bill. We also respectfully request the inclusion of the following NIDA specific report language.

Opioid Misuse and Addiction.—The Committee continues to be extremely concerned about the epidemic of prescription opioids, heroin, and synthetic opioid use, addiction and overdose in the U.S. Approximately 144 people die each day in this country from opioid overdose, making it one of the most common causes of non-dis-

ease-related deaths for adolescents and young adults. This crisis has been exacerbated by the availability of fentanyl and its analogs into 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, 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 abuse and addiction within affected populations.

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.

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.

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.

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/criminal justice 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, early evidence suggests 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. Early 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. Placing dollar figures on the problem; smoking, alcohol and illegal drug use results in an exorbitant economic cost on our Nation, estimated at over \$600 billion annually. 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—significant declines in a wide array of youth drug use—over the past several years that we think are due, at least in part, to NIDA’s public education and awareness efforts. However, areas of significant concern include the recent increase in lethalties 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 2018 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. We look forward to working with you to make this a reality. Thank you for your support for the National Institute on Drug Abuse.

PREPARED STATEMENT OF THE FRIENDS OF NATIONAL INSTITUTES OF HEALTH
BEHAVIORAL AND SOCIAL SCIENCES RESEARCH

The Friends of National Institutes of Health Behavioral and Social Sciences Research (Friends of NIH BSSR) is a coalition of professional organizations, scientific societies, and research institutions concerned with the promotion of and funding for research in the social and behavioral sciences. The coalition requests an increase of at least \$2 billion above fiscal year 2017 for the National Institutes of Health (NIH), in addition to funds included in the 21st Century Cures Act for targeted initiatives, for fiscal year 2018. Since 2003, NIH funding has declined by 23 percent after adjusting for biomedical inflation, despite recent budget increases provided by the Congress the past 2 fiscal years. The agency’s budget remains lower than it was in fiscal year 2012 in actual dollars. Thank you for the opportunity to submit this statement for the official committee record.

The Friends of NIH BSSR would like to express its appreciation to the Subcommittee and to the Congress for their continued support of the National Institutes of Health. Strong, sustained funding is essential to national priorities of better health and economic revitalization.

NIH BEHAVIORAL AND SOCIAL SCIENCES RESEARCH

NIH supports behavioral and social science research throughout its 27 institutes and centers. As a result of the strong Congressional commitment to the NIH in years past, our knowledge of the social and behavioral factors surrounding chronic disease health outcomes is steadily increasing. The NIH’s behavioral and social

science research portfolio has emphasized the development of effective and sustainable interventions and prevention programs targeting those very illnesses that are the greatest threats to our health. But this work is just beginning.

The importance of social and behavioral determinants of health are often underestimated. According to the Centers for Disease Control and Prevention (CDC), nearly 900,000 Americans die prematurely from the five leading causes [heart disease, cancer, chronic lower respiratory diseases, stroke, and unintentional injuries] of death each year—yet 20 to 40 percent of the deaths from each cause could be prevented. The CDC also reports that many of these deaths are due to avoidable risks and could be prevented by making changes in personal behaviors. Other deaths are the result of disparities due to the social, demographic, environmental, economic, and geographic attributes of the neighborhoods in which people live and work.

The behavioral and social sciences are integral to the NIH mission “to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability.” The NIH Office of Behavioral and Social Sciences Research (OBSSR), authorized by Congress in 1993, serves a convening and coordinating role among the NIH institutes and centers. Accordingly, OBSSR develops, coordinates, and facilitates the social and behavioral science research agenda at NIH; advises the NIH director and directors of the 27 institutes and centers; informs NIH and the scientific and lay publics of social and behavioral science research findings and methods; and trains scientists in the social and behavioral sciences. OBSSR’s mission ensures that it is uniquely positioned to advance the behavioral and social sciences research required to improve the Nation’s health.

In 2016, OBSSR released its third strategic plan to guide the office over the next 5 years. That plan reflects the “scientific paradigm shift” that is occurring in the behavioral and social sciences. It includes three “equally important” scientific priorities:

- (1) Improve the synergy of basic and applied behavioral and social sciences research;
- (2) Enhance and promote the research infrastructure, methods and measures needed to support a more cumulative and integrated approach to behavioral and social sciences research; and
- (3) Facilitate the adoption of behavioral and social sciences research in findings in health research and in practice.

Coordinating offices in the NIH Office of the Director including OBSSR have seen their budgets eroded by inflation since 2008. For fiscal year 2018, the Friends of NIH BSSR encourages the committee to award OBSSR an amount in proportion to the overall increase it provides for NIH.

Below are examples of NIH-supported social and behavioral research that have contributed to the U.S.’ progress in health promotion, disease prevention, and treatment:

- Saving Lives*: Researchers in economics at Harvard University, the University of Pittsburgh, and Boston College have applied economic matching theory to develop a system that dramatically improves the ability of doctors to find compatible kidneys for patients on transplant lists. Organ donation is an example of an exchange that relies on mutual convergence of need: in this case, a donor and a recipient. This system allows matches to take place in a string of exchanges, shortening the waiting time, and potentially saving thousands of lives.
- Improving the Quality of Health Care*: Medical care is fundamental to a healthy life, but the medical care system is of mixed quality. Unnecessary or inappropriate care wastes hundreds of billions of dollars annually. NIH-funded economic methods and economic models are being used by interdisciplinary teams to diagnose the valuable and less valuable parts of medical care and design interventions to improve the productivity of the system. These findings have led to a revolution in how medical care payers and providers carry out their mission, with early evidence of moderating cost growth—that is, achieving better outcomes at lower cost. One NIH-funded study led to a revolution in the pharmacy benefit system that eliminated \$100 million of costs (annually) without generating adverse health effects.
- Moving from Basic Research to Lifesaving Interventions*: Scientists studying rats discovered that the behavior of rat mothers toward their newborn pups—how they nurse, lick and groom the pups—changes the lifelong responses of those offspring to stress. The mothers’ behaviors actually change the activity of genes in their offspring’s brains—specifically, genes that are involved in the response to stress hormones. This research was translated with interventions in neonatal

nurseries, including infant massage, that enhance premature infants' weight gain and save lives.

—*Understanding and Improving Ways that People Communicate about Health-Related Issues*: Effective communication between providers and patients and their families is a critical ingredient in making the healthcare system function effectively. Social scientists are studying the use of video technology to bring patients and family members into hospice team meetings. The study measures the effect of the participation on caregivers' perception of pain management and patient pain. Studies such as this not only contribute to better patient outcomes but also lead to better management of our health resources.

—*Understanding Adolescence Peer Pressure and Smoking*: Adolescents tend to be more powerful in influencing their friends to start smoking than in helping them to quit, according to Penn State sociologists. In a study of adolescent friendship networks and smoking over time, the researchers found that friends exert influence on their peers to both start and quit smoking, but the influence to start is stronger because of availability of tobacco. While most current adolescent smoking prevention programs are aimed at building resistance to peer pressure, the study shows that school nurses and other health professionals may be able to design programs that use peer pressure to positively to influence behavior. For example, they could design programs to help nonsmoking adolescents help their smoking friends.

—*Understanding How Loneliness Hurts Human Health*: Arbitrary distinctions between "mental health" and "health" are outdated. Mental health is health. So-called mental processes, for example, stress, can underlie many physical illnesses. NIH-funded research in the interdisciplinary subfield of social neuroscience has found that social isolation—loneliness—is toxic to human health with broad consequences to morbidity and mortality. Lonely people are sicker and die sooner than those who have even a few meaningful social relationships. This knowledge could be used to improve health for people at all age levels.

The Friends of NIH BSSR recognize the fiscal challenges facing our Nation as well as the difficult decisions that have to be made. At the same time, we also recognize that ensuring the health of our Nation through the research supported by NIH is critical to our economic revitalization and our Nation's health. Again, we thank the Subcommittee for its generous support of NIH.

PREPARED STATEMENT OF THE FSH SOCIETY ON FACIOSCAPULOHUMERAL
MUSCULAR DYSTROPHY

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 Human Genome Research Institute (NHGRI) and other Institutes as appropriate.

Suggested Fiscal Year 2018 Report Language: The Committee hopes and recognizes that scientific opportunities alongside recent breakthroughs and community defined priorities in facioscapulohumeral disease (FSHD) will help NIH call for more research proposals and modestly increase projects and funding. The Committee strongly encourages the NIH to significantly accelerate basic and exploratory research efforts and increase clinical trials readiness funding to provide access to treatment of facioscapulohumeral muscular dystrophy (FSHD) and other epigenetic diseases.

Honorable Chairman Blunt, Ranking Member Murray and distinguished Members of the Subcommittee, thank you for the opportunity to submit testimony. We kindly make the case for \$28 million needed in fiscal year 2018 to NIH for research funding on facioscapulohumeral disease (FSHD).

About FSHD, about our disease, my disease. FSHD, a heritable disease, is likely the most common form of muscular dystrophy with a prevalence of 1:8,000,¹ affecting approximately 870,000 children and adults of both sexes worldwide. FSHD is characterized by the progressive lifelong 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 many other skeletal mus-

¹Deenen JC, et al, Population-based incidence and prevalence of FSHD. *Neurology*. 2014 Sep 16;83(12):1056–9. Epub 2014 Aug 13.

cles. FSHD has a high burden of disease and can cause significant disability and, in a significant number of affected individuals, premature death, mainly through respiratory complications and respiratory failure. In addition to affecting skeletal muscle and breathing the disease can bring with it sensorineural hearing loss, vision problems and non-symptomatic cardiac arrhythmias. In fact, two days ago, world renowned FSHD clinicians signaled that screening of the respiratory status with spirometry and clinical assessment is increasingly necessary and warranted in FSHD patients, even while patients are still walking (ambulant).²

The National Institutes of Health (NIH) is the principal worldwide source of funding of research on FSHD currently active projects are \$13.180 million fiscal year 2017, a portion of the estimated \$80 million spent on all muscular dystrophies in fiscal year 2017.

This Subcommittee and Congress in partnership with NIH, patients and scientists has made truly outstanding progress in identifying areas in need of funding in the nine different types of muscular dystrophy. Congress is responsible for this success by its sustaining support of the overall NIH budget, and specifically through the enactment of the Muscular Dystrophy Community Assistance, Research and Education Amendments of 2001 (MD-CARE Act, Public Law 107-84). The NIH leadership and staff published last year in Muscle & Nerve the ‘2015 NIH Action Plan for the Muscular Dystrophies.’ This roadmap to increase efforts on dystrophy was assembled under the auspices of the Federal advisory committee mandated by MD CARE Act, called the MDCC, along with working groups of experts in the field. It specifies eighty-one objectives organized in six sections (mechanism, screening, treatments, trial readiness, access to care, infrastructure including workforce) in need of immediate and further development.³

On our end, as tiny as it is, the FSH Society continues to deliver huge results in improving our understanding of FSHD. As of May 27, 2017, the FSH Society has provided approximately \$8.185 million in seed funds and grants to pioneering FSHD research areas, education worldwide and created an international collaborative network of patients and researchers. Table I illustrates the rapid pace of discovery. Many of these breakthroughs have origins in seed funding from the FSH Society to researchers who have then used preliminary data to secure funding from the NIH. In the past few years, groundbreaking clinical and preclinical papers have emerged (MRI, biomarkers, surrogate outcome measures, cell and animal models, therapeutic studies in gene therapy, genetic engineering, CRISPR, antisense oligonucleotide (ASO), morpholino, locked nucleic acid (LNA) gapmers and small molecules). We are thrilled that our grantees have data and publications that prove that the FSHD-causing DUX4 toxicity can be turned off in FSHD cell lines and animal models of FSHD!^{4,5,6}

TABLE I.

Chronology of Developments

1886	FSHD was first described.
1991	FSH Society formed.
1991	FSHD genetic location found in the subtelomere of chromosome 4q35 in an area thought to be “junk DNA” (D4Z4 macrosatellite repeat array).
2001	MD CARE Act passed.
2004	FSHD1 found to be caused by a contraction of repetitive D4Z4 array on chromosome 4.
2007–2010	Critical role for DUX4 in FSHD1 pathophysiology established in FSHD1. De-repression of the D4Z4-encoded DUX4 retrogene coding

²Moreira S, Wood L, Evangelista T et al. Respiratory involvement in ambulant and non-ambulant patients with facioscapulohumeral muscular dystrophy. *J Neurol.* 2017 May 26. doi: 10.1007/s00415-017-8525-9.

³Rieff HI, Katz SI et al. The Muscular Dystrophy Coordinating Committee Action Plan for the Muscular Dystrophies. *Muscle Nerve.* 2016 Mar 21.

⁴Himeda 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.

⁵Chen 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.

⁶Balog J, Thijsen 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.

	for a transcription factor caused by a 1–10 unit D4Z4 repeat-array contraction and use of a polyadenylation signal distal to the D4Z4 repeat array to create a stable RNA and toxic protein. NIH Director Dr. Francis Collins was quoted 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.” ⁷
2012	Critical role for DUX4 in second type of FSHD called FSHD2 is established by the loss of D4Z4 silencing of DUX4 due to a chromatin repressor gene SMCHD1 on chromosome 18 having mutations responsible for maintaining the health of D4Z4.
2014	Mechanism described for how disease modulates itself from non-manifesting to manifesting due to balance between genetic and epigenetic factors as relates to the notable inter- and intrafamilial variability in disease onset and progression.
2016	A second type of FSHD2 found to be caused by mutations in DNA methyltransferase 3B (DNMT3B) causing D4Z4 de-repression yielding DUX4.
2017	First insights that normal function of DUX4 (outside of FSHD pathology)—involved in early embryo development (affecting human infertility and recurrent pregnancy loss), the reprogramming field, cancer biology. DUX4 regulates 2C-like program in early embryos. ^{8,9}
2017	Research on the specifics of polyadenylation cleavage at DUX4 and mutations in these regions (sequences downstream of the SNP located within the β -satellite region) could explain why some people have short permissive alleles and no or mild disease. This increases our focus to an even smaller section of the FSHD genetic and epigenetic context. ¹⁰

The NIH now has increased clarity of genetic and epigenetic contributors to FSHD that control disease onset, progression and severity. With this knowledge and foundation of preliminary to robust data the NIH can presently increase the amount of research funding on FSHD with neither having to increase the NIH budget nor taking money from another area of research. Better data, higher quality science, and focus allows more efficiency out of a non-growing budget, while achieving the goals of the Plan.

We must keep moving forward. November 10–11, 2016, the FSH Society held its annual International Research Consortium meeting in Boston, Massachusetts. The meeting was 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 latest data and discuss research strategies. The FSHD clinical and research community listed the 2017 year’s priorities in Table II.

TABLE II.

2016/2017 CALENDAR YEAR RESEARCH PRIORITIES

Molecular mechanisms

- Priority 1: Understanding genetic toxicity in FSHD.
- Priority 2: Understanding 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.

⁷Kolata, 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>.

⁸Hendrickson PG, Dorais JA, Cairns BR et al. Conserved roles of mouse DUX and human DUX4 in activating cleavage-stage genes and MERVL/HERVL retrotransposons. *Nature Genetics* 49, 925–934 (2017) doi:10.1038/ng.3844.

⁹Whiddon, JL, Langford AT and Tapscott SJ et al. Conservation and innovation in the DUX4-family gene network. *Nature Genetics* 49, 935–940 (2017) doi:10.1038/ng.3846.

¹⁰Peart, N. & Wagner, E.J. A distal auxiliary element facilitates cleavage and polyadenylation of Dux4 mRNA in the pathogenic haplotype of FSHD. *Hum Genet* (2017). doi:10.1007/s00439-017-1813-8.

Priority 6: Understanding of the epigenetic regulation of the repeats helps us to 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 are critical for trial preparedness in FSHD.

Models

Priority 12: Research that helps focus to ensure that we are measuring the same kinds of things, that translate into a usable tool 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 help develop precisely how you deliver, how you formulate, how you get the conceptual entity to the effective therapeutic use of the entity requires something that you can test.

(Source: <http://www.fshsociety.org/international-research-consortium/>)

We at the FSH Society have worked hard to make sure that our annual international research meeting achieves a tangible outcome. One of the most important assets of the meeting is that now we are defining yearly our priorities (as shown above) and we are seeing that increasingly the community responds accordingly. The FSHD research/clinical fields take the above priorities very seriously and our community needs funding to achieve these goals and specified objectives. In this way, we can keep our focus and move forward as quickly as possible. Of special note is that the NIH muscular dystrophy program staff has always been very gracious, attentive and helpful at these meetings. We are most appreciative of their proactive interest in the science of FSHD and for helping to find ways to encourage increased applications from the community. We ask their leadership to move to a more proactive stance by formally requesting applications and helping to cover through funding initiatives in the gaps identified.

NIH funding for Muscular Dystrophy. Mr. Chairman, these major advances in scientific understanding and epidemiological surveillance are not free. They come at a cost. Since passing the MD CARE Act in 2001, funding at NIH for FSH muscular dystrophy is still way too underpowered given the remarkable discoveries in the past 5 years.

FSHD RESEARCH DOLLARS & FSHD AS A PERCENTAGE OF TOTAL NIH MUSCULAR DYSTROPHY FUNDING

[Dollars in millions]

Fiscal Year	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016e	2017e
All MD (\$ millions)	\$39.5	\$39.9	\$47.2	\$56	\$83	\$86	\$75	\$75	\$76	\$78	\$77	\$80	\$80
FSHD (\$ millions)	\$2.0	\$1.7	\$3	\$3	\$5	\$6	\$6	\$5	\$5	\$7	\$8	\$9	\$9
FSHD (% total MD)	5%	4%	5%	5%	6%	7%	8%	7%	7%	9%	10%	11%	11%

Sources: NIH/OD Budget Office & NIH OCPL & NIH RePORT RCDC (e = estimate).

Despite the great success of the past 5 years in the science of FSHD brought about by Congress, NIH, non-profit funding agencies, patients, families and researchers we are gravely concerned with the overall level of FSHD research funding and its sideways trend. There are 28 active projects NIH-wide totaling \$13.180 million as of May 27, 2017, versus 32 active projects NIH-wide totaling \$12.616 million on April 14, 2016, and 26 projects on March 12, 2015 (source: NIH Research Portfolio Online Reporting Tools (RePORT) <http://report.nih.gov> keyword 'FSHD or facioscapulohumeral or DUX4'). NIH's 29 projects cover 1 F32, 1 K22, 1 K23, 1 P01, 1 P50, 4 R21, 12 R01, 2 U01, and 3 U54 grants. In the last year, there was a loss of one training grant F32, one small research grant (R03), 3 research project grants (R01), offset by a gain of 1 research program project/center of research translation (P50) and 2 cooperative clinical research agreements (U01). The engine of Federal research runs on the basic building blocks of workforce training, exploratory/develop-

opmental research grants (parent R21s) and research project grants (parent R01s). We all need to work concertedly and quickly to improve the status quo.

What we need. Looking at the current portfolio against the backdrop of scientific understanding and opportunity in FSHD the NIH needs to expand its portfolio. Specifically, NINDS needs to increase its current portfolio of one R01 and no R21 grants by adding 10–15 R01s and R21s. And, the NICHD, NHLBI, NHGRI who also are heavily involved in MD CARE Act/MDCC each need to increase their current portfolios of zero R01 and zero R21 grants by adding 5–10 R01s and R21s and 5–10 training awards each. NIH can easily help increase its portfolio on FSHD by issuing one or more of the following on FSHD: Program Announcement (PA), Program Announcement with set-aside (PAS), with special review (PAR), or with set-aside special review (PAR/S). A request for applications (RFA) on FSHD for R01 and R21 applications would certainly help given the breakneck speed of discovery in FSHD, and the need should be palpable to NIH leadership and staff. We also need to together and with purpose address the acute shortage on the supply side of researchers and clinicians entering the FSHD research and clinical and dystrophy field by actively engaging the best and brightest minds through ‘K series’ career development awards and ‘T & F series’ research training grants and fellowships. We ask NIH to consider a proactive pilot program for 5 years whereby between 6 K awardees and 6 F,T awardees are brought online each year. These are easy ways for NIH to convey to researchers that it has an interest in funding research in FSHD and drawing in more applications.

What we are asking for. We request for fiscal year 2018, a doubling of the NIH FSHD research portfolio to \$28 million. We ask for the initiation of a workforce acceleration program and augmentation of R01, R21 grants for mid-level investigators to support such growth. While in the past year NIH has invested in larger cooperative research centers and collaborative research grants—most of the priorities as specified by the community call for more basic grants and exploratory research awards, expansion of post-doctoral and clinical training fellowships. Now that NIH has conveyed to researchers that it has a revised plan and an interest in funding research in FSHD these funds will be needed to fill the demand. Mr. Chairman, thank you for this opportunity to testify before your committee.

[This statement was submitted by Daniel Paul Perez, President & CEO, CSO, FSH Society on Facioscapulohumeral Muscular Dystrophy.]

PREPARED STATEMENT OF FUTURES WITHOUT VIOLENCE

Dear Chairman Blunt and Ranking Member Murray:

For more than 30 years, Futures Without Violence, has developed innovative ways to end violence against women, children, and families at home and around the world. We are writing to ask for your continued support of adult and child victims of domestic violence and child trauma as you finalize the fiscal year 2017 bill and begin work on fiscal year 2018 bill for the Departments of Labor, Health and Human Services and Education.

We understand that the Labor, Health and Human Services and Education (LHHS) Appropriations bills faces severe budget constraints and in all likelihood even tighter limits in fiscal year 2018. These programs, however, go directly to serve the women and children who are the primary victims of violence and, consequently, we ask that they be funded at the highest level possible in order to help more victims survive and heal and prevent family and sexual violence in future generations.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

The Family Violence Prevention and Services Act (FVPSA) is the only Federal funding source dedicated specifically to domestic violence shelters and programs that support lifesaving services to victims of domestic violence and their children. The Nation’s domestic violence programs address both the emergency and long-term needs of victims, and work to prevent future violence. FVPSA has been successful, helping contribute to a decline in domestic violence. In addition, due to your support of the program last year, the new children’s services program was launched, allowing twelve communities that range from Texas to Alaska and Maine to California to receive targeted training and funding to meet the needs of children exposed to domestic violence. While important, this funding remains insufficient to meet the needs of the more than 30 percent of American women who are victims of partner violence and the approximately 18.8 million children who witness or suffer from similar abuse. FVPSA should be funded at the authorized level of \$175 million.

Violence Against Women Health Program.—The Violence Against Women Health program is a prevention and response initiative that trains healthcare providers and strengthens collaborations between public health and domestic violence agencies to better identify and serve victims of violence. It has trained more than 7,000 healthcare providers to screen, assess for and respond to domestic and sexual violence in over 80 clinical settings serving more than 400,000 patients. Studies demonstrate that such collaborations can improve the health and safety of women by decreasing dating violence, the risks for unplanned pregnancy and HIV/AIDS, poor health outcomes, and by connecting victims to services to help them escape the abuse. We encourage Congress to fund this program at authorized amount of \$10 million, or at a minimum maintain the current amount of \$3.1 million, and include report language requiring the Office of Women’s Health to use the funds for State-level partnerships between domestic violence and health agencies.

Child Abuse Prevention and Treatment Act (CAPTA).—Ending child maltreatment is one of the most important investments our Nation can make, given the multi-dimensional and long-term effects of abuse and neglect of children. CAPTA remains the only program that’s primary purpose is to prevent abuse and neglect with a focus on helping children and their families through supports and services that are community-based. The recent opioid crises has put even greater strains on already underfunded systems, with some agencies reporting twice as many children coming into care. Reaching families and supporting parents before they harm or neglect a child must be supported. In addition, new efforts to better address domestic violence are only now getting underway and show great promise in reducing child fatalities. We request CAPTA community-based grants be funded at a minimum of \$40 million.

As part of the National Task Force to Prevent Sexual and Domestic Violence, FUTURES also strongly supports:

The Rape Prevention and Education Program (RPE), a State formula grant administered by the CDC’s Injury Center, works to prevent and end sexual violence and create 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. This program should be funded at the authorized amount of \$50 million.

The DELTA-Domestic Violence Prevention Enhancement and Leadership through Alliances (Community Initiatives to Prevent Abuse) program is one of the only sources of funding for domestic violence prevention work. DELTA aims to prevent domestic and dating violence through targeted community work. Communities have been able to increase their prevention activities through DELTA nearly ten-fold. DELTA should be appropriated at the House level of \$6 million.

DEPARTMENT OF EDUCATION

Student Support and Academic Enrichment Grants (ESSA Title IV, Part A)

When Congress recently reauthorized the Elementary and Secondary Education Act, it consolidated many programs that addressed student learning, health, well-being and safety into a single flexible grant that gave local school districts control over what to prioritize with those funds. Title IV, Part A of The Every Student Succeeds Act (ESSA), as this program came to be known, was then authorized at \$1.6 billion to ensure it reached school districts with a meaningful enough amount of money to address the multiple purposes of the programs. Several core functions of this program involve protecting students from violence, including sexual and dating violence, and helping teachers and administrators build skills to address the impacts of children’s trauma and cyber-sexual on student learning and behavior. During fiscal year 2017 negotiations, both the House and Senate Appropriations Committees included funding for the block grant. We ask Congress to fund this program at the authorized amount of \$1.6 billion.

Sincerely,

[This statement was submitted by Esta Soler, President, Futures Without Violence.]

PREPARED STATEMENT OF GALE, A CENGAGE COMPANY

As the global business leader of Gale, a Cengage company, and founding member of the Corporate Committee for Library Investment, I’m writing to ask that the Senate Committee on Appropriations for the Subcommittee on Labor, Health and Human Services, and Education restore to the fiscal year 2018 budget level funding

for the Institute of Museum and Library Services and the Library Services and Technology Act (LSTA), which it administers.

While LSTA funding represents roughly 0.005 percent of total Federal spend, the population-based State grants provide a critical foundation for U.S. academic, school and public libraries. Library spending not only flows to private sector companies like Gale, but it enables the dissemination of knowledge through libraries that benefits the American economy in numerous ways.

The negative impact of moving forward with proposed cuts to IMLS and LSTA in the fiscal year 2018 budget is far-reaching:

- Thousands of private sector jobs across the country will be eliminated. Businesses like Gale that support libraries operate in every State in the Nation. We collectively generate several billion dollars in annual revenue and employ thousands of people, plus many more in our service and supply chains. If libraries stop spending LSTA funds with publishing, information and technology firms, it will create a ripple effect for library vendors who will be forced to cut jobs.
- Job seekers and business owners will lose critical resources. Libraries use LSTA funding to administer programs which help the unemployed find jobs, the underemployed improve skills, and entrepreneurs start and grow their businesses. Without local library programs, local economic growth will be impacted.
- America's Research University Libraries and businesses will not compete as effectively in a global economy. Research universities generate billions in private sector grants. Private-public relationships not only reduce dependence on tax-funding for higher education, but they fuel American leadership in research-intensive fields like pharmaceuticals, technology and agriculture. Research universities could not function without their libraries, which also benefit from LSTA funds and programs.
- Underserved populations become more vulnerable. Across the U.S., LSTA grants fund the distribution of braille and other resources for the blind and visually impaired, as well as programs which provide outreach to academically at-risk children, veterans and the elderly.
- Lack of essential infrastructure will impact 30 million American households. Thousands of Michigan citizens are among the 30 million American households that have no direct access to the Internet. Libraries and professional librarians provide computers, Internet access, and skills training that enrich almost every community's ability to build a skilled workforce, boost entrepreneurship, and connect people to the digital economy.

As a taxpayer and business leader, my experience is that IMLS administration of LSTA funds is both equitable and cost-efficient. LSTA grants are provided on a population basis to State libraries which determine locally impactful programs. Over half of the States offer electronic libraries with a wide variety of authoritative resources including job skill training, academic and health and wellness research, and business entrepreneurship to name a few. Leveraging competitive bidding processes, State libraries license access for all residents at a small fraction of what it would cost individual schools and libraries to offer the same high quality resources. Simply put, Federal and State program library funding achieves economies of scale for maximum public benefit.

As a business leader and a concerned citizen, I implore you to oppose the elimination of the Institute of Museum and Library Services and to restore funding for the Library Services and Technology Act, and on behalf of the thousands of Gale and Cengage employees, I thank you for seriously considering this testimony.

Regards.

[This statement was submitted by Paul Gazzolo, Senior Vice President, General Manager, Gale, a Cengage Company.]

PREPARED STATEMENT OF GLOBAL HEALTH COUNCIL

Global Health Council, 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 of programs at the Department of Health and Human Services (HHS) that play a role in saving lives and protecting health around the world. For fiscal year 2018, GHC encourages continued robust support for HHS activities that support global health, global health research and development, and global health security.

These programs and activities include research at the National Institutes of Health (NIH), biological preparedness countermeasures at the Biological Advanced Research and Development Authority (BARDA), detection and prevention activities

at the Centers for Disease Control and Prevention (CDC), and other HHS health programs that advance new technologies, strategies, and partnerships.

These investments are smart and strategic for the United States. They propel U.S. leadership in medical innovation and keep Americans safe and healthy. They also play a powerful role in global health—pivoting promising research to reach populations in need around the world, collaborating to build strong and resilient health systems in partner countries, and advancing disease detection, prevention, and response activities that limit the spread of outbreaks and epidemics.

At NIH, global health funding supports basic and applied scientific research to identify new interventions and more effective ways to improve health and combat disease. These research activities are complemented by programs that train new researchers and scientists in partner countries so they can better undertake future global health research. At CDC, one of the premier public health agencies in the world, the Center for Global Health (CGH) and the Center for Emerging Zoonotic and Infectious Diseases (NCEZID), work in partnership with ministries of health, international organizations, and partners around the world to track diseases, 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.

These investments have impact.

- CDC immunization programs helped reduce the number of new polio cases globally by more than 99 percent between 1988 and 2010. Its Field Epidemiology Training Program has trained more than 31,000 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.
- NIH programs developed the first blood test for HIV/AIDS, advanced the first rapid diagnostic for drug resistant tuberculosis, and showed how mothers' health could lead to babies that are healthier and more likely to survive.
- BARDA's work in infectious diseases has advanced at least three Ebola vaccine candidates, at least six diagnostics for Zika, and at least five Zika vaccine candidates in under 2 years. These activities have real and tangible results, and save lives around the world, including Americans.
- The Fogarty International Center builds critical research partnerships between U.S. scientists and their international counterparts to drive forward important biomedical advances in HIV/AIDS, tuberculosis and neglected tropical diseases. The Center's work supports global health research at more than 100 U.S. universities, and their HIV program alone has trained over 2,000 scientists from 100 countries since 1988.

In addition, investments in global health research and development have an impact on the U.S. economy. Approximately 89 cents of every dollar spent by the U.S. Government on global health research and development goes directly to U.S.-based researchers and product developers. This funding creates jobs, builds U.S. research and technological capacity, and is a direct injection of investment into the U.S. economy—not to mention a health reward for Americans who also benefit from such innovation.

HHS programs have long contributed to research, systems, and partnerships that save lives and promote health around the world. To continue this legacy and continue to be a leader in research and development we must maintain strong investments in globally-focused HHS programs and activities. Funding cuts will weaken health systems abroad, and slow progress in building a country's capacity to prevent, detect and respond to infectious disease outbreaks. Ultimately this will directly impact Americans' health and health security, as it is not a matter of "if" there will be another infectious disease outbreak, but rather "when."

By maintaining U.S. investments in global health and our commitment to progress, we can continue to build on what has been achieved so far to end or prevent the persistent global health challenges of our time and ensure a healthy future for citizens around the world.

Global Health Council thanks the Subcommittee for the opportunity to submit written testimony in support of HHS activities that support global health, global health research and development, and global health security. For more information on U.S. investments in global health, visit <http://ghbb.globalhealth.org>.

[This statement was submitted by Loyce Pace, MPH, President and Executive Director, Global Health Council.]

PREPARED STATEMENT OF THE 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 2018 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 nonprofit 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 at \$32 billion, providing funding to match CDC's increased responsibilities in global health and global health security—at minimum level funding of \$427.1 million for the CDC Center for Global Health, and \$579.9 million for the CDC National Center for Emerging Zoonotic and Infectious Diseases (NCEZID)—and supporting funding that allows BARDA to continue critical work in emerging and neglected infectious diseases.

GHTC members strongly believe that in order to meet the world's most pressing global health needs, it is critical to invest in research today so that the most effective health solutions are available when we need them. Sustainable investment in research and development (R&D) for a broad range of neglected diseases and health conditions is critical to tackling both endemic and emerging global health challenges that impact people around the world and at home in the United States. This need is particularly evident now, as the world continues to address the implications of Zika and Ebola—two diseases about which we knew little, and still have no approved tools to prevent or treat.

My testimony reflects the needs expressed by our member organizations, which work with a wide variety of partners to develop new and more effective lifesaving technologies for the world's most pressing health issues. We strongly urge the Committee to continue its established support for global health R&D by:

- Sustaining and supporting US investment in global health research and product development by maintaining robust funding for NIH at \$32 billion, providing funding to match CDC's increased responsibilities in global health and global health security—at minimum level funding of \$427.1 million for the CDC Center for Global Health, and \$579.9 million for the CDC National Center for Emerging Zoonotic and Infectious Diseases (NCEZID)—and supporting funding that allows BARDA to continue critical work in emerging and neglected infectious diseases.
- Urging leaders at the NIH, CDC, the Food and Drug Administration, and other entities within the US Department of Health and Human Services, like the Office of Global Affairs, the Biomedical Advanced Research and Development Authority, and the National Center for Advancing Translational Science (NCATS), to join leaders of other US agencies to develop a cross—U.S. Government global health R&D strategy to ensure that US investments in global health research are efficient, coordinated, and streamlined.

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 health conditions. In 2014, TB killed 1.5 million people, surpassing deaths from HIV/AIDS. Sub-Saharan Africa saw 1.4 million new HIV infections. Half the global population remains at risk for malaria and drug-resistant strains are growing. One out of every 12 children in sub-Saharan Africa dies before the age of five, often from vaccine-preventable and other communicable diseases. These figures highlight the tremendous global health challenges that still remain and the need for sustained investment in global health research to deliver new tools to combat endemic and emerging threats.

New tools and technologies are critical to address unmet global health needs and meet challenges of drug resistance, replace outdated and toxic treatments, and solve challenges related to administering current health technologies in remote settings. As seen with recent outbreaks of Ebola and Zika, we simply do not have the tools needed to prevent, diagnose, and treat many neglected diseases. While it is important to work to increase access to proven, existing drugs, vaccines, diagnostics, and other health tools, it is just as critical to invest in the development of next generation tools to fight existing and emerging disease threats. Particularly in our era of

globalization where diseases know no borders, investments today in global health innovations for existing global health threats and new and emerging infections 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 the NIH, CDC, and BARDA leading much of our global health research.

NIH

The groundbreaking science conducted at the NIH has long upheld US leadership in medical research. Not only does NIH research lead to novel medical technologies for American patients, but it also fuels important discoveries and innovative applications of tools that help address both longstanding and emerging global health challenges.

Within the NIH, the National Institute of Allergy and Infectious Diseases, the Office of AIDS Research, the Fogarty International Center, and NCATS all play critical roles in developing new health technologies that save lives around the world and at home in the United States. Recent activities have led to the development of new tools to combat neglected diseases, including vaccines for dengue fever and trachoma; new drugs to treat malaria and TB; and multiple projects to develop diagnostics, vaccines, and treatments for Ebola, including the development of ZMapp and the development and testing of Ebola vaccine candidates. 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.

For this important work to continue, the NIH needs adequate funding. We recognize and are grateful for Congress' work to bolster funding for the critical programs supported by 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 infectious 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. The 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. The work of its scientists has led to major advancements against devastating diseases, including the eradication of smallpox and early identification of HIV/AIDS.

Within the CDC, the Center for Global Health and NCEZID are critical to global health R&D and global health security efforts. 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 coordinating the National Strategy for Combating Antibiotic Resistant Bacteria, focused on preventing, detecting, and controlling outbreaks of antibiotic resistant pathogens, such as drug-resistant tuberculosis.

Programs at CDC's Center for Global Health—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 NTDs like leishmaniasis, dengue fever, and schistosomiasis. In addition, the Center for Global Health plays a critical role in detecting, preventing, and responding to infectious disease threats—monitoring and responding to outbreaks, developing new tools to help detection efforts, training epidemiologists in high-burden regions, and building 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 from the international community on a coordinated Global Health Security Agenda. This increased responsibility has not been matched with increased funding. As threats multiply, this will jeopardize the Center for Global Health's operations, scale-back important programming, and ultimately put American health security at risk. While we recognize the realities of our constrained funding environment, we feel CDC's critical and unparalleled work in global health warrants attention. To-date, CDC's multi-year work on the Global Health Security Agenda has not received any independent appropriations. We urge the Committee to support all of CDC's important global health work with appropriate resources—at minimum level funding for CGH and NCEZID.

BARDA

Within the Office of the Assistant Secretary for Preparedness and Response (ASPR) at HHS, the Biological Advanced Research and Development Authority (BARDA) also plays an unmatched role on global health R&D by providing an integrated, systematic approach to the development and purchase of vaccines, drugs, therapies, and diagnostics for public health medical emergencies—both intentional and naturally occurring. While initially designed to support the development of medical countermeasures against bioterror threats, these functions have also been used to accelerate the development of urgently needed countermeasures for Ebola and Zika. This support has shown tremendous impact: BARDA has advanced at least three Ebola vaccine candidates, at least six diagnostics for Zika, and at least five Zika vaccine candidates in under 2 years.

BARDA is unique within the U.S. Government because it fills a critical gap in medical product development, supporting translational research and helping bridge the “valley of death” between basic research and later stage development, carrying products all the way through to regulatory approval and manufacturing. Similar gaps in development exist for new global health technologies—where BARDA’s support bridging basic and late-stage research could play a vital role accelerating the development of vaccines, diagnostics, and treatments for neglected and emerging infectious diseases that threaten global and American health.

GHTC thanks you for your ongoing support of BARDA’s important programming and urges you to consider a broader, more formalized role for the authority in the infectious disease space—including a establishing a permanent Emerging Infectious Diseases program.

Innovation as a Smart Economic Choice

Global health R&D brings lifesaving tools to those who need them most. However, the benefits of investing in these research efforts are much broader than preventing and treating disease. Global health R&D is also a smart economic investment in the United States, where it drives job creation, spurs business activity, and benefits academic institutions.

Biomedical research, including global health, is a \$100 billion enterprise in the United States. Eighty-nine cents of every US dollar invested in global health R&D goes directly to US-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.

In addition to direct economic benefits from US support for global health R&D, 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.

Smart investments in medical research in the past have yielded lifesaving breakthroughs for global health diseases, as well as important advances in diseases endemic to the United States. We must continue to build on these investments, and turn scientific discoveries into new vaccines, drugs, tests, and other urgently needed health tools. 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 US 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 HELEN KELLER NATIONAL CENTER

The Helen Keller National Center (HKNC), authorized by the Helen Keller National Center Act (CFDA No. 84.128), is funded by the Department of Education and the Labor/HHS/Education Appropriations Committees in the House and Senate. The Center requests an increase of \$4.7 million from its current \$10.3 million to \$15 million in funding for fiscal year 2018.

Authorized by a unanimous vote of Congress in 1967, HKNC’s mission is to enable all deaf-blind citizens (totaling more than 2.4 million Americans) to live, work and thrive in their community of choice. HKNC operates the only comprehensive national vocational rehabilitation program exclusively serving both youth and adults who are deaf-blind. The Act mandates that the Center will:

- Provide specialized intensive services, or any other services, at the Center or anywhere else in the United States necessary to encourage the maximum personal development of any individual who is deaf-blind.
- Train family members of individuals who are deaf-blind at the Center or anywhere else in the United States, in order to assist family members in providing and obtaining appropriate services for the deaf-blind individual.
- Train professionals and allied personnel at the Center or anywhere else in the United States to provide services to the deaf-blind.
- Conduct applied research, development programs, and demonstrations with respect to communication techniques, teaching methods, aids and devices, and delivery of service.
- Maintain a national registry of individuals who are deaf-blind.

The year 2017 marks HKNC's fiftieth year as a national resource. HKNC is striving to fulfill its congressional mandate by: operating a comprehensive rehabilitation training program at its headquarters in Sands Point, NY; providing technical assistance, information, referral, advocacy, and training to local communities through its ten (10) regional offices and outreach programs; enhancing the ability of service providers to better meet the needs of people who are deaf-blind at the State and local levels by sponsoring research, disseminating information, and offering training to professionals nationwide.

Essentially, HKNC has been level-funded for nearly 16 years. In the fiscal year 2016 appropriations act HKNC was granted an increase of \$1.2 million by the Committee for which we are most grateful. But a critical need remains for HKNC to receive an annual appropriation of \$15 million in fiscal year 2018 to ensure that American citizens who are deaf-blind are provided with training opportunities that promote their success, independence and full participation in their communities and for HKNC to fully meet its congressional mandate.

The lack of funding over many years to cover even moderate inflation of costs has affected services and many aspects of national service delivery. Fulfillment of our mission requires an investment by the Federal Government not only to restore capacity, but also to grow and strengthen it to become the national resource it was intended to be. Over the long period of level funding HKNC had to eliminate staff positions supporting the comprehensive vocational rehabilitation program, resulting in a 1 year waiting list for prospective participants. Fewer people are being served annually and, regrettably, a model program providing employment and life skills training to deaf-blind Americans with intellectual disabilities had to be largely discontinued.

HKNC has been able to take important steps with the increase of \$1.2 million in 2016 to strengthen its national impact with expansion of on-line web courses for professionals working with individuals who are deaf-blind and the establishment of HKNC's Deaf-Blind National Community of Practice (NCOP). The NCOP is a network of thirty-eight (38) partners consisting of State and private agencies interested in strengthening or developing vocational rehabilitation service options for adults and youth who are deaf-blind through shared learning and collaborative research on best practices. In addition, during 2016 HKNC continued to develop innovative programs such as the Deaf-Blind Immersion Program (DBIS) specifically addressing the needs of individuals who are deaf-blind and have intellectual disabilities and their community service providers. We are building a sustainable national infrastructure and have developed Long Range Service Plans (LRSPs) in thirty States nationwide and will have one in each of the fifty States by 2018. A Long Range Service Plan is a collaborative agreement among State and local agencies and HKNC with measurable objectives to strengthen service options for individuals who are deaf-blind. With increased funding HKNC can fortify the network of service providers nationwide and establish a sustainable infrastructure leading to exemplary practices and collaborative efforts in services, learning and research.

Presently there is a serious lack of qualified practitioners to meet the growing needs of all age groups of deaf-blind individuals including transition age youth, working age adults, and the burgeoning population of senior citizens.

In June of 2011, the WESTAT Corporation completed a 2-year evaluation of HKNC on behalf of the U.S. Department of Education's Rehabilitation Services Administration. Among its conclusions were that, "HKNC [is] meeting its mandate to provide services to any deaf-blind individual, family members, and service providers, and conduct applied research and demonstrations" and that, "the preponderance of evidence from multiple data sources indicates that HKNC is providing services to address the vocational and independent living needs of deaf-blind individuals, and many stakeholders familiar with HKNC's work consider HKNC to be the 'gold standard' for provision of services to deaf-blind individuals." Additionally, the WESTAT evaluation indicated that State VR agencies generally lack services and

resources for individuals who are deaf-blind, further reconfirming the necessity of HKNC's goal to build a national infrastructure. With increased funding HKNC can fortify the network of service providers nationwide and establish a sustainable infrastructure leading to exemplary practices and collaborative efforts in services, learning and research.

HKNC requires additional funding to expand field operations to implement this effort. The goal is to increase resources within the regions and leverage the national network by deploying twenty (20) deaf-blind specialists throughout the regions to offer services, build collaborative teams working with consumers, their family members and service providers to successfully achieve vocational and independent living outcomes. With this additional funding, HKNC (and the national network) can provide a wide array of services to America's deaf-blind citizens directly in their home communities, galvanize research efforts, increase sharing of expert knowledge and maximize resources. Greater Federal investment will permit HKNC to partner with researchers, universities, private and State agencies, and consumer organizations to rebuild capacity and to reestablish needed services on a State and local basis throughout the Nation.

In collaboration with State vocational rehabilitation programs and the Mississippi State University Research and Training Center on Blindness and Low Vision, HKNC has conducted five statewide needs assessments (Georgia, Arizona, Missouri, Oregon and New York) to identify professional learning needs across the United States. In response, the Center has developed training modules for vocational rehabilitation counselors, mental health professionals, Support Service Providers (SSPs), Adaptive Technology Trainers, and Orientation and Mobility Instructors among others. HKNC continues to address the expressed needs of deaf-blind individuals with course development in self-advocacy and Haptics (an innovative touch signal system that can provide optimal environmental access to individuals who are deaf-blind). The recent fiscal year 2016 increase of \$1.2 million enabled HKNC to maintain staff experts to carry out these essential projects. With additional funding, distance learning professional training resources can become one of the driving forces for systematic change and capacity building across the country.

In the year 2016, as a result of additional funding of \$1.2 million, services and outcomes have increased. The data below is a sample of performance measures which indicate the impact to individuals who are deaf-blind, their families and service providers. HKNC has effectively and efficiently demonstrated the ability to maximize and leverage resources to attain a greater impact. In 2016, the following outcomes were achieved:

- the number of deaf-blind individuals newly registered on HKNC Deaf-Blind National registry—410
- the number of deaf-blind individuals who received services and support from HKNC field services—1582
- the number of family members who received access to resources, (including professional learning, connection to other families/organizations and information & referral, transitioning to adult services)—447
- the number of service providers who increased knowledge and skills as result of training, information and collaborative support from HKNC (including provider working with senior adults with combined vision and hearing loss)—731
- the percentage of consumers who, upon completing their comprehensive vocational rehabilitation training from HKNC, are competitively employed—53%
- the number of agencies which have received information, training and support from HKNC—985
- as a result of HKNC services, the percentage of individuals who are deaf-blind living in their community of choice with greater independence—86%
- the percentage of Individualized Training Objectives completed by participants in HKNC's comprehensive vocational rehabilitation program—91%
- the number of individuals who received adaptive technology to access telecommunications given assessment and training by HKNC since the inception of the National Deaf-blind Equipment Distribution Program—565.

With a \$4.7 million increase in funding, we aim to:

- Maximize the effectiveness and outcomes of the Helen Keller National Center's Deaf-Blind National Community of Practice (NCOP) for service providers working with youth and adults who are deaf-blind.
- Replicate the HKNC Community Services Program, investing in four States to broaden and strengthen comprehensive and specialized service options by developing a core group of trained rehabilitation professionals in each State. HKNC will strengthen its national collaborative approach to service delivery by expanding its workforce with two deaf-blind specialists in each region.

- Develop and offer an array of professional learning programs and products specifically designed to increase the number of trained professionals.
- Provide further research documenting needs, trends and best practices in the deaf-blind community.
- Maintain and enhance our capacity to offer comprehensive vocational rehabilitation services to a greater number of individuals on an annual basis.

Congressional leaders 50 years ago shared our commitment and vision for services to deaf-blind citizens. The time has come for a national service delivery to be created so that all American citizens who are deaf-blind have an equal opportunity to live self-actualized lives as fully contributing and included members of their communities.

[This statement was submitted by Susan Ruzenski, Executive Director, Helen Keller National Center.]

PREPARED STATEMENT OF THE HEPATITIS B FOUNDATION
HBF RECOMMENDATIONS FOR FISCAL YEAR 2018 APPROPRIATIONS

National Institutes of Health

- Along with the biomedical research community, HBF recommends \$36.1 billion for NIH in fiscal year 2018, a \$2 billion increase (and \$9.2 billion above the Administration's request for NIH) that should be spread across all Institutes and Centers.
- HBF urges NIAID, NIDDK, NCI to issue targeted calls for hepatitis B/liver cancer research proposals in fiscal year 2018;

Centers for Disease Control and Prevention

- HBF supports \$7.8 billion for the Centers for Disease Control and Prevention programs in fiscal year 2018, and within that \$70 million for the Division of Viral Hepatitis. This is \$1.98 billion and \$68,000 more than requested by the Administration, respectively.
- HBF further urges the Division of Viral Hepatitis, which now spends only 5 percent of its budget on hepatitis B, to allocate the funding proportional to the disease burden or up to 35 percent for hepatitis B.

Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to provide testimony as you consider funding priorities for fiscal year 2018. I am Tim Block, President of the Hepatitis B Foundation (HBF).

The Hepatitis B Foundation and its research affiliate, the Baruch S. Blumberg Institute, in Bucks County, Pennsylvania have grown to more than 100 researchers and health professionals and has one of the largest concentration of nonprofit scientists working on the problem of hepatitis B and liver cancer in the United States. The Foundation is a national disease, public health, and advocacy organization that has become the world's leading portal of information about hepatitis B and a trusted global authority. The Baruch S. Blumberg Institute is internationally recognized as leader in basic scientific research and we believe, supports some of the most exciting and promising work in the field of hepatitis B and liver cancer.

Mr. Chairman, HBF joins the Ad Hoc Group for Medical Research Funding, a coalition of 300 patient and voluntary health groups, medical and scientific societies, academic research organizations and industry, in recommending \$36.1 billion, an increase of \$2 billion for the National Institutes of Health in fiscal year 2018. While HBF recognizes there are demands on our Nation's resources, we believe the ever-increasing health threats and expanding scientific opportunities continue to justify increased funding for NIH. HBF further urges that NIH investments in Hepatitis B research over 6 years in order to find a cure for the 2.2 million Americans chronically infected with the hepatitis B virus (HBV) and more than 20 deaths each day as a direct result of hepatitis B.

In addition to the NIH, there are a number of programs within the jurisdiction of the subcommittee that are important to HBF, including the Centers for Disease Control and Prevention. We join the CDC Coalition, an advocacy coalition of more than 140 national organizations, in recommending \$7.8 billion for the Centers for Disease Control and Prevention in the fiscal year 2018 bill. Within that total, we join the National Viral Hepatitis Roundtable and the Hepatitis Appropriations Partnership in urging \$70 million for the CDC's Division of Viral Hepatitis.

RECOGNIZING THE LEADERSHIP OF THE SUBCOMMITTEE

Mr. Chairman, HBF appreciates your leadership and the leadership of this Subcommittee in supporting public health service programs. Your support is greatly recognized and appreciated. We applaud the Committee's leadership in making progress in these important areas and to allocating increased funding to these programs during periods of fiscal austerity. We are particularly grateful for your leadership in securing a \$2 billion increase for the NIH in fiscal year 2017.

NATIONAL INSTITUTES OF HEALTH

As previously noted, HBF recommends a fiscal year 2018 funding level of \$36.1 billion for the NIH, which would enable real growth over biomedical 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 to cut NIH funding by \$7.2 billion is reckless and short sighted. Cuts to NIH of such unprecedented magnitude would affect every American, including patients, their families, researchers, and communities where NIH investment spurs economic growth. HBF, and the entire health research community, is in fierce opposition to the Administration's proposal.

In addition to overall funding for the NIH, HBF urges that NIH investments in hepatitis B research be increased by \$ 38.7 million in fiscal year 2018, an amount necessary to find a cure. The hepatitis B virus (HBV) is associated with 800,000 deaths each year worldwide, making it the 10th leading cause of death in the world. In the U.S., 1 in 20 Americans has been infected with HBV and an estimated 2.2 million are chronically infected. Left undiagnosed and untreated, 1 in 4 of those with chronic HBV infection will die prematurely from cirrhosis, liver failure and/or liver cancer. Although HBV is preventable and treatable, there is still no cure for this disease. In view of the epidemic scope of hepatitis B and the fact that the virus was discovered 50 years ago, it is disappointing that funding for HBV research at the NIH is only \$49 million and has declined by almost 16 percent since fiscal year 2011. The Hepatitis B Foundation scientific leadership recommends increasing NIH research funding for hepatitis B by \$38.7 million a year for the next 6 years in order to fund identified research opportunities that would help eliminate the disease once and for all. The recommended \$38.7 million increase is based on specific research targets identified by leading research scientists as included in their Hepatitis B Blueprint for a Cure and the associated professional judgement budget. fiscal year 2018 report language is requested urging the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Institute of Allergy and Infectious Diseases (NIAID) to issue targeted calls for HBV research proposals in fiscal year 2018 focused upon therapeutic development and the many new research opportunities identified by the scientific community.

In the late fall of 2016, and over the winter of 2017, the Hepatitis B Foundation convened a "virtual" workshop to create a consensus blueprint to identify the additional research needed to find a cure for hepatitis B infection, and associated diseases such as liver cancer. More than 30 of the world's leading experts were asked to identify the research questions necessary to fund and to answer in order to achieve this goal, and the panel produced two valuable reports. It is estimated that this will require a total of approximately \$232 additional NIH research funding over 6 years. We have shared this document with the leadership of NIAID, NIDDK, and NCI. And we urge Congress to include report language urging these institutes to issue targeted calls for Hepatitis B research proposals in fiscal year 2018 focused on the many research opportunities identified by the scientific community. By increasing the NIH budget for hepatitis B research the research community believes that a cure can be found. This is supported by two recent reports from the World Health Organization and the U.S. National Academies of Science, Engineering and Medicine which conclude that the elimination of Hepatitis B is now possible. There are exciting new research developments and opportunities in the field that make finding a cure very possible.

CENTERS FOR DISEASE CONTROL AND PREVENTION

Given the challenges and burdens of chronic disease and disability, public health emergencies, new and reemerging infectious diseases and other unmet public health needs, HBF joins the 140 organizations in the CDC Coalition and urges a funding level of \$7.8 billion for CDC's programs in fiscal year 2018. This is \$1.26 billion more than the Administration's request. The CDC serves as the command center for

the Nation's public health defense system against emerging and reemerging infectious diseases. States, communities and the international community rely on CDC for accurate information and direction in a crisis or outbreak. The proposed \$1.2 billion reduction in funding is reckless and we are strongly opposed.

The CDC's Division of Viral Hepatitis (DVH) is part of the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention at CDC. In collaboration with domestic and global partners, DVH provides the scientific and programmatic foundation and leadership for the prevention and control of hepatitis virus infections and their manifestations. HBF joins the National Viral Hepatitis Roundtable and the Hepatitis Appropriations Partnership in recommending \$70 million for the DVH in fiscal year 2018. This is \$36 million more than the Administration's request.

The CDC Division of Viral Hepatitis spends less than 5 percent on HBV focused projects, despite hepatitis B infected patients comprising more than 35 percent of all those infected with viral hepatitis. Furthermore, tremendous HBV-related health disparities exist for people of Asian, Pacific Islander descent and recent African immigrants. These groups represent less than 5 percent of the U.S. population but make up over 50 percent of the U.S. burden of chronic HBV infection. CDC has not adequately addressed the issue of chronic HBV infections among high-risk, foreign-born populations and their children.

The Hepatitis B Foundation urges that the following report language be included in the fiscal year 2018 Labor-HHS Report under the CDC's Division of Viral Hepatitis:

Hepatitis B.—The Committee is concerned that even though there is a hepatitis B vaccine that is more than 90 percent effective there are over 50,000 new infections occurring each year and more than 10 deaths each day due to hepatitis B. Also, as a result of the opioid epidemic, infection with the hepatitis B virus (HBV) has spiked in many parts of the Nation with, for example, acute hepatitis B infections increasing 114 percent from 2006 to 2013 in three States that have suffered from widespread opioid overuse (Kentucky, Tennessee, and West Virginia). Additionally, the Committee notes that the link between hepatitis B infection and primary liver cancer is well established with up to 60 percent of global liver cancer cases caused by HBV with many of these liver cancer cases preventable with early detection, treatment and vaccination. Despite the public health challenge of HBV, the Committee also notes that the Division allocates less than 5 percent of its budget to projects specifically focused on hepatitis B and therefore directs that the allocation for hepatitis B interventions be proportional to its disease burden.

SUMMARY AND CONCLUSION

Mr. Chairman, again we wish to thank the Subcommittee for its past leadership and as your leadership demonstrates to see advances in improving the health and well-being of our Nation adequate funding for the public health service is paramount.

The World Health Organization and the U.S. National Academies of Science, Engineering and Medicine have both concluded in recent reports that the elimination of Hepatitis B is now possible. Each year, despite an effective vaccine, there are 30 million new HBV infections worldwide and over 50,000 new infections in the U.S. Moreover, despite the availability of seven approved medications to manage chronic HBV infection, none are curative, most require lifelong use, and only reduce the likelihood of death due to liver disease by 40–60 percent. Currently, almost 1 million people die each from hepatitis B-related liver failure and/or liver cancer.

A cure was accomplished for hepatitis C with increased Federal attention and funding. It can be accomplished for hepatitis B as well. As the knowledge, capability and consensus now exists, we urge the Subcommittee to lead the campaign to conquer hepatitis B now.

[This statement was submitted by Timothy Block, Ph.D., President, Hepatitis B Foundation.]

PREPARED STATEMENT OF THE HIV MEDICINE ASSOCIATION

The HIV Medicine Association (HIVMA) of the Infectious Diseases Society of America (IDSA) represents more than 5,000 physicians, scientists and other healthcare professionals working on the frontlines of the HIV/AIDS pandemic. Our members provide medical care and treatment to people with HIV/AIDS 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 2018 appropriations process, we urge you to sustain robust funding for the Ryan White Program at the Health Resources and Services Administration (HRSA); support adequate funding for the Centers for Disease Control and Prevention's (CDC) HIV and STD prevention programs; and to invest in HIV/AIDS research supported by the National Institutes of Health (NIH), including maintaining the Fogarty International Center.

Early diagnosis and access to HIV treatment helps patients with HIV live healthy and productive lives and is cost effective.¹ Treatment not only saves the lives of individuals with HIV but directly benefits public health by reducing HIV transmission risk to near zero.² However, despite our remarkable progress in HIV prevention, diagnosis and treatment, the HIV/AIDS epidemic is far from over. HIV/AIDS continues to pose a serious disease burden and public health threat in the United States with more than 1.1 million people living with HIV infection. Almost 1 in 8 (12.8 percent) individuals living with HIV are not aware of their HIV infection and there have been nearly 40,000 new infections occurring each year as of 2014.³ As a public health issue, the Federal Government plays a significant role in leading our Nation's response to the epidemic. In the U.S. HIV infection disproportionately impacts racial and ethnic minority communities and low income people who depend on public services for their life-saving healthcare and treatment. The rate of new HIV infections in African Americans is 8 times that of whites.⁴ Globally, there are more than 35.3 million people living with HIV, the great majority of them in Sub-Saharan Africa.

The funding requests in our testimony largely reflect the consensus of the Federal AIDS Policy Partnership (FAPP), a coalition of HIV organizations from across the country, and are estimated to be the amounts necessary to mount an effective response to the domestic HIV epidemic.

Health Resources and Services Administration (HRSA)—HIV/AIDS Bureau (HAB):

With uncertainty in the healthcare insurance market, HRSA's Ryan White HIV/AIDS Program (RWP) will be more important than ever to sustain our progress in treating and preventing HIV in the U.S. The RWP has enjoyed overwhelming bipartisan support since August 1990 when Congress enacted it and President Reagan signed it into law, and today it provides care and treatment services to more than 50 percent of individuals with HIV in care.

It is essential to maintain overall funding levels for the Ryan White Program at this critical time in the HIV/AIDS epidemic, when research has confirmed that early access to HIV care and treatment not only saves lives and keeps patients engaged and working, but prevents new infections by reducing the risk of transmission from virally suppressed patients to near zero. In particular, HIVMA urges an allocation of \$225.1 million, or a \$24 million increase over current funding, for Ryan White Part C programs in fiscal year 2018, including restoration of the \$4 million cut to Part C in the fiscal year 2017 omnibus appropriations bill. Part C-funded HIV medical clinics currently struggle to meet the demand of increasing patient caseloads. The expert, team-based and patient-centered Ryan White care model has been highly successful at achieving positive clinical outcomes with a complex patient population. Patients with HIV who receive Ryan White services are more likely to be prescribed HIV treatment and to be virally suppressed.⁵ In 2015, the viral suppression rate for all Ryan White clients rose to more than 83 percent. We also know that the annual healthcare costs for HIV patients who are not able to achieve viral suppression (often due to delayed diagnosis and care) are nearly 2.5 times that of healthier HIV patients.⁶

We also urge the Committee to reject the Administration's proposal to cut the Ryan White Program by \$59 million through elimination of the AIDS Education and

¹ Kitahata, Gange, Abraham, et al. Effect of early versus deferred antiretroviral therapy for HIV on survival. *New Engl J Med* 2009;360:1815–26.

² Cohen, Myron S., et al. Prevention of HIV-1 Infection with Early Antiretroviral Therapy. 2011 *New England Journal of Medicine* 493–505: V365, no 6, <http://www.nejm.org/doi/full/10.1056/NEJMoa1105243>.

³ CDC National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, February 14, 2017 (accessed online at: <https://www.cdc.gov/nchhstp/newsroom/2017/croi-hiv-incidence-press-release.html>).

⁴ CDC Fact Sheet, February, 2014, accessed online at: <http://www.cdc.gov/hiv/risk/raciaethnic/aa/facts/index.html>.

⁵ Bradley, H., et al. Ryan White HIV/AIDS Program Assistance and HIV Treatment Outcomes in the United States. CROI 2015. Abstract: 1064. Accessed online at: <http://www.croiconference.org/sessions/ryan-white-hiv-aids-program-assistance-and-hiv-treatment-outcomes-united-states>.

⁶ Based on data from Gilman BH, Green, JC. Understanding the variation in costs among HIV primary care providers. *AIDS Care*.2008;20:1050—6.

Training Program (\$34 million) and the Special Programs of National Significance (SPINS) Program (\$25 million). The AETC program undergirds the success of the Ryan White Program through HIV medical workforce education and capacity building, and the SPNS program supports the evaluation of innovative strategies for working with complex patient populations, such as effective models for addiction treatment in Ryan White clinical settings. Both components are integral to the success of the Ryan White Program and necessary for us to improve health outcomes for our most challenging patients.

CDC—National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP):

Tuberculosis causes more deaths than any other infectious disease, with 9.6 million new illnesses and 1.5 million deaths in 2014. Approximately 480,000 of those cases were multidrug-resistant tuberculosis, including 9.7 percent that were extensively drug-resistant. Sustained funding of at least \$157.3 million is necessary for TB, HIV and STD prevention and surveillance.

There are nearly 55,000 new hepatitis transmissions each year, and the CDC estimates that between 2010 and 2014 the country saw a more than 150 percent increase in new hepatitis infections. Similar to the factors that resulted in the 2015 HIV and hepatitis C (HCV) outbreak in Scott County, Indiana, these new hepatitis infections are largely driven by increases in injection drug use. Co-infection levels among people living with HIV and HCV are 25 percent and 10 percent among individuals with HIV and HBV. We request an increase of \$28.8 million above the fiscal year 2016 level, for a total of \$62.8 million for the CDC's Division of Viral Hepatitis. We also support sustained funding for HIV and STD prevention and surveillance, as well as the Division of Adolescent School Health (DASH).

We additionally urge the Committee to reject the administration's proposed cuts to global health programs which would jeopardize efforts to end HIV as a worldwide public health threat, diminish needed resources to address drug-resistant tuberculosis and endanger domestic health security by reducing resources to detect, prevent and respond to infectious disease threats where they originate. To the contrary, an increase of at least \$3.3 million is needed for the CDC's global HIV programs for a total of \$132 million in fiscal year 2018, which includes resources for the agency's essential role in implementing PEPFAR programs in developing nations.

NIH—Office of AIDS Research (OAR):

HIVMA strongly urges the Committee to reject the Administration's proposed \$7.2 billion cut to the National Institutes of Health (NIH), and instead support an overall fiscal year 2018 funding level of at least \$2 billion above the fiscal year 2017 appropriation for the NIH. The proposed cuts of \$1.24 billion to the National Institute of Allergy and Infectious Diseases and \$544 million to HIV/AIDS research supported by the Office of AIDS Research would deal a devastating blow to U.S. leadership in combatting HIV and other infectious disease threats, and must be rejected. To the contrary, consistent with the most recent Trans-NIH AIDS Research By-Pass Budget Estimate for fiscal year 2017, we ask that at least \$3.225 billion be allocated for HIV research at the NIH in fiscal year 2018, an increase of \$225 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 capacity to sustain our Nation's historic worldwide leadership in HIV/AIDS research and innovation, and discourage the next generation of scientists from entering the field.

We also strongly oppose the elimination of the Fogarty International Center that supports critical partnerships between US-based universities and international sites to help build local capacity to monitor and control infectious diseases in lower income countries. Ending this highly effective program would leave these countries ill equipped to continue to respond to HIV as well as to emerging outbreaks and deadly infections like Ebola and Zika that pose threats to the global community, including the United States.

The NIH-Wide Strategic Plan⁷ identifies criteria for setting the NIH's research priorities, including consideration of the value of permanently eradicating a disease. Such an investment makes good economic sense: every new case of HIV diagnosed in the United States translates into a lifetime cost of approximately \$350,000 for treatment with antiretroviral drugs. Getting to zero new cases of HIV/AIDS would

⁷ NIH-Wide Strategic Plan, fiscal years 2016–2020: Turning Discovery Into Health, (December, 2015).

save our Nation an estimated \$17.5 billion annually.⁸ In addition, HIV/AIDS research has contributed to the development of effective treatments for other diseases, including cancer and Alzheimer's disease. Congress should ensure our Nation does not delay vital HIV/AIDS research progress.

Continue Progress on Federal Funding for Syringe Exchange Programs:

HIVMA applauds the subcommittee's work in advancing report language that allows for the judicious use of Federal funding for syringe exchange programs (SEPs) as an important prevention and public health intervention. We support the continuation of this policy.

Conclusion:

We are at serious risk of losing ground against the HIV pandemic if we fail to prioritize HIV public health, treatment and research programs. We must fully leverage and invest in HIV prevention, care and treatment and research to save the lives of millions who are infected or at risk of infection here in the U.S. and around the globe, and ultimately to end the HIV/AIDS epidemic.

[This statement was submitted by Wendy Armstrong, MD, FIDSA, HIV Medicine Association.]

PREPARED STATEMENT OF RICHARD I. HOROWITZ, MD

Lyme Disease is the fastest growing vector-borne infectious disease in the United States, according to the Centers for Disease Control and Prevention (CDC), and causes both early and late disabling manifestations.^{1,2} Although sometimes thought of as just an "East Coast problem," Lyme disease and associated co-infections are now found in all 50 States and world-wide. A recent study released by the CDC³ identified a 320 percent increase in reported cases of Lyme disease in the north-eastern U.S., and in the north-central States for the same periods, the number of counties having high incidence increased by greater than 250 percent with Lyme moving "northward and southward." Their conclusion was that "relatively constant rates of geographic expansion (were happening) in all accessible directions."

World Health Organization (WHO) data suggest that every year brings millions of new infections. The CDC estimated more than 300,000 new infections per year, in the United States, just for Lyme—one of several tick-borne diseases.⁴ The CDC estimates do not consider those cases that are not reported or are misdiagnosed as other medical conditions. In 2012,⁵ an estimated 0.3 percent of the United States population were diagnosed in that year with Lyme disease—over 900,000 people. This is an important worldwide problem and challenge for the medical community since the symptoms of tick-borne illness often mimic those of other commonly reported diseases, that are diagnosed based on clinical criteria and not definitive laboratory testing. These include Fibromyalgia, and Chronic Fatigue Syndrome (Systemic Exertional Intolerance Disease) which affects 5 percent of the U.S. population, as well as Multiple Sclerosis, mental illness and many others.^{6,7,8} These diseases cost our healthcare system billions of dollars each year. Some of these diseases have been shown to be due to chronic tick-borne disease, and they are both emotionally

⁸Ibid, p. 32.

¹Hofhuis A, Harms M, Bennema S, van den Wijngaard CC, van Pelt W. Physician reported incidence of early and late Lyme borreliosis. *Parasit Vectors*. 2015;8: 161. doi:10.1186/s13071-015-0777-6.

²Newman EA, Eisen L, Eisen RJ, Fedorova N, Hasty JM, Vaughn C, et al. *Borrelia burgdorferi sensu lato* spirochetes in wild birds in Northwestern California: Associations with Ecological Factors, Bird Behavior and Tick Infestation. Stevenson B, editor. *PLOS ONE*. 2015;10: e0118146. doi:10.1371/journal.pone.0118146.

³Kugeler KJ, Farley GM, Forrester JD, Mead PS. Geographic distribution and expansion of human Lyme disease, United States. *Emerg Infect Dis*. 2015;21: 1455–1457. doi:10.3201/eid2108.141878.

⁴Centers for Disease Control and Prevention. How many people get Lyme disease? | Lyme Disease | CDC [Internet]. [cited 19 Aug 2016]. Available: <http://www.cdc.gov/lyme/stats/humancases.html>.

⁵Hook S, Nelson C, Mead P. Self-reported Lyme disease diagnosis, treatment, and recovery: Results from 2009, 2011, & 2012 HealthStyles nationwide surveys. 13th International Conference on Lyme Borreliosis and other Tick-Borne Diseases; 2013 Aug 19; Boston, MA.

⁶Fallon BA, Levin ES, Schweitzer PJ, Hardesty D. Inflammation and central nervous system Lyme disease. *Neurobiol Dis*. 2010;37: 534–541. doi:10.1016/j.nbd.2009.11.016.

⁷Gaudino EA, Coyle PK, Krupp LB. Post-Lyme syndrome and chronic fatigue syndrome. Neuropsychiatric similarities and differences. *Arch Neurol*. 1997;54: 1372–1376.

⁸Pachner AR. Neurologic manifestations of Lyme disease, the new "great imitator." *Rev Infect Dis*. 1989;11 Suppl 6: S1482–1486.

and financially devastating to individuals and families and to the productivity of our country. In 2012, approximately half of all adults (49.8 percent, 117 million) had at least 1 of 10 selected chronic conditions, 24.3 percent had 1 chronic condition, 13.8 percent had 2 conditions, and 11.7 percent had 3 or more conditions. These chronic diseases cost the U.S. more than \$2.5 trillion each year.⁹

I therefore believe we need to change the current diagnostic paradigm of how healthcare is practiced and devote more money to research to solve the challenges of Lyme and associated tick-borne illness. Per the National Census Bureau, 19 percent of Americans are disabled, and the present healthcare model often treats end stage manifestations, without addressing underlying etiologies. I have seen over 12,000 Lyme patients fail the traditional healthcare system, and have identified up to 16 reasons why they remain chronically ill. I call this syndrome “Multiple Systemic Infectious Disease Syndrome” (MSIDS). The first point on the MSIDS map is infections. Ticks are now containing multiple bacterial, viral and parasitic infections which can be transmitted simultaneously with *Borrelia burgdorferi*, the agent of Lyme disease. Patients infected with Lyme disease and associated co-infections are much sicker and resistant to standard therapies. Patients with Lyme-MSIDS also have evidence of associated immune dysfunction, inflammation, environmental toxins and detoxification problems. These factors can keep the patient chronically ill, yet they are not regularly accounted for in the healthcare model used by insurers. Some of these infections are also now in the blood supply, and these infections can be transmitted from mother to fetus adversely affecting the future generations of America. Emerging scientific research has shown that chronic infections like Lyme disease which are part of the MSIDS model are contributing to the rise in many chronic illnesses, including Alzheimer’s disease and Autism, costing our healthcare system billions of dollars. There is a commonly held belief in medicine, called Pasteur’s postulate that there is “one cause for one illness”. Improved prevention and “personalized medicine” which uses a multifactorial model to address underlying etiologies responsible for chronic disease must be part of the paradigm shift needed in medicine if we are to effectively address disability from these illnesses with rising healthcare costs. We therefore need to put more financial resources into prevention, better diagnostics and treatment.

PREVENTION

Although Lyme disease is identified as a top priority in CDC’s strategic plan, investment in preventing tick-borne diseases has remained minimal. Funding for CDC’s Lyme disease program averages just \$10 million dollars per year. With each case of Lyme disease costing approximately \$11,000 in direct and indirect costs, investments in prevention via cost-effective integrated pest management techniques can pay off many times over. Reducing tick populations and reducing the ability of ticks and “reservoir hosts,” such as the White Footed Mouse, to transmit disease can help prevent all types of tick-borne diseases.

DIAGNOSTICS

A key challenge in the diagnosis and treatment of Lyme disease stems from the lack of sensitive and reliable markers of the disease. Based on currently available tests, it is difficult to determine who has the disease, the effectiveness of treatment, and the end point of treatment. False seronegativity has been extensively reported in the peer review medical literature.^{10,11,12} Even the FDA has stated “. . . a patient with active Lyme disease may have a negative test result.”¹³

The CDC-sanctioned two-tier test (ELISA and Western Blot) is an indirect assay that measures the immune response but does not confirm the presence of an infection. A 2016 systematic meta-analysis of 20 years of published data showed a mean

⁹Ward BW, Schiller JS, Goodman RA. Multiple Chronic Conditions Among U.S. Adults: A 2012 Update. *Prev Chronic Dis* 2014;11:130389. doi: <http://dx.doi.org/10.5888/pcd11.130389>.

¹⁰Steere AC. Seronegative Lyme disease. *JAMA*. 1993 Sep 15;270(11):1369.

¹¹Kaiser R. False-negative serology in patients with neuroborreliosis and the value of employing of different borrelial strains in serological assays. *J Med Microbiol*. 2000.

¹²Schutzer SE, Coyle PK, Belman AL, Golightly MG, Drulle J. Sequestration of antibody to *Borrelia burgdorferi* in immune complexes in seronegative Lyme disease. *Lancet*. 1990 Feb 10;335(8685):312–5.

¹³Brown SL, Hansen SL, Langone JJ. (FDA Medical Bulletin) Role of serology in the diagnosis of Lyme disease. *JAMA*. 1999 Jul 7;282(1):62–6.

sensitivity of only 59.5 percent.¹⁴ By comparison, the sensitivity for the HIV/AIDS antibody test is greater than 99 percent. Undiagnosed and untreated Lyme disease patients represent an enormous social and economic burden with lifelong costs for unemployment, Medicaid, Medicare, disability, and welfare for people who can no longer work or manage everyday activities.

TREATMENT

According to research by the Johns Hopkins Bloomberg School of Public Health, treatment regimens endorsed by CDC leave up to 36 percent of patients with persistent symptoms.¹⁵ We know that short term antibiotics fail in 25–71 percent of patients with late stage disease^{16,17} and frequent treatment relapses and failures with short term therapy are documented by other authors, such as Logigian (1990), Pfister (1991), Shadick (1994), and Asch (1994), where 28 percent of patients relapsed with major organ involvement 3.2 years after the initial treatment. We desperately need more funding to develop more effective treatments.

Undiagnosed and untreated Lyme disease patients represent an enormous social and economic burden with lifelong costs for unemployment, Medicaid, Medicare, disability, and welfare for people who can no longer work or manage everyday activities. A study by LymeDisease.org published in the March 2014 issue of *PeerJ*,¹⁸ an open-access medical journal, found that Lyme patients reported a poorer quality of life than patients with other chronic diseases, including congestive heart failure, diabetes, multiple sclerosis, and arthritis. Fair or poor health was reported by 73 percent of patients with chronic Lyme disease compared to 16 percent of the general population.

RESEARCH FUNDING

In 2015 alone, the estimated annual U.S. direct and indirect medical costs, lost income and tax revenue from 380,690 new cases of Lyme disease at \$10,817 per case, totaled more than \$4.1 billion. Lyme disease can cause lifelong, debilitating effects in humans and animals, and in some cases, death from direct and indirect health impacts. If additional tick-borne diseases including Babesia, Anaplasmosis, and Rocky Mountain Spotted Fever are considered, the number of cases and costs increases significantly. When misdiagnosis and underreporting are factored in, the economic burden of this epidemic is likely to be much greater as undiagnosed and untreated patients advance to the costly specialties of neurology, rheumatology, orthopedics, and cardiology.

Fiscal year 2015 NIH funding for Lyme disease was just \$24 million—barely 1 percent of the \$2 billion of NIH funding for emerging infectious diseases, despite the number of new cases of Lyme annually being many times greater than any other disease in that category. With 380,690 new cases in 2015, according to CDC estimates, this works out to just \$63 per case. By comparison, West Nile virus, with only 2,175 cases, received \$40 million, or \$18,391 per case.

Without a major investment in cost-effective, long-term solutions tick-borne diseases will continue to spread and costs will continue to increase. Funding commensurate with the magnitude of the epidemic and assurance that a preponderance of grant awards will be based on tangible benefits to patients is the surest way reduce the burden of illness on patients and the growing costs to our economy.

Especially in this time of rising healthcare costs, to reduce debt, we must examine where our healthcare dollars go. Chronic illness accounts for 87 percent of our healthcare costs and 70 percent of the deaths in America. We must address rising rates of emerging chronic illnesses which cost the healthcare system billions of dollars every year if we are to solve the bigger healthcare dilemma. Inadequate diagnostic testing for Lyme and associated tick-borne diseases, and lack of timely treat-

¹⁴ Cook M, Puri B. Commercial test kits for detection of Lyme borreliosis: A meta-analysis of test accuracy. *International Journal of General Medicine*. 2016; Volume 9:427–440. www.ncbi.nlm.nih.gov/pubmed/27920571.

¹⁵ Adrion ER, Aucott J, Lemke KW, Weiner JP (2015) Health Care Costs, Utilization and Patterns of Care following Lyme Disease. *PLoS ONE* 10(2): e0116767. <https://doi.org/10.1371/journal.pone.0116767>

¹⁶ Berglund J, Stjernberg L, Ornstein K, Tykesson-Joelsson K, Walter H. 5-y Follow-up study of patients with neuroborreliosis. *Scand J Infect Dis*. 2002;34(6):421–5.

¹⁷ Valesová H, Mailer J, Havlík J, Hulinská D, Hercogová J. Long-term results in patients with Lyme arthritis following treatment with ceftriaxone. *Infection*. 1996 Jan-Feb;24(1):98–102.

¹⁸ Johnson L, Wilcox S, Mankoff J, Stricker RB. (2014) Severity of chronic Lyme disease compared to other chronic conditions: a quality of life survey. *PeerJ* 2:e322 <https://doi.org/10.7717/peerj.322>.

ments result in increased healthcare costs, long term disability, with loss of jobs and financial security for families impacted.

There are many challenges to address the new paradigm of multi-system, chronic infectious diseases, and a long term, comprehensive approach will be required. This will not be an easy undertaking and we can expect significant resistance to the required changes in thinking, practices and policies, although potential savings will dramatically reduce healthcare and disability costs and provide relief from the suffering and hardship faced by these patients.

Key challenges that Congress can address now, include ensuring that funding for Lyme disease and other tick-borne diseases is commensurate to the magnitude and severity of the epidemic and making improving prevention, diagnostics and treatments top priorities, as discussed above. The payoff will be significantly reduced healthcare costs in return for a modest investment in resources.

Thank you for your time and attention to these matters.

Very truly yours.

[This statement was submitted by Richard I. Horowitz, MD, Hudson Valley Healing Arts Center.]

PREPARED STATEMENT OF THE INFECTIOUS DISEASES SOCIETY OF AMERICA

On behalf of the Infectious Diseases Society of America (IDSA), which represents more than 10,000 physicians and scientists involved in infectious disease prevention, care, research and education, I urge the Subcommittee to reject Trump administration's proposed budget for fiscal year 2018 as short-sighted and weakening public's health with great potential for worsening the Nation's budget. HHS agencies and programs currently contribute to the prevention, the detection and the treatment of infectious diseases (ID) that are more critical than ever before. IDSA urges the Subcommittee to provide robust fiscal year 2018 funding for public health and biomedical research activities that ultimately save lives, contain healthcare costs and promote economic growth. IDSA encourages the Subcommittee to provide \$7.8 billion for the Centers for Disease Control and Prevention (CDC) and at least \$36.2 billion for the National Institutes of Health (NIH).

IDSA members see the impact on a daily basis that antimicrobial resistance (AR) has on patients. This public health threat continues to worsen. Only with dedicated and substantial resources dedicated to AR can headway be made. We have strongly advocated for the implementation of a comprehensive Federal response to AR. We ask Congress to sustain investments initiated in fiscal year 2016 to confront this threat. Those activities include prevention, surveillance and antibiotic stewardship efforts as well as research and development (R&D) activities across Federal agencies.

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 March 2016, the Presidential Advisory Council on Combating Antibiotic-Resistant Bacteria (PACCARB) released a draft of its Initial Assessments of the National Action Plan for Combating Antibiotic-Resistant Bacteria stating: "Combating [antimicrobial resistance] requires an adequate resource base to slow down, control, and hopefully reverse the problem. Simply stated, the USG [U.S. Government] must commit sufficient resources to solving the problem with funding continued over a long period of time." IDSA urges the Subcommittee to increase support for the CDC Antibiotic Resistance Solutions Initiative. We ask that the final fiscal year 2018 Labor-HHS-Education Appropriations bill also support AR activities carried out by the NIH, Biomedical Advanced Research and Development Authority (BARDA) and the Agency for Healthcare Research and Quality (AHRQ).

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 confronting emerging public health threats such as the Zika virus. The fiscal year 2018 administration budget proposal would drastically cut funding for the Center by \$70 million dollars, given this critical work. We ask that NCEZID be funded at \$629.5 million.

We recommend \$200 million for the Antibiotic Resistance Solutions Initiative. The fiscal year 2018 administration budget proposal would reduce funding for the Initiative, shifting this funding to the Prevention and Public Health Fund (PPHF) that the Administration and Congress are seeking to repeal. This threatens recent progress toward prevention and detection of infections resistant to currently avail-

able treatments. The requested fiscal year 2018 funding would allow CDC to expand Healthcare-Associated Infections (HAI)/AR prevention efforts from 25 States to the full 50 States including six large cities and Puerto Rico. The CDC projects that over 5 years the initiative will lead to a 60 percent decline in health-care associated carbapenem-resistant Enterobacteriaceae (CRE), a 50 percent reduction in *Clostridium difficile*, a 50 percent decline in bloodstream methicillin-resistant *Staphylococcus aureus* (MRSA), 35 percent decline in health-care 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 recouping the direct costs of the program.

IDSA also supports funding at least \$21 million for the National Healthcare Safety Network (NHSN). This surveillance information provided to the NHSN is critical to gauge whether interventions designed to reduce inappropriate antibiotic use and limit the development of resistance in fact succeed. These funds mean a net increase the number of participating healthcare facilities from 19,000 to as many as 20,000 within the year. Funding for NHSN will also grow the number of sites reporting antibiotic data from 130 in 30 States to 750 in all 50 States.

IDSA recommends at least \$30 million be allocated for the Advanced Molecular Detection (AMD) initiative in fiscal year 2018. This funding will allow the CDC to rapidly determine three key pieces: where emerging diseases occur, whether these microbes are antibiotic resistant and how microbes spread through human and animal populations. During the 2014/2015 Ebola outbreak, such innovative AMD techniques allowed health authorities to understand if the virus was changing as it spread through different populations. These characteristic signals greatly facilitated responses that lead to ending the epidemic by intervening more precisely in specific locations.

CDC Global Health Programs

Proposed cuts to the CDC global health programs (\$78 million, fiscal year 2018) 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 abilities to detect, prevent and respond to infectious disease threats. IDSA urges the Subcommittee to increase, rather than diminish this investment in global health activities in fiscal year 2018. By including at least \$128 million for the Global AIDS Program, critical work toward the goal of the US investment in PEPFAR can continue leading to eliminating HIV as a global public health threat.

IDSA supports continued implementation of the CDC Global Health Security Agenda that advances efforts by the U.S. and partner nations to prevent, detect and slow the spread of infectious diseases across borders. CDC plays a central role in responding to new outbreaks such as the current Ebola virus outbreak in the Democratic Republic of Congo and the international Zika virus outbreaks across 2015/2016. The spread of Zika through South America, Central America and Caribbean to the mainland U.S. is only the most recent illustration that infectious diseases are not constrained by national borders. The CDC must be appropriately funded to maintain readiness to address future crises. Such funding should be increased to enhance international surveillance, laboratory diagnostic capacity and healthcare provider training. More funding for research and development to build medical countermeasures including vaccines and diagnostics is of critical importance—not reduced as proposed by the Administration’s budget.

IDSA also encourages the Subcommittee to increase research, monitoring, and evaluation efforts for malaria and neglected tropical diseases. Zika and Chikungunya infections, as well as Chagas disease and dengue fever have been reported in the United States. At least 40 percent of the world’s population is at risk for serious illness and death from mosquito-borne viral diseases.

National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP)

Despite a common misperception as a conquered disease, tuberculosis now causes more deaths than any other single infectious disease agent worldwide with 9.6 million new illnesses and 1.5 million deaths in 2014. Approximately 480,000 of those cases were caused by multidrug-resistant (MDR) tuberculosis, including 9.7 percent that were extensively drug-resistant (XDR) the most feared and fatal form.

IDSA recommends an increase of \$63 million for NCHHSTP to enhance responses to the viral hepatitis epidemic fueled by the injection drug use epidemic associated with opioid addiction. We also urge \$157 million for sexually transmitted disease (STD) efforts, \$243 million for TB prevention and surveillance activities, and \$822.7 million for HIV prevention efforts. Funding to address STDs is essential, as many

communities are experiencing a surge in syphilis rates, exacerbated by a shortage of bicillin—the antibiotic used to treat syphilis.

National Center for Immunization and Respiratory Diseases

Immunizations are among the most cost-effective clinical preventive services, but national adult immunization rates remain low for most recommended vaccines. Each year in the U.S., tens of thousands of adults die from illnesses that are preventable through vaccination. Diseases that include measles are a re-emerging problem, as childhood vaccination rates dip too low in some communities to provide effective herd immunity—as witnessed by the Minnesota measles outbreak. Additionally, vaccine-preventable diseases and their complications result in billions of dollars annually in direct and indirect healthcare costs. IDSA asks that the CDC Immunization Grant Program (Section 317) be funded at least at the fiscal year 2016 level of \$610 million.

IDSA recommends that the Subcommittee provide at least \$188 million for CDC efforts to control influenza. CDC plays a critical role in seasonal and pandemic influenza preparedness and response, including conducting surveillance activities that inform response efforts and providing public communications regarding influenza prevention and treatment.

NATIONAL INSTITUTES OF HEALTH

National Institute of Allergy and Infectious Diseases (NIAID)

Within NIH, NIAID should be funded at least at \$4.961 billion as approved by the Senate Appropriations Committee for fiscal year 2017. Further, we believe that NIAID should be provided an increase that is proportionate to any increase provided to the NIH as a whole. The NIAID plays a leading role in research for new rapid ID diagnostics, vaccines and therapeutics. The January 2015 IDSA report, *Better Tests, Better Care: The Promise of Next Generation Diagnostics* explains that advances in biomedical research have created the potential for increasingly simple, fast and reliable diagnostic tests for infectious diseases. By allowing physicians to quickly distinguish between bacterial and viral infections, such better diagnostics can lead to faster and targeted treatments for patients that help preserve the usefulness of our existing anti-infective drugs. Last year, NIAID awarded more than \$11 million in first-year funding for research to develop diagnostics to rapidly detect antibiotic-resistant bacteria. NIAID also recently announced awards of approximately \$5 million for non-traditional alternatives to antibiotics. These efforts as well as research on new antimicrobials and vaccines are set to ramp up with the \$100 million increase made last year. We ask that the Subcommittee continue this work in fiscal year 2018.

The Antibacterial Resistance Leadership Group (ARLG), led by researchers at Duke University and the University of California San Francisco, is an example of extramural research to address AR made possible by NIAID. The ARLG manages a clinical research agenda to increase knowledge of antibacterial resistance. The ARLG has supported early clinical research on new antibacterials as well as on diagnostics that rapidly identify resistant bacteria. Continued operation of the ARLG depends on support from the NIAID.

Fogarty International Center

IDSA is grateful for the Subcommittee's longstanding support for the Center. IDSA opposes the administration's proposed elimination of the Fogarty Center. We urge funding a minimum of \$72 million for the Center in fiscal year 2018, at least level with fiscal year 2017 funding. The program's elimination would come at a cost 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.

Office of AIDS Research

Federal investments in HIV/AIDS research have extended and save lives of people around the world. Continued investment in HIV/AIDS research through NIH is critically important. We urge the Subcommittee to provide at least \$3.45 billion for the Office of AIDS Research (OAR). The level-funding of HIV/AIDS research since 2015 threatens work towards a vaccine and discourages new investigators from entering the field.

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. PCAST has identified BARDA as best positioned to elicit private investments necessary to address antibiotic resistance. IDSA recommends that the Subcommittee provide \$520 million for BARDA in fiscal year 2018. Such funding is necessary to allow BARDA to pursue additional work on antibiotic development while maintaining its strong focus on other medical countermeasures to address biotreatments.

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.

We also request that in any final version of fiscal year 2018 appropriations language, you strongly urge BARDA to include TB in their new and emerging infectious disease efforts and invest in the development of new TB diagnostics, drugs and vaccines as part of the CARB initiative and the Emerging Infectious Diseases program at BARDA.

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. More than 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 E&M work. ID physicians often care for patients with chronic illnesses, including HIV, hepatitis C, and recurrent infections. Such care involves preventing complications and exploring complicated diagnostic and therapeutic pathways. ID physicians also conduct significant post-visit work including care coordination, patient counseling and other necessary follow up.

New research is needed to better identify and quantify the inputs that accurately capture the elements of complex medical decisionmaking. Such studies should take into account the evolving healthcare delivery models with growing reliance on team-based care, and should consider patient risk-adjustment as a component to determining complexity. Research activities should include the direct involvement of physicians who primarily provide cognitive care. We urge the Subcommittee to include report language in the fiscal year 2018 funding bill asking that “CMS undertake research necessary to develop new E&M codes and accompanying documentation requirements that more precisely describe the cognitive work in these physician-patient encounters, and that the results of such research be made publicly available no later than 2 years after the passage of this Act.” We are grateful that the Subcommittee included similar language in the fiscal year 2017 omnibus bill and we are making this request in fiscal year 2018 to ensure appropriate oversight of CMS regarding this issue.

Thank you for the opportunity to submit this statement on behalf of the Nation’s ID physicians and scientists. We rely on strong Federal partnerships to keep Americans healthy and urge you to support these efforts.

[This statement was submitted by William G. Powderly, MD, FIDSA, President, Infectious Diseases Society of America.]

PREPARED STATEMENT OF THE INTERSTITIAL CYSTITIS ASSOCIATION

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2018

-
- 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 \$36 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
-

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 im-

proving 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.

In December 2014, CDC switched the focus of the IC program from education and awareness to an epidemiology study. The IC community is concerned that eliminating 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 2018.

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 \$36 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 expanded in its second phase 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). Additionally, the NIH investigator-initiated research portfolio continues to be an important mechanism for IC researchers to create new avenues for interdisciplinary research. Recently representatives from ICA met with the leadership of NIDDK and MAPP to discuss the current state of research and how to advance research, with a goal to work towards a comprehensive State of the Science Conference to bring together all of the stakeholders in the pelvic community to discuss emerging opportunities for collaboration and how to encourage new investigators to apply for grants.

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 IPM INSTITUTE OF NORTH AMERICA

Recent dramatic increases in tick populations and tick-borne diseases and costs demand immediate action to increase resources for prevention and research. Investment to develop cost-effective, long-term solutions must be commensurate with the level of tick-borne disease—currently the investment falls far short of the costs.

To combat the increases in tick populations, tick-borne diseases and their associated costs, collaboration between the HHS, including the Centers for Disease Control (CDC) and National Institutes of Health (NIH), USDA, including the National Institute of Food and Agriculture (NIFA), and mosquito control districts to implement Integrated Tick Management (ITM) is essential.

Dr. Kirby Stafford, medical entomologist with the Connecticut Agricultural Experiment Station, defines ITM as involving the selection, integration, and implementation of several pest control actions based on predicted ecological, economic, and sociological consequences. ITM includes a variety of strategies including habitat modification, personal tick checks after visiting tick habitat, alternate host management, pesticides and treated clothing to maximize effectiveness and reduce impacts on health and environment. ITM aims for cost-effective combinations of tick prevention strategies to reduce the incidence of tick-borne diseases while minimizing impacts of tick management interventions on human health and the environment. ITM can be targeted to high-risk sites including parks, schools and other high-traffic areas to increase cost-effectiveness.

Without greater investment and collaboration to reduce tick populations and to block the potential for ticks to transmit pathogens, the number of cases of tick-borne diseases and costs will continue to increase. A greater investment in ITM solutions provides an opportunity to improve human, livestock and domestic animal health, and save taxpayer dollars.

In 2015 alone, the estimated annual US direct and indirect medical costs, lost income and tax revenue from 380,690 new cases of Lyme disease at \$10,817 per case, totaled more than \$4.1 billion. Lyme disease can cause lifelong, debilitating effects in humans and animals, and in some cases, death from direct and indirect health impacts.

If additional tick-borne diseases including babesia, anaplasmosis, tularemia and Rocky Mountain spotted fever are considered, the number of cases and costs increases by 30 percent to an estimated \$5.4 billion annually. Tick-borne diseases in humans are increasing in number of diseases, cases and geographic distribution in the US. Without a serious investment in cost-effective, long-term solutions to reduce

tick populations, tick-borne diseases will continue to spread and costs on the population's health and wallets will only increase.

Given these tremendous costs and impacts on human lives, resources for tick-borne disease prevention and research must be elevated to a level commensurate with other diseases. For example, in 2012 the NIH invested \$112 million in hepatitis C with 1300 new cases annually, or \$86,154 per new case. Similarly, there was an investment of \$29 million compared to 5700 new cases of West Nile virus, or \$5087 per new case. In comparison, only \$25 million was invested vs. 312,000 new cases of Lyme disease, which is only \$80 per new case. As Lyme disease cases rose in 2013, the NIH reduced funding to \$20 million. The investments to reduce Hepatitis C and West Nile virus have been effective and provide evidence that commensurate funding would mitigate tick-borne disease.

Although tick-borne diseases have been identified as a top priority in the CDC strategic plan, investment in reducing tick populations has remained minimal. The total 2016 CDC funding line for Lyme disease was approximately \$10.6 million dollars.

In particular, more resources for prevention are critically needed. All Federal agency funding allocation from 2006–2010 for tick-borne disease studies totaled \$368,103,780. Only 2 percent (\$7,362,075) of that funding supported tick surveillance and environmental factors, and only 3 percent (\$11,043,113) of that funding for tick-borne disease studies supported research on ticks.

For investments to effectively reduce tick-borne diseases collaboration between HHS, USDA and mosquito control districts is essential. Mosquito control districts provide an established local vector control network. CDC and NIH must work with USDA including NIFA to maximize use of the Extension education network to increase awareness and adoption of effective tick-bite prevention strategies by the public. The Extension audience includes key stakeholders such as Master Gardeners, pesticide applicators in mosquito abatement, landscape service providers and structural pest management providers. A multi-agency and government level approach will be most effective in combating the complex issue of tick-borne diseases.

At the 2016 ITM Symposium, Dr. Ben Beard, chief of the Bacterial Diseases Branch of the CDC, noted three conclusions:

1. Safe and effective prevention tools are badly needed.
2. Effective prevention requires cooperation and collaboration involving multiple partners.
3. Greater emphasis must be placed on a national strategy or plan AND on the cost savings associated with disease prevention.

Finding, verifying and implementing ITM strategies takes time and funding which will be best facilitated via coordinated collaboration.

Barriers for implementation of ITM practices include a general lack of awareness of ITM as a cost-effective approach for prevention and a lack of public and health professional literacy on tick identification, lifecycle, population distribution and tick-borne disease risks and symptoms. A unified national strategy is urgently needed including the following elements:

- Strengthen national surveillance, understand disease risk and burden.
- Increase tick-borne disease research funding which specifically addresses the reduction of the tick population.
- Identify, develop and evaluate prevention and control practices.
- Improve early and accurate diagnosis and treatment.
- Identify, characterize, and prevent illness caused by new *Borrelia* species (the bacteria that cause Lyme disease).
- Collaborate with key partners to promote the use of effective prevention tools and strategies.

Increasing the use and investigation of ITM approaches facilitates all of these conclusions.

Research by Dr. Steve Meshnick, professor and associate chair, Department of Epidemiology, University of North Carolina, indicates permethrin-impregnated clothing protects against tick bites for at least 1 year and should be recommended to those at high risk of tick-borne disease. However, better insights into what factors affect durability of protection are still needed. Additionally, alternatives to permethrin need to be evaluated for effectiveness and cost. This is one of many examples where further research must be done to increase widespread adoption of a tick prevention strategy.

ITM strategies focus on combining practices to maximize tick control efficiency. Habitat management, similarly to regular personal tick checks, is an easily implemented practice that can increase the effectiveness of other tick control treatments. According to Dr. Charles Lubelczyk, field biologist, Maine Medical Center Research

Institute, proper habitat management alone represents a temporary success by reducing nymphal stage ticks. However, when combined with other ITM tools, habitat management can be very effective in reducing tick populations. For example, clearing brush may increase tick exposure to chemical treatments and widening public access trails can provide outreach and education opportunities. Habitat management works as part of a system approach to reducing tick-borne disease incidence.

An ITM approach promotes the use and combination of least-risk, cost-effective solutions. Dr. Andrew Li, research entomologist for the USDA, is currently researching the efficacy of combining three tick reduction strategies: two different host-targeted strategies (deer and mice) and a perimeter pesticide spray. The study is designed to document the impact of using multiple strategies, either separately or in combination, to reduce the tick population and Lyme infection rate.

At the 2016 ITM Symposium, Dr. Alison Hinckley, epidemiologist with the CDC, presented on the limitations to relying on single tick reduction strategies and called for additional research on the connection between tick abundance and human exposure to tick-borne pathogens. Dr. Hinckley's research tested the use of a residential pesticide barrier spray. An immediate limitation of using pesticide barrier sprays is that many of the most effective sprays cannot be used around water ecosystems. Many potential properties are too close to water to use this prevention strategy.

Along with Dr. Hinckley, Dr. Stafford also specified that there are many tools available for killing ticks, but that killing ticks in a backyard doesn't necessarily equate to reducing risk of illness. Dr. Stafford's presentation at the 2016 ITM Symposium included the following:

- Safe, effective and affordable prevention tools and ITM data are badly needed;
- In the absence of a human vaccine, the best solutions will probably be ITM methods evaluated across a variety of local settings.

The objective of ITM is to reduce pest level (or pathogen prevalence) below the economic injury level, which is when the financial losses exceed the cost of control (cost-benefit analysis).

Tick-borne disease incidence has doubled since 2003 and tripled since 1995, the costs associated with these increases require immediate action to grow prevention and research resources. To develop long-term, safe and cost-effective solutions a level of investment must adequately meet the level of tick-borne disease. To efficiently combat tick-borne disease, collaboration between HHS, including CDC and NIH, USDA, including NIFA, and the county mosquito control districts, is needed. We urge Congress to increase the investment in ITM prevention strategies and to direct these entities to work together. Without an increase in investment and collaboration, tick-borne diseases and the associated costs will continue to increase. ITM offers an opportunity to save money and improve human health outcomes.

Thank you.

[This statement was submitted by Thomas A. Green, Ph.D., Frank Laufenberg, IPM Institute of North America, Inc.]

PREPARED STATEMENT OF THE JAMESTOWN S'KLALLAM TRIBE

Chairman Blunt, Ranking Member Murray and distinguished members of this Subcommittee, on behalf of the Jamestown S'Klallam Tribe, I would like to thank you for this opportunity to submit written testimony on our funding priorities and recommendations for the fiscal year 2018 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). This commitment includes the provision of social, medical and educational services in exchange for vast tracts of Tribal lands. Despite these unfulfilled Federal obligations, Tribal Governments, through Self-Governance and the Indian Health Care Improvement Act (IHCIA) have been able to maximize the Federal dollar through the redesign of programs and services to better address local needs and Tribally-driven priorities. However, an unbalanced approach to deficit spending, budgetary reductions to non-defense discretionary programs, delayed passage of spending bills, recent fluctuations in Federal funding, significant funding disparities, sequestration, and the government-wide shut-down have all severely impacted our ability to maximize funding to effectively and efficiently meet the basic needs of our Tribal communities and citizens and solidify our partnerships with our local surrounding communities.

Investment in Indian country holds tremendous economic potential not just for our Tribal citizens but for the local communities that surround our community. When you invest in Tribes, you invest in local and regional economies, healthcare and education. 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.

Finally, Tribal access to health and educational programs is not just the responsibility of IHS or BIE. The Federal Governments trust responsibility extends to every Federal department and agency. Funding from other Health and Human Services (HHS) agencies is often used to supplement underfunded IHS resources for Tribal healthcare and to address public health initiatives, including, prevention, education, research and the promotion of healthy lifestyles. Our communities are more vulnerable to health risks and disease due to the lack of resources. In addition, 93 percent of our students currently attend public schools. The Department of Education, not the BIE, provides funding for our Native children’s public school education. To that end, Tribes support increased funding and specific Tribal set asides for programs that serve Tribes within other departments and agencies.

TRIBAL SPECIFIC HEALTH & EDUCATION APPROPRIATION PRIORITIES

1. Fund Medicare/Medicaid Expansion

REGIONAL/NATIONAL HEALTH & EDUCATION APPROPRIATION PRIORITIES

Our Budget Request endorses the requests of the Northwest Portland Area Indian Health Board; the Affiliated Tribes of Northwest Indians; the Self-Governance Communication and Education Tribal Consortium; the National Indian Health Board; the National Indian Education Association and the National Congress of American Indians.

NATIONAL HEALTH & EDUCATION APPROPRIATION PRIORITIES

Tribal Childcare and Development Fund	\$9.54 billion
Child Welfare Programs (Title IV—B, Subpart 1 & Subpart 2)	\$280 million/\$70 million
Older Americans Act Title VI	\$30 million
4. Alcohol and Substance Abuse Treatment	\$163.6 million
ESSA Title VII Impact Aid	\$2 billion

TRIBAL SPECIFIC PRIORITIES

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 2014 data. These disparities not only affect AI/ANs, but also impact the quality of care and healthcare improvements for the broader population resulting in higher healthcare costs and economic losses related to worker productivity. Medicare/Medicaid has allowed our Tribe to partner with our local communities to provide much needed healthcare services to veterans and 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.

NATIONAL HEALTH AND EDUCATION APPROPRIATION PRIORITIES

\$9.54 Billion—Tribal Child Care and Development Fund

Jamestown’s mission is to assist our Tribal citizens as they strive to achieve economic security and self-sufficiency. We believe this goal can be accomplished through the provision of opportunities that promote employment and education. A significant challenge to Tribal citizens becoming contributing members of our community and part of a productive workforce is the fact that the Tribe is located in a rural area with limited and cost prohibitive day care options. The Tribal Child Care and Development Fund has enabled us to address this issue through the provi-

sion of financial support for childcare services. Effective programs such as this are critical to creating pathways to careers and skilled employment for our Tribal citizens.

\$280 Million—Child Welfare Programs Title IV B (subpart 1) &

\$70 Million—Promoting Safe and Stable Families Title IV B (subpart 2)

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 parenting classes, conduct home visits, and address 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.

\$30 Million—Older Americans Act

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. 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.

\$163.6 Million—Alcohol and Substance Abuse Treatment

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.

\$2 Billion—ESSA Title VII Impact Aid

Education is of high importance to the Tribe and continued and increased funding for ESSA Title VII is needed to not only ensure the success of our students and future leaders but to secure the welfare and vitality of our Tribal community. Currently, 93 percent of Native students are enrolled in local public schools. Impact Aid provides essential funding to schools serving Native students.

Thank you for this opportunity to submit this important testimony for the hearing record.

[This statement was submitted by Hon. W. Ron Allen, Tribal Chairman/CEO, Jamestown S'Klallam Tribe.]

PREPARED STATEMENT OF LAMBS FOR LIFE

“Mommy, my head hurts.”

That’s how it all started. Alex, whose nickname was Smiles, never complained. If he said his head hurt then it must really hurt, and it was hurting every single day. Four weeks and three doctors later, a simple blood test immediately revealed everything. Alex was having headaches because his red blood cell count was depleted so his brain swelled and hurt from hypoxia (low oxygen saturation). The simple test also revealed Alex had insufficient normal white blood cells, replaced by a population of BLAST cells (leukemic cancer cells). Alex would become the boy in the plastic bubble but without the bubble. The bruises we thought were from playing soccer were from Alex’s lack of platelets.

Alex’s bone marrow was no longer producing healthy red blood cells, white blood cells or platelets. It was producing cancer cells. Although he appeared healthy, he was in an extremely fragile state and had to be hospitalized immediately. The pediatrician called to notify us of the blood test results and to tell us to immediately travel to Savannah, Ga (an hour away) to the children’s hospital where a team

would be waiting for us. When we arrived, the childhood cancer rollercoaster ride began. Alex immediately received a blood transfusion and, within minutes of arriving, we were told that our 9-year old son had cancer—AML (Acute Myeloid Leukemia), a very aggressive form of Leukemia. We were advised that he was too fragile and unstable to move anywhere for a second opinion and no visitors other than parents were permitted—not even his siblings.

How was this possible? He looked great. He was at school the day before, running around with his friends. A clinical trial composed of a combination of old adult drugs was the best treatment option they had for Alex. Through the Children's Oncology Group network, Alex was essentially being cared for by all the doctors in the network. We had the head of Pediatric Oncology in Atlanta, the leading expert in AML in the country, consulting on Alex's case. Despite those overwhelming resources, Alex's care was incredibly inferior to the care and treatment for the average adult with cancer.

The doctors and nurses struggled to save Alex throughout his 14-month ordeal, but the total lack of child specific treatment options forced doctors to treat Alex as a small adult. Within 48 hours after he was finally declared cancer free, Alex died at age 10 from the toxic effects of the drugs. In the final months, Alex experienced life threatening side effects, including cardiac arrest, pulmonary failure, and kidney failure. His quality of life was greatly diminished and he was in constant pain. Blood transfusions were part of Alex's daily routine, as was some type of organ failure or a life threatening infection. Each day brought new health challenges for Alex. Every moment and every breath was a struggle.

The state of childhood cancer is not what most people perceive it to be. Anyone who has seen a child fight cancer is forever changed. Alex's struggle is commonplace in the world of childhood cancer. Children with cancer are cared for by experienced pediatric oncologists and pediatric oncology nurses, but the available treatment options are not designed for children. They are adapted for children out of necessity. Child-specific drugs are not being developed. The adult drugs being used to treat childhood cancer cause major complications. Adult drugs are adapted for use in children years after the drug has gone through initial development for adults, clinical trials for adults and used on adults for many years. If after that 15+ year process it shows enough promise, then some additional research is conducted to determine dosage for children. Clinical trials then begin on children, attempting to find the 'sweet spot', striking a balance of killing the cancer without killing the child. If a 'sweet spot' can be found, the drug is approved for use in pediatric oncology. Alex was the sixth child to receive his toxic mix of old drugs. The other five children had the same outcome. This outdated system is the best we have to offer our children when they are diagnosed with a life threatening cancer. Kids are not small adults.

The efforts being made to improve outcomes for children with cancer are failing to yield sufficient long term meaningful results. Adult cancer care continues to outpace treatment options for childhood cancer. Hospitals and research facilities are doing the best they can with the limited resources available. Several attempts to legislatively produce results have fallen short, but not for lack of effort or partisanship. The key to successfully treat childhood cancer is still missing. All efforts continue to be focused and/or based on adult cancers hoping to benefit childhood cancer. Childhood cancer needs to be classified as a separate disease from adult cancer. Only then can the correct questions be asked, creating a path for the right solutions—child specific treatment options and appropriate funding.

The Truth About Childhood Cancer in the USA

Over 60,000 children are in cancer treatment right now, and over 15,000 more children will be diagnosed each year (American Cancer Society Facts & Figures 2014). Childhood cancer represents over 16 cancers with endless subtypes (American Cancer Society Facts & Figures 2014) and 'the types of cancers that occur most often in children are different from those seen in adults' (American Cancer Society, Cancer in Children 2017). There has been a 35 percent increase in childhood cancer incidence since 1975 (SEER program 1975–2012). Cancer kills more children (57 percent) than all other diseases combined (CDC National Vital Statistics Report, 2/16/16). The average age of children diagnosed with cancer is 6, and 34 percent of survivors will die by age 36 (St. Jude Lifetime Cohort Study). This study also determined two out of three long term survivors will develop chronic health conditions, including reduction in I.Q., reduction in height development, neurologic damage, secondary cancers, cardiac damage, kidney disease, liver disease and infertility. 43 percent of those conditions will be life threatening or disabling.

Children who are fortunate enough to survive the cancer and treatment have a short and limited future rife with complications. The children who do not survive

suffer greatly, not only from the life threatening disease, but also as a result of the toxic treatment. Childhood cancer is not preventable.

Despite these overwhelming odds for saving our children, and improving the quality of life of those we cannot save, lack of funding (public and private sector) and child specific drugs remain serious obstacles. All childhood cancers combined receive only 4 percent of all Federal cancer funding (NCI 2015 Budget). The problem is also misunderstood in the private sector. All childhood cancers combined receive only 1 percent of American Cancer Society funding (American Cancer Society Facts & Figures 2014).

Of the 202 cancer drugs approved by the FDA since 1995, only two have been for childhood cancer; yet in the same period, 15 drugs were approved for prostate cancer. Of those precious two childhood cancer drugs, one was approved this year and is only used to treat neuroblastoma, which accounts for 5 percent of childhood cancers, and it is only useful for some of those patients. (Centerwatch.com/drug-information/fda-approved-drugs/therapeutic-area/12/oncology)

A great deal of legislation has been developed to tackle the issue of child specific drugs by encouraging adoption of more adult drugs for children, expediting approvals for drugs used in adults for life threatening pediatric diseases and subsidies to stimulate this process. There have been legislative efforts at increasing funding for childhood cancer. Efforts are there but not the results and solutions.

We know cancer develops differently in children. We know most cancers occurring in children are not seen in the adult population. We know children's bodies react differently to toxic adult drugs. Despite this knowledge, childhood cancer is still classified as a disease in the same category as adult cancer. The Federal Government classifies childhood cancer no different than any other singular cancer but it is not a singular cancer and is not comparable to adult cancers. Past legislative efforts all recognize the distinction of childhood cancer and considerable effort is placed on attempts to provide better solutions for children with cancer. However, the efforts are all directed toward the world of adult cancers, with no increased funding for childhood cancer, resulting in continued adoption and adaptation of adult drugs being used on children. Increased efforts encourage more of the same, but a little faster. Childhood cancer must be recognized as a separate disease so all efforts are targeted to being child specific. Without this first fundamental step, efforts will continue to be ineffective or at best, marginally effective.

Increased funding alone is not the solution. If childhood cancer funding were doubled, treatment options would not be significantly impacted. If childhood cancer is classified as its own disease group, the current funds could be better spent by focusing on child specific options. Lack of funding is a real problem, but childhood cancer needs 100 percent of its own budget and not 4 percent, or any percentage, of adult cancer's budget. Scientific breakthroughs occur every day. We are constantly learning more about diseases we thought we understood. Initially, very little was known about cancer and all cancers were classified under a singular cancer classification. A budget was provided and policies were developed. The policies continued to develop as we learned more about each cancer but, under this system a child with cancer would be treated as an adult with cancer. No distinction was made to separate childhood cancers from adult cancers, and all variations of childhood cancer were grouped into one line item, unlike the multiple varieties of adult cancer, further restricting progress for each type of childhood cancer. Despite now knowing how distinct childhood cancer really is and despite acknowledging that child specific drugs are necessary, the classification change has not occurred in the same way it has for all other diseases as we learn more about them.

Disease classification is important and common. For years, the lines were blurred between Alzheimer's and Parkinson's disease. Through research and experience, the medical community learned more and each of those neurological diseases, primarily affecting the elderly, were proven to be distinct with some shared traits and commonalities but requiring their own specific research and treatment. That is when real advances are made. This has yet to occur for childhood cancer.

Until recently autism was entirely dismissed as being a unique disease and children were misdiagnosed, ostracized and untreated. Autism is now classified as its own disease group, and even encompasses an entire spectrum of severity. Asperger's syndrome was originally understood to be a type of autism but was later classified separately. Further research found it to be a type of autism and it is once again classified within the spectrum of autism. The classification and subsequent acknowledgment of autism has progressed disproportionately to childhood cancer's efforts.

Childhood cancer has historically lacked a voice in government and in the general public. Childhood cancer is the silent cancer. The effect of childhood cancer on a family is unlike any adult cancer. Families are destroyed and silenced in the wake

of childhood cancer diagnosis, treatment, and especially in the loss of a child to cancer. It leaves a path of destruction unlike any other disease.

The request for childhood cancer classification change is not a request for more funding. Until we change the classification, the true budget needed to combat childhood cancer will remain a mystery and funds will not be spent efficiently. A classification change will encourage more efficient spending. The world of childhood cancer is reactive and based on trial and error, primarily attempting adaptation of adult drugs to treat children.

Childhood cancer classification change will provide the opportunity to focus all efforts, guidelines, budgets and policies from a child-specific perspective. This is the first step in true childhood cancer reform and the key to moving to the next stage in the fight against childhood cancer.

When Alex found out his cancer was back in January 2016, he created Lambs for Life to bring comfort to children in cancer treatment by giving every one of them a special care package. Alex said that the lamb, like his lamb (Lamby), could help these children since, as Alex said, 'because it's the lamb of God, it's holy!' We developed this organization last year while Alex was in the hospital for two reasons: to bring 'Lamby Packs' to all children in cancer treatment in the U.S., and to promote fundamental change to childhood cancer Federal policy. After Alex died on April 27, 2016, we sold our business and devoted our lives to developing the organization as Alex envisioned it. We are delivering Lamby Packs to hospitals for kids in treatment, and through strategic partnerships we are launching education programs this fall to reach millions of children throughout the country over the next year. Children in treatment need support and all children need a voice to help the government and public understand the truths about childhood cancer. Lambs for Life will support children and work with elected officials and the public to bring the necessary change. We have received the endorsement and support of pediatric oncologists, who in their words are "forced to treat sweet little children as small adults" and from the families who have suffered through this journey of hell on earth.

Neither legislation nor the medical community can stop childhood cancer from occurring. Childhood cancer is neither preventable nor detectable in early stages unless by symptomatic accident. Legislation and the medical community can however provide the tools to better care for our children in cancer treatment so survivors can hope to live longer than their mid-thirties and lead more productive lives without the lifelong health complications and other cancers resulting from the toxic side effects of adult drugs. We will also be able to better care for the sweet children like Alex with very aggressive cancers, enabling them to have a more dignified experience while in treatment, free of the extreme constant pain and discomfort associated with tougher childhood cancers.

Our children deserve the best effort we can possibly give them. As parents, our primary purpose for living is to help our children live a healthy and happy life. For government, a primary goal is to give our children a better future. Without their health, our children cannot enjoy the freedoms this amazing country provides us. The United States of America is the greatest country in the world and the leader in most medical breakthroughs. Changing the classification of childhood cancer is a policy decision that will provide the single most impactful change to childhood cancer in the history of cancer. You have an opportunity to change the entire world of childhood cancer.

Simply put, we owe it to our children to give them a shot at the future they deserve. This is something we can do, must do and most importantly, should do.

Thank you for your consideration and support.

[This statement was submitted by H Brandon Arrieta, Executive Director, Lambs for Life.]

PREPARED STATEMENT OF THE LOWER ELWHA KLALLAM TRIBE

The Lower Elwha Klallam Tribe submits this written testimony for the record in the absence of an fiscal year 2018 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". Yesterday, House Republicans unveiled the "Budget Reconciliation Legislative Recommendations Relating to Repeal and Replace of the Patient Protection and Affordable Care Act". We hope that the bill will mandate a plan to integrate medical and mental health disciplines at parity. 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) be-

cause 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 2018 budget proposal, the Lower Elwha Klallam Tribe submits the following requests for fiscal year 2018:

- + \$35 Million—Tribal Behavioral Health Grants—Substance Abuse and Mental Health Services Administration (SAMHSA);
- + \$25 Million—Increasing Tribal Access to Promoting Safe and Stable Families (PSSF); and
- + \$3 million—Tribal Court Improvement—Tribal Court Improvement Grants assist Tribal courts.

\$35 Million—Tribal Behavioral Health Grants—Substance Abuse And Mental Health Services Administration (SAMHSA)

The Tribe has a critical need to address the mental health and chemical dependency epidemic in our community. The proposed funding of \$35million, as part of the Generation Indigenous initiative, in the Mental Health (\$20 million) and Substance Abuse Prevention (\$15 million) appropriations line items is appreciated but will not have a real impact on the unmet need that increases daily in Indian Country. For the Lower Elwha 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.

+\$25 Million—Increasing Tribal Access to “Promoting Safe and Stable Families (PSSF)”—Administration for Children and Families (ACF)

We support a budget request for \$25 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 admin-

ister 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 \$36 million, including \$26 million discretionary and \$10 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.

[This statement was submitted by Hon. Frances G. Charles, Chairwoman, Lower Elwha Klallam Tribe.]

PREPARED STATEMENT OF THE LYME ACTION NETWORK

The purpose of this testimony is to draw attention to, and request immediate remedial actions to correct biases in healthcare policy pertaining to Lyme disease that were established by the CDC over 20 years ago. The CDC policy in question is based on science over 40 years old that has since been shown to have been flawed in design and interpretation. This flawed research and the resulting medical guidelines based on it have had far-reaching deleterious consequences, led to systemic medical failures, and are responsible for immeasurable human suffering.

Over the past 5 years, research teams at the University of New Haven, Northeastern University, and Johns Hopkins University have shown that *Borrelia burgdorferi*, the causative agent of Lyme disease, is a complex bacterium capable of causing permanent infections by evading and suppressing the immune system, growing in biofilms in several human tissues, and developing persister forms to survive exposure to antibiotics and assault by the immune system. Unfortunately and unbelievably, the current medical approach to diagnose and treat Lyme disease fails to take into account these research studies and is, instead, based on an outdated and disproven perspective of bacteria-human interactions. The CDC and NIH also resolutely support outdated science, despite evidence and public demands for updated policies. These new discoveries have largely resulted from research funded through private philanthropic donations, demonstrating the desperation of those afflicted with this debilitating disease to find real answers.

Understanding the nature of Lyme disease in humans and the bacteria responsible for the current epidemic has been a glacially slow process thanks in large measure to the biases of a few influential individuals within the Infectious Diseases Society of America (IDSA) and the CDC, which subscribes to the IDSA’s treatment guidelines, who have been influential in demanding professional obeisance to an

outdated and dangerous disease construct developed 40 years ago. Back at that point in history, it appears that a critical procedural error was incorporated into the earliest studies of the new disease discovered in Lyme, Connecticut, an error that shaped and colored the scientific perspective of the disease, and significantly contributed to the sacrifice of two generations of victims to an inaccurate definition of the ailment.

In 1977, Dr. Allan Steere arrived in Lyme, CT to investigate cases of what was thought to be juvenile rheumatoid arthritis. After interviewing a large number of Lyme area residents who complained of wide-ranging and varied ailments, Dr. Steere selected his study subjects on the basis of one quantifiable and unifying symptom: a bulls-eye rash. It was clear that these subjects had something in common that defined them as having the condition. Interviewees not presenting with a bulls-eye rash were dismissed and not considered in this seminal study.

Dr. Steere developed a definition of Lyme disease that endured within the scientific community for decades. The starting point of the Steere definition required that the disease be identified by the bulls-eye rash, which later was extended to include seropositivity (positive blood test), establishing a foundation for subsequent studies upon which a national treatment policy would be built. The tragedy of this effort is now obvious in hindsight. Of the rest of the ill population of Lyme, Connecticut—the people who complained of such a wide variety of ailments and symptoms that Dr. Steere could find little commonality among them—it is likely that many of them ALSO had Lyme disease, but their cases were probably more advanced, more disseminated, with fewer notable commonalities. Their versions of Lyme disease were unrecognized, and thus, ignored, and not integrated into the foundational concepts upon which much of the next 40 years of research was based.

We now know that Lyme disease presents in many forms, and a bulls-eye rash is noted in only about 30%—40 percent of Lyme patients. We now know that this rash is generally associated with the acute (early) stage of the disease, and disappears as the disease advances. We now recognize that by dismissing the individuals of the original ill population in Lyme, Connecticut who did not manifest the rash, the characteristics of advanced disease were ignored and lost to decades of scientific research. To this day, the surveillance definition of Lyme disease requires a bulls-eye rash or positive serology, confirming the continued misguided belief that this is all there is to this disease.

Our evolved understanding of the disease underscores the fact that the majority of research undertaken by such entities as the CDC and NIH have been relevant to less than half of the Lyme population. The remainder of the afflicted have been largely disregarded or worse, as many have endured appalling mistreatment as a result of their illness: denied diagnoses, treatment, recognition, insurance coverage, or any help from the Federal agencies charged with the unbiased care of the public health.

Common to nearly all discussions about Lyme disease is the qualifying statement that there is a lot of “controversy” surrounding the diagnosis and treatment of the disease, suggesting that there are legitimate and honorable philosophical or professional disagreements pertaining to scientifically established tenets about Lyme disease. This characterization is simplistic and misleading. The facts behind this “controversy” lead to the point of divergence created when a new construct that includes consideration of advanced disease confronted the original construct which does not. The perception that the CDC has no interest in exposing and addressing the original design flaw (and consequently devaluing the decades of research) has created a great deal of dispute, dissention within the medical ranks, and grave concern in the public advocacy sector.

A serious design flaw, an ERROR, which excluded an entire class of disease victims, was institutionalized into the definition of the disease, and much subsequent research carried the original flaw forward. The “controversy” is the comparison of apples to oranges: the comparison of a construct based upon the “acute” patient information versus more current and expansive information based upon acute and advanced disease experience. Adding insult to injury, all community efforts to request/encourage/require the CDC to recognize, amend, account for, or in any other form, correct the damage this flawed research has created, have been ridiculed and rejected by the CDC and NIH.

In the face of a serious epidemic, the unfortunate reality of Lyme disease is that there has been insufficient government research into the full scope of the disease, outside the definitional parameters established 40 years ago. This country is facing an epidemic of significant proportions, armed with only a fraction of the understanding and research necessary to adequately address the threat.

The CDC has assumed a defensive posture on this matter, deflecting all inquiry, defending its 40 years of dogma, and creating an internal culture that derides the

population who clamor for a CDC policy (and personnel) overhaul. The NIH, for its part, continues to honor the outdated disease definition, and pours millions of research dollars into a contaminated process that continues to produce the same results.

The failure of the CDC and the NIH to face up to the consequences of bad science is costing the U.S. over \$1.3 billion annually and hundreds of thousands of innocent people their health and well being. Were this negligence being perpetrated by the private sector, there would be waves of legal actions addressing the negligence, but as the problem resides within the CDC and NIH, legal redress is too expensive to undertake, and the hundreds of thousands of victims have only Congress to fall back upon in an appeal to correct the situation.

It is time for Congress to fully investigate the original research that has led us to this failed disease construct; identify the structural flaws unwittingly incorporated into the original definition of Lyme disease; and move swiftly and forcefully to correct the damage that has discriminatorily excluded so many people from access to diagnosis, treatment, and care. This task cannot be left to the discretion of the CDC nor the NIH, which have chosen to ignore the problem. The Lyme Action Network calls upon the members of Congress, particularly through the Appropriations Committee, to specifically appropriate the funds for independent and unbiased research to correct the faults and failures embedded in the past research and expedite corrective research to tackle the rising threat of rampant Lyme and other tick-borne diseases with a full complement of facts and research.

Respectfully.

[This statement was submitted by Christina T. Fisk, President, Lyme Action Network.]

PREPARED STATEMENT OF THE MARCH OF DIMES

MARCH OF DIMES: FISCAL YEAR 2018 FEDERAL FUNDING PRIORITIES

PROGRAM	FISCAL YEAR 2018 REQUEST
National Institutes of Health (total)	
National Institute of Child Health and Development	at least \$2,000,000,000 over FY17 for the National Institutes of Health with a proportionate amount disbursed to its Institutes and Centers
National Human Genome Research Institute	
National Institute on Minority Health and Disparities	
National Institute of Environmental Health Sciences	
National Children's Study Alternative (ECHO)	\$165,000,000
Zika in Infants and Pregnancy (ZIP) Study (NICHD/NIAID)	\$10,000,000
Centers for Disease Control and Prevention (total)	\$7,800,000,000
National Center for Birth Defects and Developmental Disabilities	\$154,560,000
<i>Zika Response Activities</i>	\$17,000,000
<i>Birth Defects Research and Surveillance</i>	\$19,000,000
<i>Folic Acid Campaign</i>	\$3,150,000
Section 317 Immunization Program	\$650,000,000
Newborn Screening Quality Assurance Program	\$29,800,000
Polio Eradication	\$174,000,000
Safe Motherhood Initiative	\$46,000,000
<i>Preterm Birth</i>	\$2,000,000
Office on Smoking and Health	\$210,000,000
National Center for Health Statistics	\$170,000,000
Health Resources and Services Administration (total)	\$7,480,000,000
Title V Maternal and Child Health Block Grant	\$667,000,000
<i>SPRANS- Infant Mortality and Preterm Birth</i>	\$3,000,000
Heritable Disorders	\$19,900,000
Universal Newborn Hearing	\$18,660,000
Healthy Start	\$ 128,303,000
Grants for Maternal Depression Screening and Treatment	\$5,000,000
Title X Family Planning Program	\$327,000,000
Office of the Secretary Health - Teen Pregnancy Prevention	\$101,000,000
Agency for Healthcare Research and Quality (total)	\$364,000,000

The March of Dimes, a unique collaboration of scientists, clinicians, parents, members of the business community, and other volunteers representing every State, the District of Columbia and Puerto Rico, appreciates this opportunity to submit testimony for the record on fiscal year 2018 appropriations for the Department of Health and Human Services (HHS). Every day, the March of Dimes works to improve the health of women, infants and children by preventing birth defects, premature birth, and infant mortality through research, community services, education, and advocacy. The March of Dimes recommends the aforementioned funding levels for programs and initiatives that are essential investments in maternal and child health. Further, the March of Dimes urges the Committee to reject deep cuts or outright eliminations of health programs proposed in President's fiscal year 2018 budget. If enacted, the recommendations would severely undermine ongoing Federal efforts to improve the health of women of childbearing age, mother, infants and children.

Zika Virus

Our Nation continues to face an unprecedented challenge in the form of a mosquito-borne virus that causes life-altering birth defects. The March of Dimes commends Congress for providing supplemental funding in fiscal year 2017 to respond to the Zika virus, but it is imperative that Congress sustain that investment in fiscal year 2018 and beyond to address the full span of activities necessary to track, treat, and ultimately prevent Zika infections. This includes a wide range of ongoing activities throughout HHS agencies, including vaccine research at the National In-

stitutes of Health (NIH); vector control, diagnostic testing, public education, and birth defects surveillance at the Centers for Disease Control and Prevention (CDC); and much more. Specifically, the March of Dimes requests at least \$10 million for NIH to continue the Zika in Infants and Pregnancy (ZIP) study, a multi-country study to evaluate the near- and long-term health risks Zika virus infection poses to pregnant women, developing fetuses and infants. The March of Dimes also urges the Committee to provide an additional \$17 million to the CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) to support ongoing Zika-related birth defects prevention, surveillance and research activities. Without additional funding, NCBDDD's enhanced Zika-related birth defects surveillance activities will end as early as July 2017.

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

The March of Dimes encourages Congress to disregard the President's proposed cuts to NIH and instead provide at least \$2 billion over fiscal year 2017 for NIH with a proportionate amount disbursed to NICHD in fiscal year 2018. This funding will allow NICHD to sustain vital research on preterm birth and related issues through extramural grants, Maternal-Fetal Medicine Units, the Neonatal Research Network and the intramural research program. This funding would also allow NICHD to continue investments in transdisciplinary research to identify the causes of preterm birth, as recommended in the Director's 2012 Scientific Vision for the next decade, the Institute of Medicine 2006 report on preterm birth, and the 2008 Surgeon General's Conference on the Prevention of Preterm Birth. Funding for NICHD will also support continuing research to determine the health risks that Zika virus infection poses to pregnant women and their developing fetuses and infants, as well as men's reproductive health.

National Center on Birth Defects and Developmental Disabilities (NCBDDD)

NCBDDD is the lead Federal agency tasked with supporting vital surveillance, research, and prevention activities on birth defects and developmental disabilities. Given the center's expertise, NCBDDD staff are playing a vital role in the international and domestic response to the Zika virus. For fiscal year 2018, the March of Dimes urges the Committee to provide \$154.56 million to NCBDDD, an increase of \$17 million over fiscal year 2017, to support the center's core work while sustaining enhanced birth defects surveillance systems put in place in 50 jurisdictions to monitor Zika-related birth defects. The March of Dimes urges Congress to reject the administration's proposal to reduce NCBDDD's budget by 27 percent. This decrease would severely limit NCBDDD's cost-saving work to prevent birth defects, improve the health and well-being of Americans with disabilities, ensure children with developmental disabilities are receiving appropriate and timely care, and protect individuals with blood disorders.

Title V Maternal and Child Health (MCH) Block Grant Program

The March of Dimes supports the recommendation in the President's budget to increase funding for the Title V Maternal and Child Health Block Grant Program to \$667 million. This increase would begin to reverse the \$90 million in cuts to the MCH Block grant over the past decade and ensure States have sufficient funding to respond to public health crises, such as Zika and the opioid epidemic. However, the March of Dimes strongly opposes the administration's ill-advised proposal to offset the \$25.3 million increase in MCH Block Grant funding by eliminating five vital MCH Bureau programs totaling \$103 million, including newborn screening programs. Together, these recommendations would result in a \$78 million net reduction for these programs.

The March of Dimes also recommends Congress specify that \$3 million within the Title V Special Projects of Regional and National Significance account be used to support current preterm birth and infant mortality initiatives, as authorized in the PREEMIE Act. This funding will support the Collaborative Improvement & Innovation Network (CoIIN) to Reduce Infant Mortality, which assists States focusing on a range of interventions proven to reduce preterm birth and improve maternal and child health.

Newborn Screening

The March of Dimes urges funding of \$29.8 million for CDC's Newborn Screening Quality Assurance Program (NSQAP) and \$19.9 million for the Health Resources and Services Administration's (HRSA) Heritable Disorders program, which play critical roles in assisting States in the adoption of additional screenings, educating providers and consumers, and ensuring coordinated follow-up care. The Heritable Disorders program also supports the work of the Advisory Committee on Heritable Dis-

orders in Newborns and Children (ACHDNC), which provides recommendations to the HHS Secretary for conditions to be included in the Recommended Uniform Screening Panel (RUSP). In 2016, the ACHDNC added two new conditions to the RUSP, bringing the total number of recommended screens to 34. Additional funding for NSQAP and the Heritable Disorders program is crucial to ensure States have adequate funds and technical assistance to implement screening tests for these new additions to the RUSP.

The March of Dimes emphatically opposes the administration's proposal in its fiscal year 2018 budget to eliminate the Heritable Disorders program. The program supports activities to address nationwide challenges for State newborn screening programs. Performing these activities at the Federal level is efficient, reduces duplicative expenditures, and, most importantly, saves the lives of newborns. The March of Dimes calls on Congress to reject this misguided proposal and ensure robust funding to support newborn screening.

Safe Motherhood Initiative

The mission of the Safe Motherhood Initiative at the CDC's National Center for Chronic Disease Prevention and Health Promotion is to promote optimal reproductive and infant health. The March of Dimes recommends funding of \$46 million for the Safe Motherhood program and strongly urges maintenance of the preterm birth sub-line at \$2 million, as reauthorized in the PREEMIE Reauthorization Act (Public Law 113-55), to retain current preterm birth research at CDC. The March of Dimes was pleased that the President's budget recognizes the importance of the Safe Motherhood initiative and echoes our recommendation for level funding at \$46 million.

Grants for Maternal Depression Screening and Treatment

Research shows that up to one in seven pregnant women or new mothers experience some sort of maternity-related depression, yet only about 15 percent of those affected receive treatment. The 21st Century Cures Act (Public Law 114-255) seeks to address this gap by authorizing a grant program for States to improve screening for and treatment of maternal depression in pregnant women and those who have given birth in the past 12 months. The March of Dimes urges the Committee to make available the full authorized amount of \$5 million for this new and innovative grant program.

Funding to Promote Optimal Birth Spacing and Improved Birth Outcomes

Research shows that appropriate birth spacing—waiting at least 18 months between pregnancies—can dramatically reduce the risk of poor birth outcomes. Additionally, we know that the youngest mothers have some of the worst birth outcomes. We can reduce these risk factors by ensuring women have access to evidence-based counseling and education prior to pregnancy and access to all forms of contraception approved by the Food and Drug Administration. To support these important goals, the March of Dimes recommends funding of \$327 million for Title X Family Planning Program and the Teen Pregnancy Prevention Program (TPP) administered by the Office of the Assistant Secretary for Health. The March of Dimes was pleased that the President's budget acknowledged the effectiveness of the Title X Family Planning Program by recommending level funding in fiscal year 2018, but additional resources are needed to address unmet need in the program. The March of Dimes also urges Congress to reject the Administration's proposal to eliminate the TPP. Instead, Congress should provide \$110 million for this successful, evidence-based program.

Conclusion

March of Dimes volunteers and staff look forward to working with appropriators and all of Congress to secure the resources needed to improve the health of our Nation's mothers, infants, children and families.

PREPARED STATEMENT OF THE MARFAN FOUNDATION

THE FOUNDATION'S FISCAL YEAR 2018 L-HHS APPROPRIATIONS RECOMMENDATIONS

—\$7.8 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.

—\$500,000 for a Marfan syndrome and related disorders education program at the National Center for Chronic Disease Prevention and Health Promotion

(NCCDHP) to advance awareness activities that ensures all school aged children are appropriately screened for potentially life-threatening cardiovascular disorders prior to sports participation.

- At least \$36 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 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 2018 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.—People with Marfan syndrome are born with it, but features of the disorder are not always present right away. Some people have a lot of Marfan features at birth or as young children—including serious conditions like aortic enlargement. Others have fewer features when they are young and don’t develop aortic enlargement or other signs of Marfan syndrome until they are young adults. Some features of Marfan syndrome, like those affecting the heart and blood vessels, bones or joints, get worse over time. This makes it very important for people with Marfan syndrome and related disorders to receive accurate, early diagnosis and treatment. Without it, they can be at risk for potentially life-threatening complications that could lead to a sudden early death. The earlier some treatments are started, the better the outcomes are likely to be.

Please provide \$500,000 for a Marfan Syndrome Program at the Centers for Disease Control and Prevention’s (CDC). Disorders like Marfan syndrome, continue to claim the lives of high school athletes across the country who have not received an appropriate sports physical prior to participation. A CDC program that promotes education and awareness activities would ensure that all young athletes are appropriately screened for potentially life-threatening cardiovascular disorders.

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

My name is Kevin Songer and I have Marfan syndrome. In 2011, I experienced a near fatal aortic dissection and a post-operative infection of the prosthetic aorta and heart valve I had just received. Today my descending aorta—down into my kid-

ney and legs—is still torn. The inside diameter is seventy-five percent obstructed and blood flow to my vital organs and lower body is greatly reduced.

Had I been properly diagnosed earlier in life, preventive health measures could have been taken that may have helped me avoid emergency aortic replacement surgery. With two children in college, today I am fighting as hard as I can to remain healthy, contribute to society, and see my family establish lives of their own.

Yet life with Marfan syndrome is difficult. Some medical professionals still do not properly understand connective tissue implications, missing opportunities for proactive treatment and proper medications. Regulatory agencies may not comprehend connective tissue disorders, suspending driver licenses or denying much needed health benefits. Insurance policy guidelines can exclude us from much needed benefits. A connective tissue life can sometimes be seemingly impossible to navigate in today's society.

Life with connective tissue challenges leaves me wondering each night if I will wake the next morning. Each time I feel a new pain in my chest or abdomen, I wonder if my dissected aorta has ruptured. This sense of impending sudden death is an ongoing challenge. However, I have hope. Many of us aortic dissection survivors continually band together and help others through support groups, advocating, and sharing. But we cannot do this alone. We need your help to encourage and make possible additional medical research, proper insurance guidelines, and appropriate medical care.

Aortic dissection can strike anyone at any time in our lives, but for those with connective tissues disorders, it is usually a matter of when not if. I am reminded of Flo Hyman, John Ritter, and others. Your help in making possible medical research and care, awareness and resources, and adequate insurance has a direct impact on America.

There lies so much potential in those of us challenged by connective tissue diseases such as Marfan syndrome. Your help in mitigating some of the daily burden and providing opportunities to overcome challenges can free us to contribute more to ourselves, our families, and our great Nation.

[This statement was submitted by Michael Weamer, President and CEO, The Marfan Foundation.]

PREPARED STATEMENT OF MEADVOCACY.ORG

Dear Ladies and Gentlemen of the Committee:

MEadvocacy.org¹ is a project of the non-profit organization May12.org and is asking Health and Human Services to fund \$250 million for research into the disease myalgic encephalomyelitis (ME).

There is an urgent need for a systemic overhaul at the Department of Health and Human Services (HHS), including the National Institutes of Health (NIH) and the Centers for Disease Control (CDC), in regard to its funding and handling of this disease.

ME is a chronic, disabling, neuroimmune disease affecting an estimated one million American men, women and children in the U.S. Yet, for more than 30 years, since the Lake Tahoe outbreak (1984) where the disease was redefined, there have been few biomedical scientific advances and no FDA approved treatments for this heavily burdened disease. This is due to an institutional bias at HHS, CDC and NIH leading to marginalization, neglect, underfunding and mistreatment of the myalgic encephalomyelitis patient community.

Scientific advances in myalgic encephalomyelitis have been repeatedly squashed by the gross lack of funding by NIH. In addition, misinformation and badly outdated information published by the CDC, along with the lack of education about the disease in medical schools, has caused a dearth of palliative care for patients nationwide. Most importantly, after 30 plus years, we still are not any closer to finding an FDA approved treatment or cure to help the estimated 17 million ME patients worldwide.

MEadvocacy.org is a non-profit grassroots movement of advocates and patients who are rising up and saying it is time for a change. We are lawyers, laborers, teachers, students, fathers, mothers, and children. Our productive lives have been cut short by this disease and we currently have no hope of treatment or cure. We have had enough and are saying, "No More!"

¹[Http://www.meadvocacy.org](http://www.meadvocacy.org).

ME Incidence and Prevalence:

ME, which in the U.S. has been lumped in with chronic fatigue syndrome (CFS) and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), sickens an estimated 1 million people in the U.S. and 17 million worldwide. A majority of patients are disabled, unable to work, attend school or participate in activities of daily life. A quarter, an estimated 250,000 people, are so severely affected as to render them bedbound, unable to care for themselves.

ME History, Criteria and Name:

ME has a long history, appearing worldwide in epidemic and endemic forms. A 1955 outbreak in London resulted in what Dr. A. Melvin Ramsay² described it as an infectious ?neuromuscular illness and formally used the term “myalgic encephalomyelitis.” Disregarding this, the CDC broadly redefined the disease and renamed it the marginalizing name chronic fatigue syndrome (CFS) in response to 1985 cluster outbreaks of the disease in Incline Village, Nevada and Lyndonville, New York. This redefinition resulted in three decades of confused research findings rather than answers to the cause and treatment of this disease. In addition, the undignified name and poor criteria causes stigmatization and marginalization of patients.

Disease Burden and Funding:

Some ME patients have died prematurely from complications of ME. Others have died at their own hands due to the severity and length of their suffering without proper palliative care, as well as dismissal and stigmatization by the medical community. If we do not act on behalf of these severely affected patients, we are complicit in their suffering and untimely deaths. The patients will no longer carry this burden quietly and we are looking at Congress to require HHS to properly fulfill their duty to their constituents who are ME sufferers.

In 2009, Dr. Nancy Klimas, the director of AIDS research at the Miami Veterans Affairs Medical Center stated: “My H.I.V patients for the most part are hale and hearty thanks to three decades of intense and excellent research and billions of dollars invested. Many of my CFS patients, on the other hand, are terribly ill and unable to work or participate in the care of their families. I split my clinical time between the two illnesses, and I can tell you if I had to choose between the two illnesses, (in 2009) I would rather have HIV.”³

In the intervening 8 years, nothing has changed. It is very clear that real change at HHS regarding this disease will not come about naturally. We have come to you, the subcommittee for Labor, Health and Human Services, Education, and Related Agencies, for help in addressing this dire need for oversight and investigation.

It is estimated that the burden to the economy for ME is between \$17 to \$24 billion, yet NIH funding for research has gone from a mere \$5 to \$6 million for many years to an expected approx \$12 million dollars in 2017. This figure is less than funding for hay fever. HHS has historically placed funding for ME at the rock bottom of their funding budget list (4). The yearly allocation for ME/CFS is a fraction of what other similarly burdened diseases receive.

HHS/NIH funding data for 2016 for several diseases: HIV/AIDS \$3 billion; M.S. \$97 million; Parkinson’s \$161 million; Alzheimer’s \$929 million; ME/CFS \$7 million.⁴

The great divide between NIH funding for ME and other diseases cannot be explained away. Simply advising and recommending that NIH increase funding for ME, has not worked. The Secretaries of Health and Human Services have not responded to most of the nearly 100 recommendations made by the, federally chartered, Chronic Fatigue Syndrome Advisory Committee (CFSAC)⁵ during the past 10 years. It ignored specific requests by CFSAC, medical experts, patient advocates, patients and their families to adopt ME expert authored, well defined criteria for the disease and calls for RFAs and increases in NIH funding.

HHS has not listened to the many recommendations by this Appropriations Committee over the past 20 years. In order to fund ME on par with MS, a similarly serious disease, ME would need \$250 million a year to bring them on par with other similarly burdened diseases yet gets a mere \$7 million. This is just on a premise of equality, not equity. If evaluated based on equity, a disease with no FDA approved treatment and an abysmal quality of life (lower than AIDS and MS), it

² <http://www.name-us.org/DefintionsPages/DefRamsay.htm>.

³ <http://consults.blogs.nytimes.com/2009/10/15>.

⁴ https://report.nih.gov/categorical_spending.aspx.

⁵ <http://www.hhs.gov/advcocfs/recommendations/index.html#>.

should be getting much more funding to bring it up to par. To be equitable ME should be funded at greater than \$3 billion.

We need a different approach and a complete overhaul at all agency levels. We need an investigation by Congress into the mishandling and neglect of ME by HHS, NIH and CDC and active, ongoing Congressional oversight until HHS' negative institutional bias is rectified. We are therefore coming to you for help in this matter.

The following are the recommendations and goals that we at MEadvocacy.org feel the Appropriations Committee needs to require that HHS meet, in order to bring myalgic encephalomyelitis back on par with other similarly burdened diseases:

- Fund biomedical research for ME commensurate with its severity and burden to patients and the economy. We are asking for specific funding in the amount of \$250 million, the amount we believe is needed to bring ME on par with other similarly burdened diseases. HHS should clearly allocate funds to study patients from past ME cluster outbreaks as well as the study of the epidemiology of patients with severe ME. The additional funding needed for ME might be accomplished by means of a sliding scale of allocation from other diseases related to immune, cognitive and nervous system dysfunctions.
- Heed the ME stakeholders' request to adopt the diagnostic and research criteria authored by those experienced in the disease. An international group of ME experts created the 2011 International Consensus Criteria (ICC)⁶ in order to provide an updated replacement for the 2003 Canadian Consensus Criteria (CCC).⁷ This updated ICC version should be adopted. The CCC was endorsed by an Open Letter from ME/CFS Advocates to the Honorable Kathleen Sebelius at HHS on October 28, 2013⁸ as well as a petition⁹ signed by over 6,000 patients.
- Retain the historical name for this disease, myalgic encephalomyelitis, which has been coded since 1969 by the World Health Organization under neurological disease with the code G93.3 and is similarly coded in the 2015 U.S. ICD Codes as U.S. ICD-10-CM.

Additionally, we request that the Appropriation Committee recommends HHS:

A-Ensure that NIH completes their 2015 promise of placing ME into the National Institute of Neurological Disorders and Stroke (NINDS), which also manages similar neuroimmune diseases such as MS, fibromyalgia, and Lyme Disease. The Office of Research on Women's Health, where ME is currently housed, is entirely inappropriate for a disease which also strikes men and children.

B-Provide opportunities for dissemination of information through the development of a curriculum for all U.S. based medical schools, as well as physician continuing education, about ME as defined solely by disease experts, in order to provide the tools needed for physicians and other medical professionals to appropriately recognize and treat this disease. Currently, this would mean using either the 2011 International Consensus Criteria or the 2003 Canadian Consensus Criteria, not the overly broad criteria developed by the non-expert IOM panel which the CDC is defiantly implementing in their educational materials. In addition, the ICC Primer¹⁰ should be widely distributed and made available to clinicians, particularly primary care physicians, nationwide in order to facilitate the best care for their ME patients.

C-Partner openly and transparently with stakeholders within 1 year to establish a comprehensive, aggressive and fully funded cross agency strategy and implementation plan, with well defined objectives and milestones, and to develop a plan to monitor progress and provide for Congressional oversight.

"We've documented, as have others, that the level of functional impairment in people who suffer from CFS is comparable to multiple sclerosis, AIDS, end stage renal failure, chronic obstructive pulmonary disease. The disability is equivalent to that of some well known, very severe medical conditions."—Dr. William Reeves, former CDC Chief of Viral Diseases Branch (2006 CDC Press Conference)

PREPARED STATEMENT OF MEALS ON WHEELS AMERICA

Dear Chairman Blunt, Ranking Member Murray and Members of the Subcommittee:

⁶http://www.meadvocacy.org/the_international_consensus_criteria_what_is_it_do_i_fit_the_criteria.

⁷<http://www.name-us.org/DefintionsPages/DefinitionsArticles/ConsensusDocument%20Overview.pdf>.

⁸https://thoughtsaboutme.files.wordpress.com/2013/10/sebelius_letter_advocates2.pdf.

⁹<https://secure.avaaz.org/en/petition/>

¹⁰Stop the HHSIOM contract and accept the CCC definition of ME?pv=4.

¹⁰http://www.name-us.org/DefintionsPages/DefinitionsArticles/2012_ICC%20primer.pdf.

Thank you for the opportunity to present testimony concerning fiscal year 2018 appropriations for Older Americans Act (OAA) Nutrition Programs 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 more than 5,000 Meals on Wheels programs—both congregate and home-delivered—in communities across the country. We are grateful for your ongoing support of these proven and effective services, including the recent \$3 million increase provided for OAA Nutrition Programs in the Consolidated Appropriations Act of 2017 signed into law last month. For fiscal year 2018, we reiterate our plea that you continue to build on the bipartisan, bicameral support that exists and, at a minimum, fund OAA Nutrition Programs at the levels authorized under the Older Americans Act Reauthorization Act (Public Law No: 114–144), as unanimously approved in the Senate last year. Those levels equate to a total of \$874,637,011, and the individual line items are as follows:

- Congregate Nutrition Services (Title III, C-1)—\$469,916,692
- Home-Delivered Nutrition Services (Title III, C-2)—\$237,233,817
- Nutrition Services Incentive Program (Title III, NSIP)—\$167,486,502

At this critical juncture in our Nation's history, when both the need and demand for nutritious meals are continuing to climb exponentially, we ask that you give this request your utmost consideration. OAA Nutrition Programs represent one of the best examples of a successful public-private partnership, leveraging about \$3 for every \$1 appropriated through the OAA with additional State, local and private contributions, as well as an army of two million volunteers. The nourishing meals, friendly visits and safety checks delivered each day are providing an efficient and vital service for our most vulnerable seniors, our communities and taxpayers, as a whole. OAA Nutrition Programs (both congregate and home-delivered) enable seniors to live healthier and more independent lives longer in their own homes—where they want to be—reducing unnecessary visits to the emergency room, admissions and readmissions to hospitals and premature nursing home placement. Not only are they providing more than just a meal to those who are fortunate enough to receive their services, but these programs are also an essential part of the solution to our Nation's fiscal and demographic challenges by helping to bend the cost curve on the mandatory side of the budget.

SERVING THE MOST VULNERABLE

For nearly five decades in communities large and small, rural and urban, OAA Nutrition Programs have been effectively serving seniors in the greatest economic and social need. 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 these services to remain in their own homes. They are primarily women, age 76 or older, who live alone. Additionally, they have multiple chronic conditions, take six or more daily medications, are functionally impaired, and the single meal provided through the OAA Nutrition Program represents half or more of their total daily food intake. Significant numbers of seniors are impoverished, live in rural areas and belong to a minority group. In short, the individuals served through the OAA nutrition network are high-risk, high-need and invariably high-cost to Medicare and Medicaid.

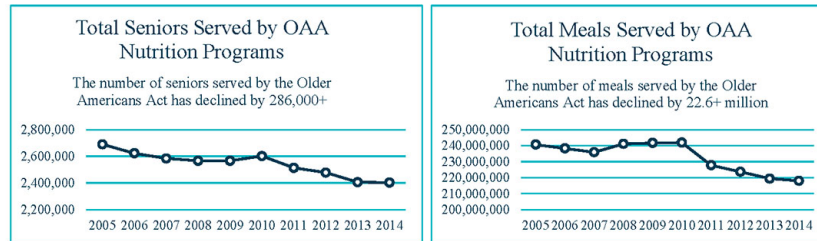
The extreme frailty of this population was further underscored in a groundbreaking 2015 study entitled *More Than a Meal*, commissioned by Meals on Wheels America, which found that those eligible for Meals on Wheels services are, by magnitudes, more vulnerable than a nationally representative sample of comparably-aged Americans. Specifically, seniors on Meals on Wheels waiting lists were significantly more likely to:

- Report poorer self-rated health (71 percent vs. 26 percent);
- Screen positive for depression (28 percent vs. 14 percent) and anxiety (31 percent vs. 16 percent);
- Report recent falls (27 percent vs. 10 percent) and fear of falling that limited their ability to stay active (79 percent vs. 42 percent); and
- Require assistance with shopping for groceries (87 percent vs. 23 percent) and preparing food (69 percent vs. 20 percent).

DEFINING THE ENORMITY OF THE PROBLEM

Today, 10.2 million seniors, or one in six, struggles with hunger—a 65 percent increase since the start of the recession 10 years ago and a 119 percent increase since 2001. In 2014, funding provided through the OAA supported the provision of meals to 2.4 million seniors nationwide, while the President's fiscal year 2018 budget request would reduce that number to 2.3 million seniors. The problem—simply put—

is worsening year after year, and too few seniors who need meals are getting them. In fact, a 2015 Government Accountability Office report found that about 83 percent of food insecure seniors and 83 percent of physically-impaired seniors did not receive meals [through the OAA], but likely needed them. The OAA network overall is serving 23 million fewer meals to seniors in need than it was in 2005, which is due in large part to Federal funding not keeping pace with inflation or demand. As a result, waiting lists are mounting in every State, and one in four Meals on Wheels programs report having a waiting list, with an average of 200 seniors and growing. The graphs on the following page illustrate this highly troubling trend.



Source: Older Americans Act (OAA) Title III Programs data derived from the AGING Integrated Database (AGID) system, the AGID State Profiles. Full reports available at: www.agingnet.acl.gov

PRESENTING THE ECONOMIC CASE

We all know that proper nutrition is essential to one's health and well-being. This is particularly true for seniors, for whom even a slight reduction in nutritional intake can exacerbate existing health conditions, accelerate physical impairment, and impede recovery from illness, injury and/or surgery. For example, *The Causes, Consequences, and Future of Senior Hunger in America*,—the first ever assessment of the state of senior hunger in America released in 2008—found that a senior at risk of hunger has the same chance of much more severe activities of daily living (ADL) limitations as someone 14 years older. This means there is a large disparity between a senior's actual chronological age and his or her "physical" age, such that a 67 year old senior struggling with hunger is likely to have the ADL limitations of an 81 year old.

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, in-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 reduced levels of anxiety, feelings of isolation and loneliness and worry about being able to remain at home) and reductions in hospitalizations, falls and the fear of falling. Further, in addition to being a preventative measure for emergency department visits and hospital admissions, investing in Meals on Wheels is also a proven way to reduce hospital readmissions and post-discharge costs.

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. I have also shared compelling results from a 2012 Brown University study which showed that investments of \$25 more per senior per year in Meals on Wheels could reduce the low-care nursing home population by 1 percent, which translates annually to millions of dollars in Medicaid savings alone.

INVESTING IN A PROVEN, COST-EFFECTIVE MODEL

In summary, individuals who need home-delivered and congregate meal services represent our Nation's most frail and vulnerable senior population. This is a group with significant health and social support deficits. The good news is that the infrastructure and cost-effective interventions to support this unique population already exist through the OAA network of 5,000 local, community-based programs.

We well understand the difficult decisions with which you and your colleagues are tasked. However, the evidence demonstrates that these programs are saving lives and taxpayer dollars every day. They are effectively reaching 2.4 million of our Nation's most at-risk seniors today, and they have the capacity to serve significantly more who desperately need it, if properly resourced. When considering the reduction

in falls alone, which cost Medicare \$31 billion in direct medical costs in 2015, further investments in OAA Nutrition Programs are an untapped but readily available solution with the potential to produce billions of dollars in savings to the mandatory side of the budget. These programs represent only one-sixth of 1 percent of the entire non-defense discretionary budget, yet they are delivering a significant social and economic return on investment, as they help prevent and mitigate the effects of chronic disease, improve quality of life, expedite recovery after an illness, injury, surgery or treatment and reduce unnecessary Medicare and Medicaid expenses both today and in the future. After all, a program can deliver Meals on Wheels to a senior for an entire year for, on average, about the same or lower cost as just one day in the hospital or ten days in a nursing home.

As your Subcommittee crafts and considers the fiscal year 2018 Labor-HHS-Education Appropriations Bill, we ask that you provide, at a minimum, \$874,637,011 for all three nutrition programs authorized under the OAA (Congregate Nutrition Program, Home-Delivered Nutrition Program and the Nutrition Services Incentive Program). Again, we thank you for your leadership and continued support through the appropriations process, as well as the efforts you made to ensure passage of S. 192, the Older Americans Act Reauthorization Act of 2016. 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 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 2018 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 a \$2 billion increase over fiscal year 2017 appropriations for NIH, as well as the full authorized amount of \$5 million to implement the National Neurological Conditions Surveillance System at the CDC. These appropriations will bring us closer to better treatments and a cure for Parkinson's disease (PD). As the world's largest nonprofit funder of PD research, MJFF is dedicated to accelerating a cure for Parkinson's and developing improved therapies for those living with the disease today. In providing more than \$700 million in PD research to date, the 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. Currently, there is no therapy to slow, stop or reverse the progression of PD, nor is there a cure. Additionally, existing treatments are limited in their ability to address patients' medical needs and remain effective over time.

NIH RESEARCH FURTHERS PROGRESS TOWARD NEW TREATMENTS AND A CURE

It is estimated that one million people in the United States are living with PD, which is the second most common neurodegenerative disease after Alzheimer's. As age is the greatest risk factor for Parkinson's, the PD community is projected to increase substantially over the next few decades as the U.S. population ages. The annual economic burden of Parkinson's in the United States currently tops \$16.6 billion, and this will rise as the number of people with PD grows.

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. It also is estimated that 80,000 veterans are living with Parkinson's. New treatments would relieve the burden on Medicare, Medicaid and the VA. Additionally, NIH funds research in all 50 States, and every dollar of funding generates two dollars in local economic growth.

As this committee knows well, NIH funding has not kept pace with medical inflation and NIH purchasing power has declined since 2003. In 2016, NIH was only able to fund 12 percent of investigator-initiated grants, leaving an untold number of possibilities undiscovered. Patients and the medical community deserve stable and reli-

able funding that allows for research progress and supports innovative projects that bring us closer to cures.

The following discoveries demonstrate the critical importance of NIH-funded research in advancing understanding of and new treatments for Parkinson's disease.

Alpha-Synuclein: Unlocking the Secrets of Neurological Diseases

Many progressive neurodegenerative diseases like Parkinson's and Alzheimer's are characterized by abnormal protein clumping that contributes to brain cell damage. In Parkinson's disease, clumps of the protein alpha-synuclein, called Lewy bodies, form in the brain. Lewy bodies are believed to cause the death of brain cells, leading to PD symptoms. As such, alpha-synuclein is a major target of Parkinson's research.

The alpha-synuclein gene was first linked to Parkinson's in 1997 by researchers at NIH. This led to the major breakthrough discovery of Lewy bodies in the brain. In the years since, alpha-synuclein has been the focus of intensive efforts by NIH-funded researchers working to definitively characterize its role in Parkinson's and its potential as a target for neuroprotective therapies. MJFF built on these discoveries to support clinical development of alpha-synuclein treatments. Today, based on the groundwork laid by those NIH scientists and the work that followed, five approaches targeting the alpha-synuclein protein are in early clinical trials.

A better understanding of the abnormal protein clumping in Parkinson's would be beneficial not only to the broad population of people with PD, but to other neurological diseases that experience similar protein misfolding. The Parkinson's and Alzheimer's fields are constantly learning from one another, and discoveries in these areas would be broadly applicable, touching the lives of many Americans affected by neurological conditions.

Repurposed Drugs Hold Great Promise for Parkinson's

Testing drugs that have been approved to treat one disease to see if they are safe and effective for other conditions is called repurposing. Because they are already available, repurposed drugs typically progress more quickly through the drug development pipeline and reach patient hands faster.

Inosine, a dietary supplement, and isradipine, a blood pressure drug, are promising therapies that may be repurposed for the treatment of Parkinson's disease. Inosine raises levels of urate, an antioxidant, which is associated with a slower rate of disease progression in people with PD. Isradipine targets a particular type of calcium channel on the brain cells that are typically lost in Parkinson's, potentially preventing cell death. MJFF supported pre-clinical work on both of these drugs and Phase II trials of inosine. NIH is now supporting Phase III trials of both. This exemplifies how public and private researchers and funding can work together to move science forward and improve patients' lives.

INCREASED DATA NEEDED TO SPEED BREAKTHROUGHS

While there are rough estimates of the number of people diagnosed with Parkinson's, 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 by the 21st Century Cures Act, will collect data on the number and location of people with neurological diseases. The surveillance system aims to facilitate neurological disease research by gathering vital information related to age, race, sex, geographic location and family history. 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. The 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.

To accomplish this goal, the bill authorizes \$5 million to be appropriated to the Centers for Disease Control for fiscal years 2018 through 2022. With this funding, we can begin to lay the groundwork for research that will lead to new therapies and healthcare service allotments, saving future costs and improving quality of life for people with neurological diseases. It is important that the CDC receives full funding in order to create the system.

CONTINUED SUPPORT FOR RESEARCH IS CRITICAL TO DRIVE PROGRESS

Momentum in Parkinson's disease research is strong. Today, we have the best pipeline for new treatments that we've seen in decades. Robust investments in NIH and the CDC will continue to propel research forward, leading to life-changing treatments and, ultimately, a cure. Please increase NIH funding by at least two billion over fiscal year 2017 and allocate \$5 million for the CDC's surveillance system. Thank you for the opportunity to testify.

[This statement was submitted by Todd Sherer, Chief Executive Officer, The Michael J. Fox Foundation for Parkinson's Research.]

PREPARED STATEMENT OF THE MUSEUM OF SCIENCE

Chairman Blunt, Ranking Member Murray, and members of the subcommittee:

As president and director of the Museum of Science, Boston, I appreciate the opportunity to submit this written statement in support of the Institute of Museum and Library Services. On behalf of our 1.4 annual visitors, 300 plus employees and 10.5 million students impacted by our engineering curricula programs, I respectfully urge the subcommittee to continue its investment in museums in fiscal year 2018 by fully funding the Office of Museum Services (OMS) at the Institute of Museum and Library Services (IMLS) at the authorized level of \$38.6 million. Most recently, a record 37 of your Senate colleagues joined a bipartisan letter calling for robust funding in fiscal year 2018 for the OMS at the IMLS.

While we are grateful for the subcommittee's recommendation of \$31.269 million for OMS in its fiscal year 2017 omnibus, we are equally alarmed by the proposed near elimination of the IMLS in the fiscal year 2018 Administration's proposed budget. This relatively small Federal competitive grant program is an important investment in fostering STEM education, revealing our planet's scientific wonders, educating students and lifelong learners, and bolstering local economies around the country. For every Federal dollar the Museum receives in Federal competitive grants, we are able to garner an additional \$3-\$4 in private and philanthropic donations. These museum funders realize the value of Federal competitive peer-reviewed grants as something akin to the "Good Housekeeping" stamp of approval.

The Museum of Science OMS grants have enabled us to tackle the following research topics and visitor enhancements:

- We designed, prototyped and evaluated two new Design Challenges focused specifically on the active engagement of girls visiting the museum in coed student groups. This advanced the museum's ability to identify and anticipate gender differences, explore their significance, and adjust programming accordingly to better empower girls and women for living and working in a world where science, technology, engineering, and math skills are increasingly essential.
- We conducted a research study for the museum field to enhance understanding of the institutional conditions that prevent museum professionals from including people with disabilities in museum learning. We generated new understandings to alter institutional conditions, cultures, and practices so that museum professionals are better able to create museum learning experiences that are welcoming and inclusive of people with disabilities.
- We then designed exhibits that incorporated our new understandings and principles of universal design for learning and are inclusive of visitors with disabilities.
- We incorporated innovative digital projection system and highly sophisticated software platform to present cutting edge visitor experiences in earth and space science.
- We created a cluster of online and physical resources and tools for educators to implement new K-12 science standards that specifically focus on engineering and technology.

As a result, of these investments, we were able to better inform our visitors and the science museum field at large creating a multiplier effect throughout the Nation. We know science museums are economic engines and play an essential role in the Nation's educational infrastructure, spending more than \$2 billion a year on education. They are also community anchors, addressing challenges in the fields of engineering, technology, energy, health, and wellness.

IMLS is driven by its mission to inspire libraries and museums to advance innovation, lifelong learning, and cultural and civic engagement by providing leadership through research, policy development, and grant making. OMS offers and administers competitive grant programs that undergo a rigorous peer review process in an effort to identify well-designed projects in communities across the country.

For these reasons, we urge to support the OMS at IMLS at its authorized level of \$38.6 million.

[This statement was submitted by Ioannis Miaoulis, President and Director, Museum of Science.]

PREPARED STATEMENT OF THE NATIONAL ACADEMIES OF SCIENCES

The first recommendation of the National Academies of Sciences, Engineering, and Medicine (NAS) report *Hearing Health Care for Adults: Priorities for Improving Access and Affordability* is to “Improve population-based information on hearing loss and hearing healthcare.” In short, we need more information and data about hearing loss to have a better understanding of, at a minimum, risk factors associated with hearing loss, hearing healthcare needs, and the impact of hearing loss and its treatment on health, function, economic productivity and quality of life.

The National Institute on Deafness and Other Communication Disorders (NIDCD) at the National Institutes of Health (NIH) has been at the forefront of research since its authorization in 1988. As NIDCD Director James F. Battey, Jr., M.D., Ph.D., has said, “NIDCD-supported scientists have made astonishing advances in the NIDCD’s mission areas of hearing, balance, taste, smell, voice, speech, and language. Numerous discoveries have expanded our knowledge base and led to improved diagnosis, treatment, and technology for people with communication disorders.”

HLAA recently submitted written testimony to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies to support increased funding for the NIH. In our testimony we spoke of the strong role of the NIDCD in advancing research on hearing healthcare. We also noted that NIH funding for fiscal year 2017 has not yet been finalized. We urged Congress to act to finalize the funding for 2017 and move forward with an increased budget for fiscal year 2018.

Read our full testimony.

The American College of Radiology (ACR) has submitted testimony with the House Labor, Health and Human Services, Education and Related Agencies (LHHS) Appropriations Subcommittee supporting increased funding in fiscal year 2018 for the National Institutes of Health (NIH). The subcommittee held a hearing March 8 to collect input from public stakeholders and NIH advocacy groups.

The ACR’s testimony supported the recommendation of the Ad Hoc Group for Medical Research—a coalition of more than 300 patient and voluntary health groups, medical and scientific societies, academic and research organizations, and industry. It asks Congress to increase the NIH budget by at least \$2 billion above its fiscal year 2017 funding level, in addition to funds in the 21st Century Cures Act for targeted initiatives.

Testimony highlighted the important contributions of the National Cancer Institute and the National Institute of Biomedical Imaging Bioengineering (NIBIB) have made in the advancement of medical imaging and their importance to NIH’s value and success.

Subsequent to the LHHS Appropriations Subcommittee deliberations, the White House released the “President’s Budget Blueprint” on March 16 outlining administration priorities for fiscal year 2018. Among the requested \$54 billion in reductions to non-defense programs, the Budget Blueprint calls for a \$5.8 billion reduction for NIH, representing a decrease for the agency of approximately 19 percent. However, as always, Congress ultimately controls Federal spending via the appropriations process.

The ACR will submit similar testimony with the Senate LHHS Appropriations Subcommittee to reiterate its support for increased NIH funding in the next Federal fiscal year.

PREPARED STATEMENT OF THE NATIONAL ALLIANCE FOR EYE AND VISION RESEARCH

EXECUTIVE SUMMARY

NAEVR (National Alliance for Eye and Vision Research) thanks the Senate LHHS Appropriations Subcommittee for its leadership in supporting \$2 billion NIH funding increases in each fiscal year 2016 and fiscal year 2017. NAEVR urges Congress to reject the Trump Administration’s fiscal year 2018 budget proposal and support a \$2 billion NIH funding increase to \$36.1 billion to continue the pattern of predictable and sustained funding increases to rebuild NIH’s base—which had lost 22 per-

cent of purchasing power since fiscal year 2003, in terms of constant dollars, prior to the fiscal year 2016/2017 increases. The fiscal year 2018 increase should bolster NIH base funding, especially for the Institutes and Centers—in addition to the supplemental funding for specific projects in the 21st Century Cures Act—reflecting real growth above biomedical inflation, estimated at 2.7 percent in fiscal year 2018.

NAEVR also urges Congress to fund the NEI (National Eye Institute) at \$800 million in fiscal year 2018 to continue to restore our Nation's commitment to vision research, since the Institute has lost nearly 25 percent of purchasing power since fiscal year 2003. Although the overall NIH increase in each fiscal year 2016 and 2017 was six percent, NEI's increase was only 4.6 percent and 2.3 percent, respectively, in fiscal year 2016 and 2017. Even more dramatic, NEI's fiscal year 2017 enacted funding level of \$733 million is just 4 percent greater than its pre-sequester fiscal year 2012 funding level, meaning that it had taken five fiscal years for its budget to experience any meaningful growth. We must maintain the momentum of vision research since vision health is vital to overall health and quality of life.

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. The convergence of factors that reduced past NEI funding has affected both early-stage and seasoned investigators, threatening the continuity of research and the retention of trained staff while making institutions more reliant on philanthropic funding.

NEI'S BUDGET IS NOT KEEPING PACE WITH THE BURDEN OF EYE DISEASE

NEI's fiscal year 2017 enacted budget of \$733 million is just 0.5 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/>.

As in fiscal years 2013–2016, NEI's fiscal year 2017 funding may be reduced even further as a result of a transfer back to the NIH Office of AIDS Research (OAR) for funding of the successfully completed NEI-sponsored Studies of the Ocular Complications of AIDS (SOCA). Although OAR's funding was not committed indefinitely to NEI, its return to NIH Central in the amounts of \$5.6 million (fiscal year 2013), \$6.9 million (fiscal year 2014), \$7.4 million (fiscal year 2015) and \$7.9 million (fiscal year 2016) have essentially cut NEI's budget further, resulting in new baselines upon which funding increases have been calculated.

During fiscal year 2016, a number of major studies issued that provide insight into the future burden of eye disease and blindness, including:

- 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>.
- In September 2016 the National Academies of Sciences, Engineering, and Medicine (NASEM, formerly the Institute of Medicine, IOM) issued a report entitled Making Eye Health a Population Health Imperative: Vision for Tomorrow. Recognizing that vision and eye health have not received the investment they warrant with respect to public health, NASEM presented nine recommendations regarding a national strategy for vision loss prevention that make a direct call for government action—especially by the Department of Health and Human Services that would directly engage the NEI— including a “Call to Action” and “Coordinated Public Awareness Campaign” to reduce the burden of vision impairment across the lifespan and promote policies and practices that encourage eye and vision health, as well as the creation of an “Interagency Workgroup” to develop a common research agenda that targets the leading causes, consequences, and unmet needs of vision impairment. <http://www.nationalacademies.org/hmd/Reports/2016/making-eye-health-a-population-health-imperative-vision-for-tomorrow.aspx>.

NEI RESEARCH IS VITAL IN MEETING VISION LOSS PREVENTION GOALS

NEI-funded vision research is critical to the NASEM report's goal of transforming vision impairments from common to rare and to eliminating correctable and avoidable vision impairments by year 2030. Without adequate funding, however, the NEI may not be able to fund breakthrough research—two examples of which include:

- NEI's Audacious Goals Initiative of regenerating neurons and neural connections in the eye and visual system, thereby restoring vision and returning individuals to productive, independent, and quality lives. Planned for the next 10–15 years, success would transform life for millions of Americans with eye diseases and have major implications for the future of the practice of medicine with respect to vision and neurological disorders. <https://nei.nih.gov/audacious/>
- NEI's prize competition, the 3-D Retina Organoid Challenge. Since blinding diseases are often caused by degeneration of the retina—the light-sensitive back of the eye—the challenge for the vision community is to build in lab dishes 3-dimensional retinas that closely resemble the architecture and function of the human eye. The “mini-retinas” will provide a human platform more relevant than animal models for researchers to better understand retinal biology and discover treatments for these diseases. <https://nei.nih.gov/content/3-d-roc-challenge-details>.

Our Nation's past NIH/NEI investment has resulted in tools to diagnose and monitor disease, as well as drug therapies to treat them. One such example is Optical Coherence Tomography (OCT), which is a non-invasive, high-speed, high-resolution imaging technology that displays a three-dimensional cross-sectional view of the layers of the retina. OCT is used to diagnose and monitor progression of diseases such as Age-related Macular Degeneration (AMD, the leading cause of vision loss) and Diabetic Retinopathy, the leading cause of vision loss in the working-age population. OCT has enabled better personalization of eye care to facilitate more efficient use of prescription drug therapies, saving Medicare billions of dollars over the last decade. As the technology continues to be applied to new medical conditions, such as Alzheimer's disease and Parkinson's disease, it supports a growing private industry of nearly \$1 billion and a workforce of more than 16,000.

INVESTING NOW IN THE NEI CAN SAVE ON FUTURE EXPENDITURES

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 \$6,690 per-person, per-year. <http://costofvision.preventblindness.org/>.

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.

CONGRESS SHOULD ROBUSTLY FUND THE NEI AS IT NEARS ITS 50TH ANNIVERSARY DURING THE “DECADE OF VISION 2010–2020”

In 2018, NEI will celebrate its 50th anniversary as the NIH's lead institute that manages and funds the Nation's research commitment to save and restore vision. In 2009, Congress recognized NEI's 40th anniversary by passing S. Res. 209 and H. Res. 366, which also designated 2010–2020 as “The Decade of Vision.” This decade especially reflects the growing public health problems of vision loss:

- The first wave of the “Silver Tsunami”—the 78 million aging Baby Boomers—will turn 65 in 2010, and each day for 18 years afterwards, about 10,000 Americans will turn 65 and be at greatest risk for eye disease. The 2014 Prevent Blindness study reports that the age 90-plus population will see the highest rates of growth in prevalence/cost of eye disease, including Cataract, AMD, Glaucoma, and Diabetic Eye Disease.
- African Americans and Hispanics, who increasingly account for a larger share of the population, experience both a disproportionately greater risk and prevalence of eye disease. The 2014 Prevent Blindness study noted that the \$717 bil-

lion annual cost by 2050 will also be driven by the incidence of Glaucoma and Diabetic Eye Disease in these populations.

—Vision loss is a co-morbid condition of many chronic diseases, such as diabetes, which is at epidemic levels due to the increased prevalence of obesity.

Congress has 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 a \$2 billion NIH increase in fiscal year 2018 to a funding level of \$36.1 billion, with NEI funding of \$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.eyeresearch.org.

[This statement was submitted by James Jorkasky, Executive Director, National Alliance for Eye and Vision Research.]

PREPARED STATEMENT OF THE NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS

NASTAD represents the Nation’s chief State health agency staff who have programmatic responsibility for administering HIV and viral hepatitis healthcare, prevention, education and supportive service programs funded by State and Federal Governments. On behalf of NASTAD, we urge your support for increased funding for Federal HIV and hepatitis programs in the fiscal year 2018 Labor-Health-Education Appropriations bill, and thank you for your consideration of the following critical funding needs for HIV and hepatitis programs in fiscal year 2018:

Agency	Program	NASTAD Funding Request (\$ million)
Health Resources and Services Administration	Ryan White Part B Base	437.5
Health Resources and Services Administration	Ryan White Part B ADAP	943.3
Centers for Disease Control and Prevention	Division of HIV Prevention	832.7
Centers for Disease Control and Prevention	Division of Viral Hepatitis	62.8

Domestic prevention efforts must match the commitment to the care and treatment of people who are living with HIV. To be successful, we must expand traditional efforts (e.g., outreach and screening for HIV/STDs) and scale-up proven new biomedical prevention modalities such as pre-exposure prophylaxis (PrEP) and treatment as prevention (TasP), while reimagining how the compendium of effective prevention tools can work in tandem to curb incidence in the United States. We must also prioritize funding and efforts to the populations most disproportionately impacted by HIV in the United States—men who have sex with men (MSM), especially young MSM of color. Among the services necessary to improve health outcomes are the needs for linkage to, and retention in care, and access to medications that suppress viral load, reducing HIV transmission, which make HIV more difficult to transmit—ultimately leading to fewer new infections. The Centers for Disease Control and Prevention (CDC)’s prevention programs and the Ryan White Program are crucial to preventing new infections and improving health outcomes.

HIV/AIDS CARE AND TREATMENT PROGRAMS

The Health Resources and Services Administration (HRSA) administers the \$2.3 billion Ryan White Program that provides health and support services to more than 500,000 people living with HIV (PLWH). NASTAD requests a minimum increase of \$65.8 million in fiscal year 2018 for State Ryan White Part B grants, including an increase of \$22.8 million for Part B and \$43 million for AIDS Drug Assistance Programs (ADAPs). The Ryan White Part B Program funds State health departments to provide care, treatment and support services for low-income uninsured and underinsured individuals living with HIV. With these funds States and territories provide access to HIV clinicians, life-saving and life-extending therapies and a full range of vital coverage completion services to ensure adherence to complex treatment regimens. The State ADAPs provide medications to low-income PLWH who have limited or no coverage from private insurance, Medicare and/or Medicaid.

Throughout and following the ACA implementation, health departments will require capacity-building support in order to create new infrastructure and leverage

existing systems to ensure continuous, high quality care for PLWH. The Ryan White Program will continue to serve PLWH in order to ensure that clients do not experience gaps in coverage or access to treatment.

HIV/AIDS PREVENTION AND SURVEILLANCE PROGRAMS

NASTAD requests an increase of \$77 million in fiscal year 2018 for CDC's Division of HIV Prevention. The flagship HIV prevention program, HIV Prevention by Health Departments, funds State and local health departments to provide the foundation for HIV prevention and control nationwide. Health departments are the cornerstone implementers of Federal public health policy and are essential to lowering HIV infections. HIV prevention activities and services are targeted to communities where HIV is most heavily concentrated, particularly among racial and ethnic minorities and gay men/MSM of all races and ethnicities.

The number of new HIV infections must decrease to address in order to see meaningful improvements in individual and community level health outcomes, particularly among disproportionately impacted populations. It is increasingly clear that early detection, linkage to and retention in care, and adherence to treatment will suppress individual and community viral loads and reduce the incidence of HIV. Unfortunately, only thirty percent of people living with HIV have an undetectable viral load. Addressing interventions along the HIV care continuum is our newest and most effective tool to get to zero new HIV infections; however, health departments need additional support to successfully implement these strategies.

Robust surveillance systems are essential for high-impact prevention, including using surveillance data for program planning and response, strategically directing resources to populations and geographic areas and linking and retaining individuals in care. Additional resources will allow improvements in core surveillance and expand surveillance for HIV incidence, behavioral risk and receipt of point of care information, including CD4 and viral load reporting. This will, in turn, contribute to improved testing and linkage to care, retention and re-engagement in care, and reducing risk behaviors.

NASTAD requests that the Committee allow States and localities the discretion to use Federal funds to support cost-effective and scientifically proven, syringe services programs (SSPs). Overwhelming scientific evidence has shown SSPs and access to sterile syringes are an evidenced-based and cost-effective means of lowering HIV and hepatitis infection rates, reducing use of illegal drugs and helping connect people to HIV and hepatitis medical treatment, including substance abuse treatment.

VIRAL HEPATITIS PREVENTION PROGRAMS

NASTAD requests an increase of \$31.5 million in fiscal year 2018 for the CDC's Division of Viral Hepatitis (DVH). This increase will better enable State and local health departments to provide the basic, core public health services to combat hepatitis, increase surveillance, testing and education efforts nationwide and effectively implement the recommendations set by the IOM's Hepatitis and Liver Cancer: A National Strategy for Prevention and Control of Hepatitis B and C, the Action Plan for Viral Hepatitis, and the CDC and United States Preventive Services Task Force (USPSTF) viral hepatitis testing recommendations for populations with risk factors, including baby boomers.

NASTAD requests that CDC dedicate at least \$10.5 million for the viral hepatitis prevention coordinators (VHPC) program to support and expand programs in all existing jurisdictions. The IOM report and the Viral Hepatitis Action Plan, set prevention goals, established program priorities and assigned responsibilities for actions to HHS operating divisions, including CDC. In turn, CDC has provided funds to State and local health departments to coordinate prevention and surveillance efforts via the VHPC. For over a decade, the VHPC program has been and remains the only national program dedicated to the prevention and control of the hepatitis epidemics. The CDC has estimated that up to 5.3 million people are living with hepatitis B (HBV) and/or hepatitis C (HCV) in the United States and as much as 75 percent are not aware of their infection. Additionally, recent alarming epidemiologic reports indicate a rise in HCV infection among young people throughout the country. Some jurisdictions have noted that the number of people ages 15 to 29 being diagnosed with HCV infection now exceeds the number of people diagnosed in all other age groups combined—a trend that is following the prescription drug overdose epidemic and increasing use of heroin in rural and suburban areas. NASTAD encourages the committee to prioritize disproportionately impacted populations and increase funding for primary prevention efforts.

As you contemplate the fiscal year 2018 Labor-Health-Education Appropriations bill, we ask that you consider all of these critical funding needs. We thank the

Chairman, Ranking Member and members of the Subcommittee, for their thoughtful consideration of our recommendations. Our response to the HIV and hepatitis epidemics in the United States defines us as a society, as public health agencies, and as individuals living in this country. There is no time to waste in our Nation's fight against these epidemics.

[This statement was submitted by Murray Penner, Executive Director, National Alliance of State and Territorial AIDS Directors.]

PREPARED STATEMENT OF NATIONAL ALLIANCE ON MENTAL ILLNESS

Chairman Blunt and members of the Subcommittee, I am Mary Giliberti, Chief Executive Officer of NAMI (the National Alliance on Mental Illness). I am pleased, today, to offer NAMI's views on the Subcommittee's upcoming fiscal year 2017 bill. NAMI is the Nation's largest grassroots advocacy organization dedicated to building better lives for the millions of Americans affected by mental illness.

Through NAMI State Organizations and over 900 NAMI Affiliates across the country, we raise awareness and provide support, education and advocacy on behalf of people living with mental health conditions and their families.

An estimated 1 in 5 people live with a mental health condition in the United States which means more than 43 million Americans are affected. Almost 10 million of those live with a serious mental illness, such as schizophrenia, bipolar disorder, and major depression. People with mental health conditions are our neighbors, our families and ourselves. They work in all sectors of the U.S. economy, from the boardroom to the factory floor, from academia to art.

But, without investment in research and appropriate services and supports, the social and economic costs associated with mental health conditions are tremendous.

Over 42,000 American lives are lost each year to suicide, more than 2 ½ times the number of lives lost to homicide. Suicide is the 2nd leading cause of death for Americans age 15–24 and the 10th leading cause of death for adults.

Mental illness is the 3rd most costly medical condition in terms of overall healthcare expenditures, behind only heart conditions and traumatic injury. The direct and indirect financial costs associated with mental illness in the U.S. has been estimated to be well over \$300 billion annually.

Investing in mental health research and services and supports can make these startling statistics a thing of the past and improve the lives of millions of Americans who live with mental health conditions and their families. NAMI views these investments as the highest priority for our Nation and this Subcommittee.

National Institute of Mental Health (NIMH) Research Funding

As a member of the Ad Hoc Group for Medical Research Funding, NAMI supports an overall allocation of no less than \$35 billion for the National Institutes of Health (NIH). This \$2.3 billion increase represents 5 percent real growth above the projected rate of biomedical inflation and will help ensure that NIH-funded research can continue to improve our Nation's health and enhance our competitiveness in today's global information and innovation-based economy. It also includes the projected \$352 million in additional funding set forth in the 21st Century Cures bill that was signed into law in December—\$86 million of which is allocated for the BRAIN Initiative. As you know, an outline of the President's fiscal year 2018 budget is expected to be released as early as next week. Press reports reveal that the Trump Administration is poised to ask Congress to impose deep cuts on Non-Defense Discretionary (NDD) spending and again subject NDD to possible sequestration in fiscal year 2018. This would be disastrous for the progress that has been made over the past 2 years to get small increases for the NIH. Congress and the President need to come to an agreement that would allow for an upward adjust to the caps on NDD and a removal of the threat of a sequester.

Fiscal Year 2017 Continuing Resolution

Mr. Chairman, as you know, the NIH and NIMH are still operating under a continuing resolution for fiscal year 2017. The \$1.8 billion increase for the NIH in this Subcommittee's draft fiscal year 2017 bill enjoyed strong bipartisan support. NAMI would urge you to press forward to secure this increase as part of any omnibus appropriations bill or continuing resolution for the remaining months of fiscal year 2017. For NIMH, the consequences are significant. For example, under the House bill NIMH could fund an additional 130 new and competing research grants with the \$1.6 billion allocation that was in your bill, and an additional 170 grants under the draft Senate bill. NAMI urges you to fight for these resources for NIH and flat funding through the rest of this fiscal year.

Supporting the NIMH Strategic Plan

NAMI supports the current 5-year NIMH 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 eventually 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.

Accelerating the Pace of Psychiatric Drug Discovery

In NAMI's view, there is an urgent need for new medications to treat serious mental illness. Existing medications can be helpful, but they often have significant limitations; in some cases requiring weeks to take effect, failing to relieve symptoms in a significant proportion of patients, or resulting in debilitating side effects. However, developing new medications is a lengthy and expensive process. Many promising compounds fail to prove effective in clinical testing after years of preliminary research. To address this urgent issue, NAMI is encouraging NIMH to accelerate the pace of drug discovery through an 'experimental medicine' approach to evaluate novel interventions for mental illnesses. This "fast-fail" strategy is designed not only to quickly identify candidates that merit more extensive testing, but also to identify targets in the brain for the development of additional candidate compounds. Through small trials focused on proof-of-concept experimental medicine paradigms, we can make progress to demonstrate target engagement, safety, and early signs of efficacy.

Advancing Services and Intervention Research

NAMI enthusiastically supports the NIMH Recovery After an Initial Schizophrenia Episode (RAISE) Project, aimed at preventing the long-term disability associated with schizophrenia by intervening at the earliest stages of illness. The RAISE Early Treatment Program (RAISE ETP) will conclude this year. The RAISE Connection Program has successfully integrated a comprehensive early intervention program for schizophrenia and related disorders into an existing medical care system. This implementation study is now evaluating strategies for reducing duration of untreated psychosis among persons with early-stage psychotic illness. NAMI also urges investment in continued studies into maintaining the gains made with Coordinated Specialty Care services over the long-term and in expanding research into similarly effective interventions with young people struggling with other serious mental illnesses, such as bipolar disorder.

When individuals with schizophrenia and bipolar disorder progress to later stages of their illness, they become more likely to develop—and die prematurely—from medical problems such as heart disease, diabetes, cancer, stroke, and pulmonary disease than members of the general population. NIMH-funded research is demonstrating progress in improving the health of people with serious mental illness. NIMH needs to advance this research to large-scale clinical trials aimed at reducing premature mortality with people living with serious mental illness.

Investing in Early Psychosis Prediction and Prevention (EP3)

As many as 100,000 young Americans experience a first episode of psychosis (FEP) each year. The early phase of psychotic illness is a critical opportunity to alter the downward trajectory and social, academic, and vocational challenges associated with serious mental illnesses such as schizophrenia. The timing of treatment is critical; short- and long-term outcomes are better when individuals begin treatment close to the onset of psychosis. Unfortunately, the majority of people with mental illness experience significant delays in seeking care—up to 2 years in some cases. Such delays result in periods of increased risk for adverse outcomes, including suicides, incarceration, homelessness and in a small number of cases, violence.

NIMH-funded research has focused on the prodrome, the high-risk period preceding the onset of the first psychotic episode of schizophrenia. Through the North American Prodrome Longitudinal Study (NAPLS) and other studies focused on early prediction and prevention of psychosis, NIMH has launched the Early Psychosis Prediction and Prevention (EP3) initiative. EP3 is showing 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

NAMI supports efforts at NIMH to translate basic research findings on brain function into more person-centered and multifaceted diagnoses and treatments for mental disorders. The Research Domain Criteria (RDoC) is showing promise toward efforts to build a classification system based more on underlying biological and basic behavioral mechanisms than on symptoms. Through continued development, RDoC should begin to give us the precision currently lacking with traditional diagnostic approaches to mental disorders.

Funding for Programs at SAMHSA's Center for Mental Health Services (CMHS)

As noted above, the costs of untreated mental illness to our Nation are enormous—as high as \$300 billion when taking into account lost wages and productivity and other indirect costs. These costs are compounded by the fact that, across the Nation, States and localities devote enormous resources to addressing the human and financial costs of untreated mental illness through law enforcement, corrections, homeless shelters and emergency medical services. This phenomenon of “spending money in all the wrong places” is tragic given that we have a vast array of proven evidence-based interventions that we know work, such as assertive community treatment (ACT), supported employment, family psycho-education and supportive housing for adults and interventions such as Incredible Years, multi-systemic therapy (MST) and functional family therapy (FFT) for children and families.

NAMI supports programs at the Center for Mental Health Services (CMHS) at SAMHSA that are focused on replication and expansion of these evidence-based practices that serve children and adults living with serious mental health conditions. The most important of these programs is the Mental Health Block Grant (MHBG). NAMI is extremely grateful for the \$50 million increase for the MHBG that this Subcommittee enacted for fiscal year 2016, boosting funding to \$532.57 million that remains in place in the current fiscal year.

NAMI strongly supports the 10 percent set aside in the in the MHBG for early intervention in psychosis—a requirement that was codified in the 21st Century Cures law. 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 decision-making—which NAMI strongly supports—with the recipient of services taking an active role in determining treatment preferences and recovery goals.

In 2014, CMHS issued guidance to the States specifying that funding as part of this set aside must be used for those who have developed the symptoms of early serious mental illness, not for “preventive intervention for those at high risk of serious mental illness.” NAMI supports this guidance and we recommend that the Subcommittee continue this 10 percent set aside for FEP in fiscal year 2018. It is critically important for Congress to continue supporting the replication of evidence-based FEP programs in all 50 States.

NAMI also recommends the following priorities for CMHS for fiscal year 2018:

- Continuation of the Children’s Mental Health program at \$117 million,
- Suicide prevention programs under the Garrett Lee Smith Memorial Act at \$41.6 million,
- Continuation of the \$15 million in funding for States and localities as part of the Assisted Outpatient Treatment (AOT) pilot program that Congress reauthorized in the 21st Century Cures law. NAMI supports efforts develop a variety of approaches to engaging people with serious mental illness in treatment, including voluntary approaches for engaging people before they reach the point of requiring court-based interventions.
- Allowing children’s mental health System of Care dollars to be used to address the prodrome phase of psychosis (early prediction and prevention) and to support outreach and engagement of youth in order to reduce the duration of untreated psychosis.
- \$12.5 million for crisis services and online bed registry databases

Early Mortality and Serious Mental Illness, Integrating Primary and Behavioral Health Care

The CMHS Primary Behavioral Health Care Integration (PBHCI) program supports community behavioral health and primary care organizations that partner to provide essential primary care services to adults with serious mental illnesses. Because of this program, more than 33,000 people with serious mental illnesses and substance use disorders are screened and treated at 126 grantee sites for diabetes, heart disease, and other common and deadly illnesses in an effort to stem the

alarming early mortality rate from these health conditions in this population. NAMI urges the Subcommittee to continue to fund PBHCI at \$50 million.

Addressing the Needs of Homeless Individuals Living with Serious Mental Illness

NAMI recommends allocating \$100 million for services in permanent supportive housing at CMHS. Years of reliable data and research demonstrate that the most successful intervention to solve chronic homelessness is linking housing to appropriate support services. Current SAMHSA investments in homeless programs are highly effective and cost-efficient. However, funding for SAMHSA homeless programs has remained flat for the past 4 years, often making it difficult for communities to increase the number of homeless households they are serving with the service dollars. As communities are investing additional housing resources into serving high-need homeless populations, Congress should increase investments in services to help those populations address their long-term health related issues.

For the Projects for Assistance in Transition from Homelessness (PATH) program, NAMI recommends \$75 million for fiscal year 2018. PATH provides funding for essential outreach to homeless people with serious mental illness and helps them navigate both the homeless and mainstream services systems to get the services they need. PATH-supported programs served over 185,000 people through outreach in fiscal year 2014. Of these, 28 percent were unsheltered at the time they started receiving PATH services. 64 percent needed mental health services and 52 percent had co-occurring substance use disorders. NAMI also recommends an allocation of \$10 million from PATH to a demonstration program to create permanent statewide coordination capacity for the SSI/SSDI Outreach, Access and Recovery (SOAR) program. Finally, NAMI urges an allocation of \$100 million, the fully authorized level, for services for people experiencing homelessness within the Programs of Regional and National Significance (PRNS) accounts of both SAMHSA's Center for Mental Health Services and Center for Substance Abuse Treatment.

CONCLUSION

Chairman Blunt, thank you for the opportunity to share NAMI's views on the Labor-HHS-Education Subcommittee's fiscal year 2018 bill. NAMI's members across the country thank you for your leadership on these important national priorities.

[This statement was submitted by Mary Giliberti, Chief Executive Officer, National Alliance on Mental Illness.]

PREPARED STATEMENT OF THE NATIONAL ALLIANCE TO END SEXUAL VIOLENCE

The National Alliance to End Sexual Violence (NAESV), the voice in Washington for the 56 State and territorial sexual assault coalitions and local programs working to end sexual violence and support survivors, respectfully asks the committee to increase the appropriation for the Rape Prevention and Education Program (RPE) from the current fiscal year 2017 funding level of \$44.4 million with \$5.6 million of that amount going to evaluation to the full authorization of \$50 million to ensure States have adequate funding to meet the demand for prevention education in their communities. 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. If our children are to face a future free from sexual violence, RPE must be fully funded.

Those who have been victimized by sexual violence are more likely to be re-victimized AND those who have perpetrated are more likely to reoffend, pointing to the increased need to stop the violence before it ever happens. 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 2016 survey by the NAESV revealed that almost 40 percent of programs had a waiting list of a month or more for prevention programming.

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.”

NAESV additionally recommends the following report language to ensure adequate funding for States:

At least 75 percent of the funds appropriated for the Rape Prevention & Education Program must go to States for the purpose of local and State rape prevention activities.

Currently, States and territories receive approximately 72 percent of RPE funds. While we support national efforts to evaluate the RPE program and build the evi-

dence base for sexual violence prevention, local communities cannot meet the demand for prevention and must be assured an adequate percentage of RPE goes out by formula to the States.

[This statement was submitted by Terri Poore, Policy Director, National Alliance to End Sexual Violence.]

PREPARED STATEMENT OF THE NATIONAL ALOPECIA AREATA FOUNDATION
THE ASSOCIATIONS'S FISCAL YEAR 2018 L–HHS APPROPRIATIONS RECOMMENDATIONS

—At least \$36 billion in program level funding for the National Institutes of Health (NIH).

—Proportional funding increases for National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), National Institute of Allergy and Infectious Diseases (NIAID) and the National Center for Advancing Translational Science (NCATS)

Chairman Blunt and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the community of individuals affected by alopecia areata as you work to craft the fiscal year 2018 L–HHS Appropriations Bill.

ABOUT ALOPECIA AREATA

Alopecia areata is a prevalent autoimmune skin disease resulting in the loss of hair on the scalp and elsewhere on the body. It usually starts with one or more small, round, smooth patches on the scalp and can progress to total scalp hair loss (alopecia totalis) or complete body hair loss (alopecia universalis).

Alopecia areata affects approximately 2.1 percent of the population, including more than 6.5 million people in the United States alone. The disease disproportionately strikes children and onset often occurs at an early age. This common skin disease is highly unpredictable and cyclical. Hair can grow back in or fall out again at any time, and the disease course is different for each person. In recent years, scientific advancements have been made, but there remains no cure or indicated treatment options.

The true impact of alopecia areata is more easily understood anecdotally than empirically. Affected individuals often experience significant psychological and social challenges in addition to the biological impact of the disease. Depression, anxiety, and suicidal ideation are health issues that can accompany alopecia areata. The knowledge that medical interventions are extremely limited and of minor effectiveness in this area further exacerbates the emotional stresses patients typically experience.

ABOUT THE FOUNDATION

NAAF, headquartered in San Rafael, California, supports research to find a cure or acceptable treatment for alopecia areata, supports those with the disease, and educates the public about alopecia areata. NAAF is governed by a volunteer Board of Directors and a prestigious Scientific Advisory Council. Founded in 1981, NAAF is widely regarded as the largest, most influential, and most representative foundation associated with alopecia areata. NAAF is connected to patients through local support groups and also holds an important, well-attended annual conference that reaches many children and families.

Recently, NAAF initiated the Alopecia Areata Treatment Development Program (TDP) dedicated to advancing research and identifying innovative treatment options. TDP builds on advances in immunological and genetic research and is making use of the Alopecia Areata Clinical Trials Registry which was established in 2000 with funding support from the National Institute of Arthritis and Musculoskeletal and Skin Diseases; NAAF took over responsibility financial and administrative responsibility for the Registry in 2012 and continues to add patients to it. NAAF is engaging scientists in active review of both basic and applied science in a variety of ways, including the November 2012 Alopecia Areata Research Summit featuring presentations from the Food and Drug Administration (FDA) and NIAMS.

THE PATIENT PERSPECTIVE

Testimony 1—Juanita Lawrence, Millington, NJ

My daughter, Corinne, is 7 years old and has alopecia areata. Last year she lost all of her hair in a two week period. This was a very difficult time for our whole family. Every day activities are more difficult for my child to take part in. Her appearance attracts attention wherever we go. She is constantly treated differently, stared at, teased, questioned, and made to feel different. As an adult I have a hard time dealing with people's reactions toward her so I can't imagine how she copes with it on a constant basis. There is anxiety in any simple outing, starting a new class, riding the bus, going to a party, school, play grounds, grocery stores, the list is endless. Corinne sees a therapist that addresses her anxiety, self-esteem, confidence, and behavior changes attributed to her sudden hair loss. We have tried steroid creams that severely irritated her scalp so we discontinued using them. It is frustrating because all of the therapies are not guaranteed and often are either painful injections or irritating creams. This disease is not life threatening but it is life altering. The emotional toll is debilitating. I am so proud of my daughter but my heart breaks because of the struggles she has to face due to this auto immune disease and her loss of hair.

Testimony 2—Vashti Wood, Reston, VA

My daughter Sophia, now 9 has, alopecia universalis. She was first diagnosed at 5. The first time only 40–50 percent fell out and then grew back and for almost 3 years she had a full head that she combed admiringly many times a day and was a bit obsessed with it for her age but I could understand since she had experienced the loss. About a year ago, I noticed a bald spot the size of a pencil eraser and within days it was the size of a softball, and within weeks every piece of her beautiful hair was gone. One of the hardest things in my life was trying to stay strong for her and not burst into tears every time I looked at her beautiful face and bald head, but I had to be because she was not. It was devastating to her and she cried and cried. A few months ago her eyebrows disappeared and then her eyelashes. She is a vibrant girl and one who had much confidence but this condition has taken that away. I fear for the challenges she has ahead of her, going into puberty and middle school is so stressful and hard even for those that appearance is perfect, that I will do anything and everything in my power to try to find a way to get her hair back. We have put thousands of dollars on credit cards this past year for hair accessories, a wig, (that insurance doesn't cover at all), and of course a dermatologist to no avail unless I would like to inject steroids into my 9 year old. No thanks! My husband and I fight over what I am spending and doing and that breaks our daughter's heart even more, but I refuse to not keep trying. I have asked her, do you want me to keep searching, trying things or do you want me to stop? She wants me to keep on finding a way to get her hair back.

NATIONAL INSTITUTES OF HEALTH

NIH hosts a modest alopecia areata research portfolio, and the Foundation works closely with NIH to advance critical activities. NIH projects, in coordination with the Foundation, have the potential to identify biomarkers and develop therapeutic targets. In fact, researchers at Columbia University Medical Center (CUMC) have identified the immune cells responsible for destroying hair follicles in people with alopecia areata and have tested an FDA-approved drug that eliminated these immune cells and restored hair growth in a small number of patients. This huge breakthrough has led to NIAMS providing a research grant to the researchers at Columbia to continue this work. In this regard, please provide NIH with meaningful funding increases to facilitate growth in the alopecia areata research portfolio.

ADDITIONAL ACTIVITIES

FDA nominated alopecia areata as a potential condition for specific review through the Patient-Focused Drug Development Initiative (PFDDI). The condition was chosen as many of the impacts of alopecia areata have to be reported by patients and cannot be measured biologically. While we appreciate that FDA falls under the jurisdiction of the Agriculture Appropriations Subcommittee, we ask that you work with your colleagues on the Appropriations Committee to support this important program.

Thank you for your time and your consideration of the community's requests.

[This statement was submitted by Dory Kranz, Chief Executive Officer, National Alopecia Areata Foundation.]

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION FOR GERIATRIC EDUCATION

As president and past president of the National Association for Geriatric Education (NAGE), we are pleased to submit this statement for the record recommending at least \$51 million in fiscal year 2018 to support geriatrics programs under the Geriatrics Workforce Enhancement Program (GWEP) administered by the Health Resources and Services Administration (HRSA). We thank you for your past support and hope our testimony provides ample justification to continue this critical workforce program despite the recommendation that the program be eliminated.

The aging of the US population is well documented and celebrated across all racial and ethnic populations. Our current 47.8 million adults 65 and over represents an increase of 30 percent in just 10 years (2005) with projections of 98 million older adults in 2060. Importantly, aging is also occurring within older Americans; the 85+ population which is currently 6.7 million, will more than double to 14.6 million in 2040. As age increases, we know risk for dementia increases and older adults may need more assistance from family or paid caregivers for supports and services. These population increases require a workforce that is prepared to care for older adults in primary care and in all community and long-term care settings.

Currently, the Geriatrics Workforce Enhancement Program (GWEP) is the only Federal program designed to improve healthcare quality and safety for older adults, plus reduce associated costs of care through appropriate training of healthcare professionals, caregivers, and direct service workers. In 2015 the Health Resources and Services Administration (HRSA) combined the geriatric education programs in Titles VII and VIII along with portions of the Alzheimer's Disease Prevention, Education, and Outreach Program to establish GWEPs.

Our 44 funded GWEPs in academic year 2015–16, have provided geriatric focused degree programs, field placements, and fellowships for 18,451 students and fellows; 59 percent of this training was in primary care and 35 percent of the care sites are located in underserved communities. GWEPs also provided 104,657 faculty and practicing professionals' trainings in 1,173 unique continuing education courses to improve care and practice for current healthcare professionals because older adults are served by current practitioners. Thousands of healthcare providers and family caregivers are better prepared as a result of these trainings. GWEPs are critical to the training of physicians, nurse practitioners, physician assistants, dentists, behavioral and mental health professionals, pharmacists, nurses, rehabilitation therapists, social workers, podiatrists, public health, allied health and other professionals providing care for frail and vulnerable older adults. Importantly, GWEPs all over the country also train family caregivers, volunteers, direct care staff and others who provide paid and unpaid care to older adults.

NAGE requests a total of at least \$51 million for GWEPs. Our funding request would allow for eight additional GWEPs in rural and underserved communities. In this request, we propose to reestablish the Geriatrics Academic Career Award (GACA) by providing \$100,000 to each GWEP to create a GACA. Current funding is \$38.7 million in fiscal year 2016. We recognize that the Subcommittee faces tough decisions in a constrained budget environment, but we believe that a continued commitment to geriatric education programs that help the Nation's health professions better serve the older and disabled population is critical. The Nation faces a shortage of geriatric health professionals. There simply are not enough geriatricians, geriatric nurse practitioners and other health professionals trained to care for this rapidly increasing older population.

We all have stories of poor communication, conflicting multiple medications, dangerous transitions across care settings, and inappropriate hospitalizations. 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 a rare and expensive resource and (b) direct service workers and family caregivers are prepared to support a lower cost, independent lifestyle for community residing elders.

GWEP centers train healthcare professions faculty, students, and field practitioners in interprofessional diagnosis, management and prevention of disease, disability, and other chronic health problems of older adults. They encourage team-based care, demand evidence-based practice, and appropriate management of older adults among caring professionals.

—Grantees also provided more than 1,349 different curricular most of which were new continuing education, academic courses and workshops which reached 57,557 people.

—GWEP grantees supported 331 different faculty-focused training programs and activities during the academic year, reaching 6,103 faculty-level trainees.

New GWEP awardees received expanded authorization to provide to family caregivers and direct service workers 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.

Geriatric education programs 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. We need your continued support for geriatric programs to adequately prepare the next generation of health professionals for the rapidly changing and emerging needs of the growing and aging population.

We absolutely agree with President Trump’s proclamation during Older Americans month “that, as we age, many of us will need more assistance from our friends and family. We therefore recommit ourselves to ensuring that older Americans are not neglected or abused, receive the best healthcare available, live in suitable homes, have adequate income and economic opportunities, and enjoy freedom and independence in their golden years. They deserve—and we owe them—nothing less.” To give older Americans the best healthcare, access to services and to ensure older adults are not abused and neglected, geriatric workforce enhancement programs are critical.

On behalf of NAGE and those who have benefitted in Florida and North Carolina and from our colleagues around the country, thank you for this opportunity to share our request for support for these critical programs. We ask that you thoughtfully consider our request for the modest increased funding of GWEPs in fiscal year 2018.

NAGE is a non-profit membership organization representing Geriatrics Workforce Enhancement Programs, Geriatric Education Centers, and other programs that provide education and training to health professionals in the areas of geriatrics and gerontology.

[This statement was submitted by Kathryn Hyer, PhD, MPP, Professor, School of Aging Studies, Director, Fl., Policy Exchange Center on Aging, College of Nursing, University of South Florida; and Jan Busby-Whitehead, MD, Mary and Thomas Hudson Distinguished Professor of Medicine, Chief, Division of Geriatric Medicine, Department of Medicine, Director, Center for Aging and Health, University of North Carolina School of Medicine.]

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF COUNCILS ON DEVELOPMENTAL DISABILITIES

Dear Chairman Blunt and Ranking Member Murray:

The National Association of Councils on Developmental Disabilities (NACDD) is pleased to present this testimony to you and the Members of the Subcommittee. NACDD is the national membership organization for the Councils on Developmental Disabilities (DD Councils) appointed by Governors, and located in every State and territory. NACDD respectfully requests that Congress appropriate \$76 million for the DD Councils in fiscal year 2018 and makes no changes to the structure or funding level of the DD Councils as proposed in in the President’s fiscal year 2018 budget.

NACDD’s funding history includes:

	Fiscal Year				
	2012	2013	2014	2015	2016/2017
NACDD’s Request	\$75,000,000	\$75,000,000	\$75,000,000	\$75,000,000	\$76,000,000
Actual Appropriations	\$74,774,000	*\$70,661,000	\$70,876,000	\$71,692,000	\$73,000,000

* After sequestration

The DD Councils were first authorized in 1970. They are currently part of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act). The DD Act has always been a bipartisan piece of legislation. The DD Councils are catalysts that create effective solutions and fulfill the mandate to improve service and systems with and for people with developmental disabilities (DD). The central purpose of the DD Act is to “is to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of com-

munity life, through culturally competent programs.”¹ DD Councils consist of people with DD, their families, representatives of other programs funded under the DD Act, other stakeholders in the community, and representatives of State agencies. The President’s fiscal year 2018 budget proposal to restructure the DD Councils would remove the voices of persons with DD from the DD Act. Losing the direct input of persons with DD about how to create and improve services and systems to support them will dilute the entire essence of the DD Act. The DD Councils are charged with investing in dynamic and innovative programs that improve State services and systems with the limited funding they receive. By statute, the DD Councils are required to expend 70 percent of their funding on programs that serve people with DD in the community. The DD Councils, through their innovative programming and investments, ensure persons with DD can realize the same goals we all have, to receive a quality education, live in their communities, and be taxpayers.

For 47 years, the DD Councils, in partnership with the University Centers for Excellence in Developmental Disabilities (UCEDDs) and Protection and Advocacy program for Developmental Disabilities (P&As) have provided critical services and supports for those with DD and their families. The concept of the triumvirate in the DD Act was designed by and for individuals with DD and was masterful in its partnering together of three distinctly different programs that together work collaboratively to meet the overall intended purpose of the DD Act through their individual responsibilities. The DD Councils, P&As, and UCEDDs are linked in their responsibilities ensuring a well-trained cadre of experts providing services to individuals with DD and their families, protecting the rights of individuals with DD, and ensuring that people with DD are fully included in the work to improve services and systems to make them fully inclusive.

The DD Act requires DD Councils to assess and review Federal and State programs for people with DD and develop a comprehensive 5-year State plan to address the needs of persons with DD. The State plan is carried out by a series of identified goals, objectives and activities designed to address the identified needs. The DD Councils are unique in that people with DD, who are encountering barriers and challenges, are the majority of the people creating the State’s plan for how it can address those barriers and challenges through investing in dynamic and innovative programs. The DD Councils just began their first year of a new 5-year State plan that lays out the goals, objectives, and activities of the DD Council, and what each DD Council will accomplish in the next 5 years with its funding.

Employment is a key component of community living. Given the high unemployment, underemployment and low employment retention rates for persons with DD, the majority of DD Councils have prioritized efforts in their State plans to improve employment outcomes for persons with DD. More than half of the DD Councils have led in implementing an innovative program, Project Search, which immerses students in employment opportunities during their final years of special education. The projects teach independence and work skills that meet the needs of both the individuals and the employers. About 80 percent of graduates of Project Search go on to hold regular, paid, integrated employment with employers. For example, 5 years ago, the Kansas Developmental Disabilities Council implemented Project Search and the management and support of the program was transferred to a Managed Care Company. As of 2017, the Project Search program has expanded three times without any financial support from the DD Council.

The Mississippi Developmental Disabilities Council graduated its first Project Search class in May of 2016. In addition, the Council funded the Farm Entrepreneurship and Independence Initiative at \$70,000. This initiative uses an employment model of youth inclusiveness in the Delta, which pairs youth with and without disabilities to train and employ young farmers. Students are grouped in threes (one with a disability and two without disabilities), who are then familiarized with farming. Students have the opportunity to learn new skills associated with processing, sorting, packaging, quality control, food safety transportation and record keeping. Students in the program also gain the skills and knowledge to help farmers meet the Good Agricultural Practice (GAP) food safety standards.

DD Councils also fund programs that support quality education for people with DD. Education is critical to securing competitive community-based employment, launching and advancing one’s career, being independent and economically self-sufficient, and achieving personal goals. The Massachusetts Developmental Disabilities Council undertook a pilot initiative to provide a unique educational opportunity to teach teenagers and young adults with intellectual and other developmental disabilities skills that will assist them in gaining independence as adults. The program includes a core curriculum and elective options, and a practicum that must be com-

¹42 U.S.C. 15001(b).

pleted in order to graduate. Thirty-one students successfully graduated from Independence College in 2016, and over 50 students have applied for enrollment in 2017.

The Maryland Developmental Disabilities Council funded the development of an online training for childcare providers about serving children with disabilities that offers Continuing Education Units. It is the second most requested training on a national website for providers. Available nation-wide, over 500 people have enrolled in the program. The Council also has produced two videos for \$5000 about the inclusion of children with disabilities, which they use to train over 14,000 childcare providers.

Many DD Councils work to ensure that people with DD are able to safely and fully access all aspects of life in the community. For example, the Florida Developmental Disabilities Council (FDDC) in partnership with the Florida Department of Transportation (FDOT) implemented two transportation voucher pilot programs in 2016. FDDC and FDOT funded \$75,000 to each project for a total of \$150,000 per site: one urban and one rural. The voucher pilot enabled HARTPlus to contract with Yellow Cab of Tampa. Prior to the voucher pilot, HARTPlus required a three-day notice to provide rides to its 3,000 clients, only serving individuals within \leq mile of the standard bus schedule and each trip cost HARTPlus \$36. The voucher pilot allowed HARTPlus to secure trips for \$16 per person for up to a 7.6-mile ride. As a result, HARTPlus was able to offer 27,813 trips at a cost of \$445,008, rather than the typical cost of \$1,001,268, saving \$556,260. Riders now receive 24-hour service and are able to book trips for a multitude of purposes. This availability to efficient transportation positively affected safety and satisfaction while opening the door to a wider variety of community access, including employment and recreational events.

HARTPlus credits the voucher pilot with its 8 percent growth, improved on-time performance and its ability to exceed expectations in accessibility to wheelchair users. The urban model is self-supporting after 1 year of funding, and the rural model is working towards independent sustainability with a second year of funding. Preliminary reports from the rural model include an individual who transitioned from working at McDonald's earning \$8.05 per hour to welding, now earning \$16.00 per hour and another individual who initially had to turn down a job offer was able to become an employee at Walmart.

The Missouri Developmental Disabilities Council has led a Victimization Task Force that includes several State agencies, DD service providers, the UCEDD, the P&A, various victim services stakeholders, (FBI Victim's Unit, rape crisis centers, abuse hotlines, forensic interviewers, law enforcement, the Attorney General's Office), persons with disabilities who had been victimized, parents of children with DD, MO Ombudsman and other stakeholders. The task force identified gaps and barriers in the various systems and as a result, developed approximately 40 recommendations for the State to work to implement to improve safety and ensure victims are protected from abuse. To educate people about the issue, the DD Council provided a \$200,000 grant to the Arc in MO to implement an awareness campaign with the tag line, "It's Happening." A website (www.andwecanstopit.org) was established that provides information, and resources for community members to recognize when someone is being victimized, and how it can be reported.

Unfortunately, the timely need for the establishment of the Victimization Task Force and implementation of the recommendations was seen in April 2017. A man with intellectual and developmental disabilities was reported missing when a new service provider took over management of the group home where he was living. The police discovered the man's body in a storage container that was filled with concrete. The discovery of the man's body indicated that he had likely died several months before he was reported as missing by the provider. To address this serious failure of the system, once the outcome of the investigation is known, the Council plans to re-convene the Victimization Task Force and work with stakeholders to identify and recommend additional changes to policies that must be made to keep people with DD safe.

As you can see in the examples above, the funding provided to the DD Councils ensures that people with DD have the opportunity to achieve what we all want, to receive a quality education, live in and fully access all parts of the community, and be taxpayers. The President's budget proposal to combine the DD Councils with two other entities that represent different parts of the disability community, are not national in scope, have different authorizing statutes and mandates, will result in a significant loss of the voices of and focus on those living with DD. Under this proposed structure and funding reduction, the DD Councils will not be able to meet the stated goals of the DD Act that has led to significant improvements in the lives of persons with DD in the last 47 years.

In summary, the DD Councils are highly accountable for their outcomes and bring the voice of individuals with DD to the forefront in making decisions of how to im-

prove services and systems. NACDD requests that the DD Councils be provided their requested funding for fiscal year 2018 and are not restructured into a brand new program called Partnerships for Innovation, Inclusion, and Independence, just as they begin their important work in their new 5-year State plan.

[This statement was submitted by Cindy Smith, MS, CAS, JD, Director of Public Policy, National Association of Councils on Developmental Disabilities.]

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF
CHRONIC DISEASE DIRECTORS

Thank you Chairman Blunt, ranking member Murray and members of the Committee for considering this testimony of the National Association of Chronic Disease Directors (NACDD). NACDD strongly encourages your continued support for the Centers for Disease Control and Prevention (CDC) in the fiscal year 2018 appropriations process, specifically the National Center for Chronic Disease Prevention and Health Promotion at the CDC. We strongly urge you to maintain fiscal year 2017 funding levels in the CDC chronic programs and, where possible, provide targeted increases to key public health programs. Without the grant support and work of this important Center at CDC most States would have exceedingly limited resources to address the leading causes of death, disability and rising healthcare costs.

NACDD is the single voice of State and territorial health department chronic disease prevention and control professionals. Representing over 6,500 specialized professionals in every State and territory, NACDD works in States and communities to promote health and prevent disease. Guided by our governors and State legislatures for whom we work, our Federal partners at the CDC help us knit together a coordinated, national approach to addressing our most urgent health problems and improving the health of our Nation.

CHRONIC DISEASE: A THREAT TO OUR NATION'S HEALTH AND PROSPERITY

As the United States seeks ways to boost our economic and global position, we must remember that poor health of the population due to chronic conditions can directly undermine workforce productivity, educational potential and military readiness. Further, chronic diseases are the primary driver of costs in healthcare. According to the CDC, chronic disease accounts for approximately 75 percent of the Nation's aggregate healthcare spending—or an estimated \$5,300 per person in the U.S. annually. In terms of public insurance, treatment of chronic disease constitutes an even larger portion of spending—96 cents per dollar for Medicare and 83 cents per dollar for Medicaid. As the American population ages and more people are categorized as “high risk” for multiple chronic diseases, healthcare costs are projected to continue their rise.

CHRONIC DISEASE PREVENTION PROGRAMS: A HIGH-VALUE INVESTMENT

No strategy to reduce our Nation's healthcare costs and enhance economic performance is complete without a robust approach to preventing chronic diseases and their complications. Avoiding diseases and their costly complications in the first place enhances the health and wellness of all Americans which in turn contributes to workforce participation and productivity, educational outcomes of our children, fitness levels of our military recruits, and reduction of skyrocketing healthcare costs.

Central to the Nation's chronic disease prevention strategy are State Public Health Chronic Disease Prevention and Control Programs, supported in large part by the CDC. These programs are implementing diverse, cost-effective interventions to prevent and control cancer, diabetes, heart disease, stroke, arthritis and more. Examples of such high value investments include evidence-based diabetes classes in the community, proven tools to assist patients to manage their own blood pressure, and tailored outreach and support for women needing cancer screenings.

States are also implementing science-based initiatives to stop chronic diseases from developing in the first place such as promoting fitness, good nutrition and tobacco-free living. Often our programming focuses on children where healthy habits can last a lifetime. Examples include professional development for teachers and daycare staff on physical activity and nutrition guidelines and supporting healthy food options in schools.

EMPOWERING INDIVIDUALS, AVOIDING COSTLY CARE

As an example, here in Connecticut, CDC resources have supported us to work with community health centers to identify over 16,000 at-risk-patients in the New Haven region and implement programs to educate and empower hundreds of pa-

tients to take charge of their own conditions. In one instance a community health worker identified a 55 year-old woman with diabetes who was struggling to care for herself. She was overweight and needed many medications to stabilize her condition. The community health worker identified her as at risk for serious complications and connected her with a primary care doctor, a gym membership, and wellness coaching services.

With this support, she developed a love for Zumba and weight-lifting. Over time, she slimmed down from a size 12 to a size 4. She was able to reduce her need for diabetes medication from six pills to half a pill per day, reduced her blood pressure by 10 percent, cut her cholesterol by almost a quarter, and dropped her blood sugar by more than a third. Her family was so impressed by her success that she is now a source of inspiration and encouragement to her brother, sister, and her sister in-law, who all have gone on to adopt healthy lifestyle changes.

Multiply these examples by the tens of thousands across the Nation and you can see how public health programs by reaching, educating and empowering individuals in the community and before they become sick are a good investment that saves healthcare dollars for Medicaid, Medicare, and the entire healthcare system.

STATE CHRONIC DISEASE PROGRAMS: BRINGING RESEARCH TO THE FINISH LINE

Many of our program approaches were developed by this committee’s long-standing investments in research at the National Institutes of Health (NIH) and the CDC. We are part of the implementation of many NIH discoveries, and we bring them to your cities, suburban areas, and especially to rural areas where they are often most needed. In fact, in rural areas, State health agencies are often the primary source of this information and services to your constituents. Without the work of chronic disease prevention practitioners, some of the important findings of Federal research would sit on the shelf and never realize its full potential to improve health.

MODEST FUNDING NEEDED TO MAINTAIN FOUNDATIONAL PROGRAMS

Today only a small fraction of the United States’ governmental healthcare investment supports prevention and health promotion. We urge you to maintain the existing funding mechanisms of this Center, which provide resources and technical expertise through State health departments, national organizations, and local partner groups. Maintaining the existing funding mechanisms allows for ongoing accountability, transparency and measurable outcomes with Congress, States and taxpayers. Looking to fiscal year 2018 funding decisions, we support sustained categorical funding for the Diabetes, Heart Disease and Stroke, Nutrition, Physical Activity and Obesity, and Tobacco Control and Arthritis programs with targeted increases where possible. We also encourage sustained funding for key cancer programs within the Center along with other programs as indicated in our requests in the table below. Finally, we strongly encourage at a minimum the full restoration of the Preventive Health and Health Services Block Grant, administered by the CDCs Office for State, Tribal, Local and Territorial Support.

FISCAL YEAR 2018 FUNDING REQUEST

Program	Fiscal Year			
	2016	2017	2018 President's Request	2018 NACDD Request
Alzheimer’s Disease	\$3,353,000	\$3,500,000	\$3,493,000	\$10,000,000
Arthritis	\$9,599,000	\$11,000,000	*	\$16,000,000
Cancer Registries	\$49,440,000	\$49,440,000	\$49,346,000	\$65,000,000
Colorectal Cancer	\$43,294,000	\$43,294,000	0	\$70,000,000
Comprehensive Cancer Control	\$20,000,000	\$19,675,000	\$67,143,000	\$50,000,000
Heart Disease and Stroke Prevention	\$160,037,000	\$130,037,000	*	\$160,037,000
Diabetes	\$170,129,000	\$140,129,000	*	\$170,129,000
Nutrition, Physical Activity & Obesity	\$49,920,000	\$49,920,000	*	\$72,092,000
		(+ \$10,000,000 for high rate counties)		(+ \$7,500,000 for high rate counties)
Healthy Schools, Healthy Youth	\$15,383,000	\$15,400,000	\$15,371,000	\$23,400,000
Tobacco Control	\$210,000,000	\$205,000,000	*	\$220,000,000
Breast & Cervical Cancer Early Detection	\$206,993,000	\$210,000,000	\$210,00,000	\$275,000,000
WISEWOMAN	\$21,120,000	\$21,120,000	\$21,120,000	\$21,120,000

FISCAL YEAR 2018 FUNDING REQUEST—Continued

Program	Fiscal Year			
	2016	2017	2018 President's Request	2018 NACDD Request
Breast Cancer Awareness for Young Women	\$4,690,000	\$4,960,000	\$4,960,000	\$4,490,000
Preventive Health and Health Services Block Grant	\$160,000,000	\$160,000,000	0	\$170,000,000

* Denotes programs that could be supported by the new America's Health Block Grant.

[This statement was submitted by Mehul Dalal, MD, MSc, MHS, President, National Association of Chronic Disease Directors.]

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 \$244 million in fiscal year 2018.

According to the Bureau of Labor Statistics (BLS), the registered nurse (RN) workforce will grow 16 percent from 2014 to 2024, outpacing the 7 percent average for most other occupations. BLS also projects that this growth will result in 439,300 job openings, representing one of the largest numeric increases for all occupations.

In addition, employment of APRNs is projected to grow 31 percent from 2014 to 2024, much faster than the average for all occupations. Growth will occur because of an increase in the demand for healthcare services. Several factors will contribute to this demand, including a large number of newly insured patients resulting from healthcare legislation, an increased emphasis on preventive care, and the large, aging baby-boom population.

BLS notes that the healthcare sector is a critically important industrial complex for the Nation. It is key to economic recovery with the number of jobs climbing steadily. Healthcare jobs are up nationwide, and BLS projects healthcare occupations and industries to have the fastest employment growth and which will add the most jobs between 2014 and 2024. Over three million workers are in hospital settings, which often are the largest employer in a State. Healthcare has been a stimulus program generating employment and income, and nursing is the predominant occupation in the healthcare industry with more than 4.570 million active, licensed RNs in the United States in April 2017.

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.

The current Federal funding falls short of the healthcare inequities facing our Nation today. Absent consistent support, even slight 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 more than 15-year nurse and nurse faculty shortage felt throughout the U.S. health system.

NACNS believes that health inequities, inflated costs, and poor quality of healthcare outcomes in this country will not be reversed until the concurrent shortages of nurses, advanced practice registered nurses, 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 \$244 million in fiscal year 2018.

[This statement was submitted by Vince Holly, MSN, RN, CCRN, CCNS, 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. City, county, metropolitan, district, and tribal health departments work to ensure the public's health and safety. On behalf of local health departments, NACCHO submits the following requests for funding in fiscal year 2018:

Funding for Zika Virus

NACCHO thanks Congress for providing emergency supplemental funding to respond to the Zika virus last year. The threat of Zika has not gone away and is expected to ramp up during the spring and summer of 2017. The Centers for Disease Control and Prevention (CDC) disclosed evidence last year that links the virus to miscarriages and birth defects with a lifetime of healthcare costs for affected children with microcephaly and other health problems. Funding to respond to the Zika virus allows CDC to support State and local health departments with increased virus readiness and response capacity; enhanced laboratory, epidemiology and surveillance capacity in at-risk areas to reduce the opportunities for Zika transmission and surge capacity through rapid response teams to limit potential clusters of Zika virus in the United States. Supplemental funding runs out at the end of fiscal year 2017 and should continue in fiscal year 2018.

Public Health Emergency Preparedness—CDC

NACCHO urges the Subcommittee to provide \$705 million for Public Health Emergency Preparedness (PHEP) in fiscal year 2018, and reject the President's proposed cut of \$107 million. More than 55 percent of local health departments rely solely on Federal funding for emergency preparedness. Recent events include the threat of infectious diseases like Zika and mumps, as well as severe and frequent weather events causing natural disasters. Sustained funding to support local preparedness and response capacity is needed to make sure that every community is prepared for disaster. NACCHO thanks the Subcommittee for restoration of \$44 million cut from PHEP grants in fiscal year 2016 that had been redirected to CDC's Zika response.

Prevention and Public Health Fund—HHS

In fiscal year 2018, NACCHO requests \$1 billion for the Prevention and Public Health Fund (PPHF), a dedicated Federal investment in programs that prevent disease at the community level, and continued allocation of the PPHF through the annual appropriations process. If the PPHF is eliminated as part of repeal of the Affordable Care Act, NACCHO requests continued funding for the following programs that are supported through this mechanism.

317 Immunization Program—CDC

Immunizations continue to be one of the most cost-effective public health interventions. In an effort to prevent and control the spread of infectious diseases, the promotion of vaccinations is needed more now than ever.

From January 1 to January 28, 2017, 27 States in the U.S. reported mumps infections in 495 people to CDC. From January 1 to April 22, 2017, 61 people from 10 States were reported to have measles. Currently a measles outbreak is impacting the Somali community in Minneapolis. These diseases can be highly contagious, but are preventable with the proper vaccines. The 317 Immunization Program funds vaccine purchase for at-need populations and immunization program operations, including support for implementing billing systems and emergency response. According to the CDC, childhood vaccines have an estimated \$10.20 in savings for every

\$1 invested. NACCHO urges you to reject the President's proposed \$86 million decrease for the 317 program in fiscal year 2018.

Epidemiology and Lab Capacity Grant Program—CDC

In fiscal year 2018, 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. ELC funding is critical to the continued response to Zika virus, bolstering capacity at the ground level to detect disease and control its spread, sparing families from devastating birth defects. NACCHO urges you to reject the President's proposed \$40 million decrease for the ELC program in fiscal year 2018.

Preventive Health and Health Services Block Grant—CDC

NACCHO urges Congress to provide \$160 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. NACCHO also asks for report language asking the CDC to expand grantee reporting requirements to include the amount of money going to local communities.

The following additional programs at CDC are critical to the ability to respond to pressing health needs in local communities across the United States.

Prescription Drug (Opioid) Overdose Prevention—CDC

The Prescription Drug (Opioid) Overdose Prevention Program provides States with the funding for prescription drug abuse and overdose prevention programs in the hardest hit communities, enhances prescription drug monitoring programs (PDMPs), implements insurer and health system interventions to improve prescribing practices, and collaborates with a variety of State entities such as law enforcement. The number of deaths due to opioid overdose has increased to 90 people per day according to CDC. Thus, NACCHO requests \$112 million in funding for fiscal year 2018 and urges CDC to ensure that these funds reach local communities in order to respond effectively to this epidemic.

Thank you for your attention to these recommendations for programs that protect the public's health and safety. NACCHO is happy to provide any additional information you may need.

PREPARED STATEMENT OF NATIONAL ASSOCIATION OF DIVERSITY OFFICERS
IN HIGHER EDUCATION

Dear Senators Cochran, Blunt, Leahy, and Murray:

The American Association for Access, Equity and Diversity (AAAED) and the National Association of Diversity Officers in Higher Education (NADOHE) submit this letter to jointly express our opposition to the proposed merger of the Office of Federal Contract Compliance Programs, U.S. Department of Labor (OFCCP) into the Equal Employment Opportunity Commission (EEOC).¹ In so doing, we join the Federal contractor and civil rights communities who have expressed their collective opposition to this merger.² In our view, such an action is inefficient, and it will undermine more than 50 years of progress towards equal opportunity, not only in academic institutions but in the entire employment sector of the United States.³

Founded in 1974 as the American Association for Affirmative Action (AAAA), AAAED has four decades of leadership in providing professional training to members, enabling them to be more successful and productive in their careers. It also promotes understanding and advocacy of affirmative action and other equal opportunity and related compliance laws to enhance the tenets of access, inclusion and equality in employment, economic and educational opportunities. AAAED was

¹ Fiscal Year 2018, Congressional Budget Justification, Office of Federal Contract Compliance Programs, <https://www.dol.gov/sites/default/files/BJ-2018-V2-10.pdf>.

² See, e.g., Letter of the Institute for Workplace Equality to the Secretary of Labor and Director of OMB, May 19, 2017; and Letter of 73 Civil Rights organizations to Secretary Acosta and Director Mulvaney, May 26, 2017.

³ It should be noted that colleges and universities are among the top 200 Federal contractors: See, Top 200 U.S. Government Contractors fiscal year 2015, <https://blog.forecastinternational.com/wordpress/top-200-u-s-government-contractors-fy2015/>.

founded by equal employment opportunity and affirmative action professionals in higher education. Its membership now includes equal opportunity, affirmative action, and diversity professionals in the private sector and government as well as the academic sector.

The National Association of Diversity Officers in Higher Education (NADOHE) was established to serve as the preeminent voice for diversity officers in higher education by supporting their collective efforts to lead their member institutions towards inclusive excellence. NADOHE's membership includes chief diversity officers (CDOs) at colleges and universities throughout the United States.

The Office of Federal Contract Compliance Programs (OFCCP) enforces Executive Order 11246, signed by President Lyndon Baines Johnson in 1965. It also enforces Section 503 of the Rehabilitation Act of 1973 and Section 4212 of the Vietnam Era Veterans' Readjustment Assistance Act of 1974. Taken together these laws require nondiscrimination and affirmative action by companies doing business with the Federal Government.⁴ The laws enforced by OFCCP prohibit discrimination based on race, color, religion, national origin, sex, disability, veterans' status, gender identity and sexual orientation. Executive Order 11246 also prohibits Federal contractors and subcontractors from, under certain circumstances, taking adverse employment actions against applicants and employees for asking about, discussing, or sharing information about their pay or the pay of their co-workers.⁵

Unlike the EEOC, which is a semi-independent agency, the OFCCP is a product of the government's procurement process and administrative structure. It is a sub-agency of the Department of Labor, which is part of the President's Cabinet. The Federal contractor universe within OFCCP's jurisdiction covers approximately one-quarter of the civilian labor force.

OFCCP's History

The OFCCP's origins date back to 1941, with President Roosevelt's Executive Order 8802 integrating the Defense industries, reportedly when the Brotherhood of Sleeping Car Porters threatened a March on Washington. There have been successive executive orders on equal employment opportunity since then.⁶

In its Final Report to President Eisenhower, the President's Committee on Government Contracts, headed by Vice President Richard M. Nixon, concluded:

Overt discrimination, in the sense that an employer actually refuses to hire solely because of race, religion, color, or national origin is not as prevalent as is generally believed. To a greater degree, the indifference of employers to establishing a positive policy of nondiscrimination hinders qualified applicants and employees from being hired and promoted on the basis of equality.⁷

Vice President Nixon's "positive policy of nondiscrimination" is embodied in the laws enforced by OFCCP.

President Kennedy incorporated the concept of "affirmative action" into Executive Order 10925, which he issued in 1961. In that year, the Kennedy Administration established "Plans for Progress," a "voluntary program to provide leadership in achieving equal employment opportunity."⁸ These plans called for "continuous, systematic and vigorous action to open new job opportunities to members of minority groups."⁹ This program evolved from the President's Committee on Equal Employment Opportunity chaired by then Vice President Lyndon Johnson. In 1963 participants in Plans for Progress included 115 leading companies and institutions of higher education who held government contracts and sought a means of communicating policies of equal employment opportunity internally and externally.¹⁰

⁴U.S. Department of Labor, Executive Order 11246 as amended, 30 FR 12319, 12935, 3 CFR, 1964-1965 Comp., p.339; Section 503 of the Rehabilitation Act of 1973, as amended, 29 USC Sec. 793; Vietnam Era Veterans' Readjustment Assistance Act of 1974, as amended, 38 USC Sec. 4212.

⁵U.S. Department of Labor, OFCCP, https://www.dol.gov/ofccp/regs/compliance/ca_11246.htm.

⁶National Archives, Executive Order 8802: Prohibition of Discrimination in the Defense Industry, June 25, 1941, <https://www.archives.gov/historical-docs/todays-doc/?dod-date=625>; OFCCP, History of Executive Order 11246, <https://www.dol.gov/ofccp/about/50thAnniversaryHistory.html>; See, Nicholas D. Brown, *The Brotherhood of Sleeping Car Porters: the Civil Rights Movement*, University of Toledo, 2015.

⁷See AAAED, About Affirmative Action, Diversity and Inclusion, <https://www.aaed.org/aaed/AboutAffirmativeActionDiversityandInclusion.asp>.

⁸John F. Kennedy Presidential Library and Museum, Plans for Progress Program, July 31, 1963, <https://www.jfklibrary.org/Asset-Viewer/Archives/JFKWHSFLCW-023-011.aspx>.

⁹Statement by the President Upon Signing the Plans for Progress, Washington, DC, July 12, 1961, <https://www.jfklibrary.org/Asset-Viewer/Archives/JFKPOF-035-026.aspx>.

¹⁰Plans for Progress Program, July 31, 1963, John F. Kennedy Presidential Library and Museum, <https://www.jfklibrary.org/Asset-Viewer/Archives/JFKWHSFLCW-023-011.aspx>.

In 1965, President Johnson signed Executive Order 11246, which gave the Secretary of Labor responsibility for administration and enforcement of the Order mandating that contractors not discriminate against any employees or qualified applicants because of race, color, religion, or national origin. The agency that was created to administer the Order was the Office of Federal Contract Compliance. Before signing the order in September 1965, President Johnson uttered the words that continue to resonate today during his speech at Howard University's Commencement, June 4, 1965:

"Freedom is not enough. . . . You do not take a person who, for years, has been hobbled by chains and liberate him, bring him up to the starting line of a race and then say, 'You are free to compete with all the others,' and still justly believe that you have been completely fair."¹¹

In 1967, "sex" was added to the Order after intense lobbying by the women's rights community. This year, we celebrate the 50th anniversary of Executive Order 11375, which added "sex" to EO 11246.¹²

In the 1970s, the Nixon Administration strengthened the OFCC's program by issuing Order No. 4, authorizing flexible goals and timetables to correct "underutilization" of minorities by Federal contractors.¹³ In 1973, Section 503 of the Rehabilitation Act was enacted and in the following year, Section 4212 of the Vietnam Era Readjustment Assistance Act became law. The Office of Federal Contract Compliance became the Office of Federal Contract Compliance Programs. Both of these statutes were signed by a Republican president. In 1978 the contract compliance programs, situated in approximately eleven Cabinet agencies, were merged into the Department of Labor's OFCCP.

In the 1980s, despite attempts to eviscerate Executive Order 11246, the order was saved when members of the Federal contractor community, along with Members of Congress of both parties, rallied in support of leaving it unchanged. In the 1990s, after the *Adarand v. Peña* decision led to a comprehensive review of Federal affirmative action programs, President Clinton, speaking at the National Archives, declared his support for affirmative action in his "Mend it; Don't End it" speech.¹⁴

OFCCP is an Integral Part of the Federal Procurement Process

We provide this partial history to reflect the more than half of a century of bipartisan support for the OFCCP and its equal employment opportunity mission. The agency has more than political, business and moral support to justify retaining it in the Department of Labor, however. Unlike the EEOC, the OFCCP is fundamentally a component of the Federal procurement system. Under Executive Order 11246, and the related statutes, companies (including institutions of higher education) that provide supplies and services or that perform construction services in an amount designated by the government must comply with the Equal Opportunity (EO) Clause in each contract.¹⁵

To enforce the EO Clause, the agency's regulations set forth the administrative compliance process, which includes evaluations and reviews of contractors, desk audits, pre-award reviews, and other mechanisms. Contractors are selected for reviews

¹¹ Commencement Address at Howard University: "To Fulfill These Rights" <http://www.presidency.ucsb.edu/ws/?pid=27021>.

¹² Executive Order 11375—Amending Executive Order No. 11246, Relating to Equal Employment Opportunity, October 13, 1967, <http://www.presidency.ucsb.edu/ws/?pid=60553>.

¹³ See, AAAED, "More History of Affirmative Action Policies from the 1960s," https://www.aaaed.org/aaaed/History_of_Affirmative_Action.asp.

¹⁴ Washington Post, reprint of President Clinton's speech, "The Job of Ending Discrimination in This Country Is Not Over," July 19, 1995, <http://www.washingtonpost.com/wp-srv/politics/special/affirm/docs/clintonspeech.htm>.

¹⁵ § 60-1.4 Equal opportunity clause.

(a) Government contracts. Except as otherwise provided, each contracting agency shall include the following equal opportunity clause contained in section 202 of the order in each of its Government contracts (and modifications thereof if not included in the original contract):

During the performance of this contract, the contractor agrees as follows:

(1) The contractor will not discriminate against any employee or applicant for employment because of race, color, religion, sex, sexual orientation, gender identity, or national origin. The contractor will take affirmative action to ensure that applicants are employed, and that employees are treated during employment, without regard to their race, color, religion, sex, sexual orientation, gender identity, or national origin. Such action shall include, but not be limited to the following: Employment, upgrading, demotion, or transfer, recruitment or recruitment advertising; layoff or termination; rates of pay or other forms of compensation; and selection for training, including apprenticeship. The contractor agrees to post in conspicuous places, available to employees and applicants for employment, notices to be provided by the contracting officer setting forth the provisions of this nondiscrimination clause. Title 41 C.F.R. Part 60-1, https://www.ecfr.gov/cgi-bin/text-idx?c=ecfr&sid=3b71cb5b215c393fe910604d33c9fed1&rgn=div5&view=text&node=41:1.2.3.1.1&idno=41#se41.1.60_61_14.

based on the EEO-1 or other data that they file annually with the Joint Reporting Committee or by other means. The selection process requires a neutral procedure, and cannot violate the Fourth Amendment's prohibition against unreasonable searches and seizures.

Where there is no conciliation when noncompliance is found, the OFCCP, represented by the Solicitor of Labor, may institute administrative enforcement proceedings, which may be brought to enjoin violations, to seek appropriate relief, and to impose appropriate sanctions.¹⁶ The ultimate sanction is debarment from receiving future contracts or modifications or extensions of existing contracts, subject to reinstatement.¹⁷ The Administrative Review Board makes the final determination of debarment. Such determinations may be appealed in Federal court.

While both the EEOC and the OFCCP may provide make-whole relief to a victim of discrimination, only the OFCCP may debar a company or academic institution from obtaining contracts. Moreover, the agency fundamentally represents the interests of the United States Government. There is no private right of action and no "right to sue" letter, as the EEOC provides.

The Proposed Merger Would Result in a Substantial Reduction in Resources and Staffing

Any merger of the two agencies would have to include not only the staff and offices of the OFCCP, both in the national office and the regional and district offices, but also the civil rights legal staff of the Office of the Solicitor, both in Washington, DC and nationwide. Moreover, the OFCCP has six regions and offices from Boston to Honolulu and the Solicitor's Office also has staff throughout the country. In addition, the Administrative Review board may require transfer of staffing and resources. This is, therefore, not an inconsequential proposal, but would upend an entire administrative structure that the EEOC, underfunded and understaffed, could not easily absorb. This proposal, therefore, is the antithesis of efficiency.

When the contract compliance programs were consolidated into the Department of Labor, we understand that the program maintained a total of approximately 1800 Full Time Equivalents (FTEs). In the late 1990s the agency had approximately 800 FTEs. Today, it has approximately 600 FTEs to cover nearly one-quarter of the civilian labor force. It is axiomatic that a transfer of the OFCCP to the EEOC would result in deeper reductions in staffing and resources. This will result in fewer compliance reviews and less equal employment opportunity. Moreover, this transfer would require substantial training of the EEOC staff who are unfamiliar with the OFCCP compliance process, the affirmative action program regulations, and the laws that EEOC does not currently enforce, including the Vietnam Era Veterans' Readjustment Assistance Act (VEVRAA) and the sexual orientation and gender identity provisions of Executive Order 11246.

Unlike the EEOC, the OFCCP's Primary Compliance Focus is Systemic

OFCCP looks to promote equal employment opportunity from the hiring process and compensation practices to the executive suite. While it may receive complaints of discrimination, pursuant to a Memorandum of Understanding with the EEOC, most individual complaints are forwarded to the EEOC for processing. Most importantly, the OFCCP does not have to have a complaint in order to conduct a compliance review. The burden under EO 11246 and related laws is on the government to ensure that no Federal dollars are used for discriminatory purposes. Under Title VII of the Civil Rights Act, the burden of compliance is primarily on the complainant, with all of the costs and consequences to one's self and one's career that such an effort entails.

Conclusion

The American Association for Access, Equity and Diversity and the National Association of Diversity Officers in Higher Education respectfully oppose the proposed merger of the Office of Federal Contract Compliance Programs (OFCCP) into the Equal Employment Opportunity Commission. An agency that enforces the contractual obligations of the Federal Government should not be relocated into a semi-independent entity. Moreover, while sharing the goal of equal employment opportunity, the similarity of the two agencies' missions and enforcement processes ends there. The OFCCP's focus is systemic discrimination; the EEOC's is primarily individual. The former agency shoulders the burden of enforcing equal employment opportunity laws and policies on behalf of the Federal Government's contracting authority; for the latter, the burden is on the complainant to seek redress. Lastly, the OFCCP

¹⁶ § 60-1.26 Enforcement proceedings.

¹⁷ § 60-1.27 Sanctions.

seeks “positive nondiscrimination,” to cite the recommendation of Vice President Nixon and his Committee on Government Contracts. The EEOC must, with a few exceptions, wait until a complaint is filed to seek relief from acts of discrimination.

To remove the Federal Government’s only tool to promote the nation’s long-standing policy of nondiscrimination in employment where Federal dollars are involved would not only be inefficient, it would be unconscionable. Moreover, the thousands of discrimination complaints filed annually with the EEOC call for a more systemic tool than EEOC can provide.¹⁸ They call for the OFCCP and its ancillary agencies—the Office of the Solicitor and the administrative board, to remain undisturbed and undiminished, in the Department of Labor.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF FOSTER GRANDPARENT PROGRAM DIRECTORS

Chairman Blunt, Ranking Murray, and Members of the Subcommittee, thank you for the opportunity to submit this testimony in support of fiscal year 2018 funding for the Foster Grandparent Program (FGP), the oldest and largest of the three programs known collectively as the National Senior Volunteer Corps, or “Senior Corps,” which are authorized by Title II of the Domestic Volunteer Service Act (DVSA) of 1973, as amended and administered by the Corporation for National and Community Service (CNCS). The Foster Grandparent Program recently celebrated its 50-year anniversary. I respectfully request that the Subcommittee provide the Corporation for National and Community Service at least \$107,702,000 for the Foster Grandparent Program in fiscal year 2018. The National Association of Foster Grandparent Program Directors (NAFGPD) is a membership-supported professional organization who administers Foster Grandparent Programs nationwide, as well as local sponsoring agencies and others who value and support the work of FGP.

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 volunteers 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 2018 proposed budget 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, we need your support now more than ever.

For over 50 years, the Foster Grandparent Program has made efficient use of Federal dollars to make real changes in children’s lives. FGP has thousands of supporting organizations in communities across the country.

The Foster Grandparent program was started in 1965 by Sargent Shriver as part of President Lyndon Johnson’s War on Poverty. The Foster Grandparent Program provides volunteer opportunities for low-income seniors age 55 and older to serve children and youth in their community. Foster Grandparents serve as the role of mentors, tutors, counselors, role models, and friends to these children. Since its inception, the Foster Grandparent Program has grown from just 20 programs, to over 300 programs across the United States. The Foster Grandparent Program is one of three Senior Corps programs at the Corporation for National and Community Service.

Foster Grandparents volunteer an average of 15 to 40 hours a week. Volunteers who meet certain income guidelines (200 percent of the national poverty level) receive a small, non-taxable stipend of \$2.65 per hour, which enables those living on limited incomes to serve at no cost to themselves. Volunteers receive assistance with the cost of transportation, a daily meal, and an annual physical exam.

In fiscal year 2014, 25,190 Foster Grandparent volunteers, of whom 760 were veterans, contributed more than 23 million hours of service. During that time, Foster Grandparents served 189,000 children and youth with special or exceptional needs—including 2,000 children of military families. A 2006 national performance measurement survey of the Foster Grandparent Program found that 81 percent of children served demonstrated improved academic performance; 90 percent demonstrated increased self-image; 56 percent improved school attendance and 59 percent were reported to have a reduction in risky behavior. Foster Grandparents develop a strong bond with the children. Often, a Foster Grandparent may be the only positive, support system in a child’s life. The Foster Grandparent can help put the child on a path towards success. The children view these Foster Grandparent volunteers as a

¹⁸In fiscal year 2016, the EEOC received 91,503 complaints of discrimination. <https://www.eeoc.gov/eeoc/statistics/enforcement/all.cfm>.

mentor and a role model; as someone they can look up to who will be there to support and encourage them.

To further demonstrate the positive impacts of the Foster Grandparent Program, here are just a few testimonials from teachers and principals about the important role Foster Grandparents play in their classroom or school:

“Having the Foster Grandparents here at Cooper Elementary is invaluable to our students and staff. Words cannot express the value they are as they work individually with our kindergarteners to help them become readers, our first graders to improve on the skills they have acquired, and our teachers to allow them to better instruct our students. All of our Grandmas are positive and loving members of our school community who would be greatly missed by all if they were not in our building.” -Bruce Hartley, Principal, Cooper Elementary

“My Grandma is a life-saver to me. She works with students in both reading and math that need an extra boost. She listens to students when they get upset and I have 24 other students in my room to teach. When students miss some on a paper they have done independently and need to have someone go over it with them, she is the one that helps me out when time runs out for me to get to everyone.” -Gail Thompson, Teacher, Feelhaver Elementary

“Grandma Pam works every day with students to help them become better readers and writers. She builds relationships with the students and shows them she cares about them. She also helps me out doing little tasks that allows me to get something else finished. We would also have more students not meeting the standards and they are helping close the gap. They are here to help us give those few struggling students that extra support they might not get at home.” -Christie Gruber-Swanson, Teacher, Cooper Elementary

Foster Grandparent programs represent the best in Federal partnerships with local communities, with Federal dollars flowing directly to local sponsoring agencies, which in turn determine how the funds are used. Foster Grandparent programs have forged partnerships with thousands of community organizations that value and support the Foster Grandparents’ service. FGP serves local communities in a high quality, efficient and cost-effective manner, saving local communities money by helping our older volunteers stay independent and healthy and out of expensive in-home or institutional care.

In closing, I would like reiterate NAFGPD’s request that the Subcommittee provide at least \$107,702,000 for FGP in fiscal year 2018 appropriations bill. A reduction in funding would result in fewer hours of service given to children who have special or exceptional needs, 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 Kristen Tracy, President, National Association of Foster Grandparent Program Directors.]

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 nonpartisan, 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 authorized levels in the 2016 Older Americans Act Reauthorization for the Older Americans Act Title III(C) senior nutrition program within the Administration for Community Living (ACL) in the Department of Health and Human Services and for the Senior Community Service Employment Program within the Department of Labor. These authorization levels would fund the Title III(C) nutrition program at \$864.7 million for fiscal year 2018 and the Senior Community Service Employment Program at \$454.5 million for fiscal year 2018.

OLDER AMERICANS ACT TITLE III(C) SENIOR NUTRITION PROGRAMS

Older Americans Act 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.

So far in fiscal year 2017, the Older Americans Act Title III(C) nutrition program is on track to receive overall appropriations of \$835 million, as part of multiple Continuing Resolutions from fiscal year 2016. Unfortunately, this does 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. Additional funding for congregate and home-delivered meals in fiscal year 2018 is critical to help to counteract inflation and provide millions of additional meals when combined with State and local funding.

Our major concern rests with a proposed \$54 billion cut to non-defense discretionary programs, we know that all programs in the Labor-HHS-Education Appropriations budget could suffer. If applied across the board, it could be twice as high as the 5 percent sequestration cut from fiscal year 2013. The OAA nutrition program deserves your consideration for priority funding.

In fiscal year 2013 when sequestration was in effect, our nutrition programs had lengthy wait lists and some sites even closed for lack of funding. One NANASP program created its first wait list in over 90 years of operation. Jobs and volunteers were lost and meal provision was cut back—many sites and programs had to stop serving meals some days per week. Sixty-two percent of home-delivered meals recipients reported to ACL that home-delivered meals represent at least half their food intake each day; these seniors went hungry on days where meals were not delivered.

Thankfully, your Subcommittee listened to the struggles of these older adults and restored pre-sequester funding for the senior nutrition program in fiscal year 2014. We need you to remember their stories again to avoid another year of devastation for meals program and the older adults it serves. We cannot afford to return to this era.

Our request is based on the fiscal year 2018 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.

Investing in the OAA nutrition program is, in fact, fiscally responsible in general. Access to OAA meals is essential to keeping these older adults out of costly nursing facilities and hospitals. Further, on average, a senior can be fed for a year for about \$1,300. The cost of feeding a senior for a year 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 program provides jobs to thousands across the country. The program itself is also flexible, allowing local communities to tailor their local programs to meet the needs of the seniors they serve. This program is 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. In short, the OAA nutrition program is the model of successful government, and it has worked for 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.

In fiscal year 2017, SCSEP was cut by \$34.4 million to \$400 million. This is not enough to meet the growing need for SCSEP—both in participants and in wages.

SCSEP also deserves your consideration for priority funding. Again, we base our request for SCSEP on the fiscal year 2018 authorization levels of the 2016 OAA reauthorization, which you supported.

SCSEP is the only Federal program targeted to serve specifically low-income older adults seeking employment and training assistance; moreover, the Government Ac-

countability 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 2018. RSVP is a senior volunteer program of Senior Corps administered by the Corporation for National and Community Service (CNCS). The National Association of RSVP Directors (NARSVPD) seeks a fiscal year 2018 funding level of \$63 million for RSVP. This would restore funding for RSVP to the level it enjoyed in fiscal year 2010 and would support an additional 75,000 volunteers. NARSVPD also proposes that this increase be used to strengthen existing RSVP programs.

RSVP deploys 232,400 volunteers in 627 programs that support the efforts of more than 28,000 community organizations across the Nation. RSVP 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 their interests and skills 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 is not means tested and recruits volunteers without regard to income. Most serve between 10 and 40 hours a week, but there is no set schedule.

RSVP volunteers improve the lives of their neighbors and friends every day. Because RSVP is flexible, volunteers provide a wide variety of needed services, including transportation to medical care, 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, among many other activities.

We estimate that in fiscal year 2018 RSVP volunteers will serve over 300,000 veterans in activities such as transportation and employment service referrals; mentor more than 70,000 children; provide independent living services to nearly 800,000 adults—primarily frail seniors; provide respite services to more than 20,000 families or informal caregivers; and leverage an additional 18,000 volunteers to support RSVP activities—such as delivering meals to those in need and tutoring at-risk children in addition to serving vulnerable populations through many other activities.

RSVP is cost-effective and an excellent investment:

The average Federal RSVP grant is about \$75,000 (many programs are below the average)—less than the national annual median cost of a semi-private room in a nursing home in 2016 of \$82,128.

—The average annual cost per volunteer is \$202. Using Independent Sector's estimate of the value of an hour of volunteer service, RSVP volunteers provide more than \$1 billion worth of non-stipend 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 contribute \$39 million in non-Federal support in fiscal year 2017.

—RSVP volunteers deliver an estimated 40 million hours of service annually.

RSVP is an important source of disaster prevention and relief. For example:

—In the year following the 2013 tornado, more than 90 volunteers from RSVP of Central Oklahoma contributed 4,515 hours to nine nonprofit and State organizations working in the recovery effort. RSVP volunteers answered disaster hotlines, performed follow-up calls to families affected by the disaster, served food and provided companionship at day shelters. They provided survivors with rides to medical appointments and collected and distributed donated goods to disaster survivors. Shell Company of the Americas contributed \$50,000 to support the vital disaster recovery and preparedness services being provided by the RSVP of Central Oklahoma.

—In recent years, RSVP volunteers also responded to flooding in Colorado, Missouri, Kentucky, and South Carolina, an industrial accident in West, Texas, forest fires in Northern California, and damage from Super Storm Sandy in New York.

RSVP volunteers help their neighbors.

—In 2015, RSVP volunteers who serve through St. Louis OASIS Lifelong Adventure gave 17,520 volunteer service hours in intergenerational tutoring and the CATCH Healthy Habits programs in 45 volunteer stations. OASIS promotes successful aging for adults 50 and older through lifelong learning, health promotion, and volunteer engagement. In summer 2015, the OASIS Institute partnered with Earthdance Farms, Ferguson Municipal Public Library, and the Strength & Honor summer camp program for Ferguson youth to bring two of its highly-acclaimed intergenerational programs to Ferguson. CATCH Healthy Habits teaches children the benefits of regular physical activity and good nutrition. The OASIS Tutoring Program helps students practice reading and writing and build confidence. Both programs were part of camp for 40 boys in the North County community.

—In Tennessee, FiftyForward's RSVP program supports at-risk youth, frail seniors, and veterans across Davidson and Williamson counties. In 2015, FiftyForward's 531 RSVP volunteers supported 2,500 U.S. armed forces members, 1,200 service family members, and 500 veterans. The RSVP signature program is Friends Learning in Pairs, an intergenerational volunteer tutoring program. Through weekly one-on-one tutoring sessions throughout the school year, RSVP volunteers provide the individual support, encouragement and friendship 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.

—The more than 1,000 RSVP volunteers at RSVP of Central Oklahoma mentor children, tutor adults taking high school equivalency exams, provide transportation to medical services for low-income seniors, do home renovation for seniors in need of home repairs, staff nonprofits, help sort donated food at food pantries, deliver meals to homebound seniors, and cook meals for the homeless, help teach elementary school students to read, and support military families.

—In the past year, 605 RSVP volunteers serving through the Council of the Southern Mountains RSVP in West Virginia provided almost 100,000 volunteer hours. They made telephone reassurance calls, home visits, visits to the Veterans Hospital, and donated more than 50,000 hours to hospice patients. They volunteered at food pantries and participated in neighborhood watch groups. In addition, they organized 405 community volunteers under the age of 55, in McDowell, Raleigh, Wyoming, and Mingo counties.

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 RSVP 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. With RSVP volunteer assistance, 86 seniors remain in their homes yearly and save over \$5,650,200 in nursing home costs to Alabama. Another 25 RSVP Volunteers call 85 frail homebound seniors, mostly living in a rural area, 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. Additionally, 15 RSVP volunteers assist with local meal deliveries to an average of 89 frail and 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.

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.

—RSVP of Enid and North Central Oklahoma's bridges the gap between those who need and those who give. The program empowers veterans to lead high-quality lives with respect and dignity by ensuring that veterans and their families can access the full range of benefits available to them. RSVP volunteers served more than 5,000 hours of service to Disabled American Veterans (DAV) last year. The DAV utilized their mobile command unit to help search and rescue for Moore tornado victims. Even though Moore was not in the project's service area, volunteers helped raise over \$1.2 million dollars in claims for the affected veterans.

RSVP is a "destination" for retiring "baby boomers."

Some 10,000 "baby boomers" are retiring every day and will do so every day for the next 20 years. RSVP is the only national program able to place large numbers senior volunteers in high quality volunteer positions. CNCS reported that RSVP has increased the number of baby boomers in the program and provides those volunteers with high quality activities that make use of their skills. Baby boomers 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.

We are well aware of the difficult budget situation and appreciate the Subcommittee's continued support. It is important to reiterate that RSVP is open to all Americans aged 55 and above, regardless of income; that no RSVP volunteers are paid or stipended; and that RSVP is flexible enough to be deployed to meet a wide variety of pressing problems that face our communities.

We believe, therefore, that restoring funding for RSVP to \$63 million will result in significant benefits to both the volunteers and the communities in which they serve.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF STATE HEAD INJURY ADMINISTRATORS

Dear Chairman Roy Blunt and Ranking Member Patty 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 2018 appropriations for programs authorized by the Traumatic Brain Injury (TBI) Act within the U.S. Department of Health and Human Services (HHS). Specifically, we are writing in support of the HHS's Administration for Community Living (ACL) Federal TBI State Implementation Grant program, which is eliminated in the President's budget. We also support at, a minimum, level funding for the Centers for Disease Control and Prevention's (CDC) National Center for Injury Prevention and Control TBI Program at \$6.7M; the Injury Control Research Centers \$7.414M; elderly falls prevention; and \$5 million additional funding to establish and oversee a national concussion surveillance system.

My name is Susan L. Vaughn and I am the Director of Public Policy for NASHIA, having previously worked for almost 30 years for Missouri's State agencies administering developmental disabilities, mental health and brain injury services, including serving as the director of the Missouri Head Injury Advisory Council and the co-project director for Federal grants through the Federal TBI State Grant Program authorized by the TBI Act.

NASHIA is a non-profit organization comprised of State governmental officials who administer an array of short-term and long-term rehabilitation and community services and supports for individuals with TBI, which enable them to live and work in the community as independently as possible.

The President's budget is calling for elimination of the only program, the ACL Federal TBI State Implementation Grant Program, that assists States in addressing the complex needs of individuals with TBI and their families, and combining it with the State Developmental Disabilities and Independent Living (Part B) program, creating a new "innovation" program with less than half of the funding these programs receive when combined. While the Federal TBI State Implementation Grant program is a relatively small program, it was created to help States improve access to systems because individuals with TBI and their families could not find resources and assistance needed largely due to these problems:

- Ineligible for State intellectual/developmental disabilities systems, because the disability must occur before age 22, or 18 in some States;
- Ineligible for behavioral services from mental health systems as their diagnosis did not fit the State's eligibility or services for individuals with serious mental illness;
- Lack of TBI rehabilitative specialized services and professionals in systems where they might be eligible, such as programs for individuals with physical disabilities or special healthcare needs;
- Insurance coverage insufficient to pay for extensive rehabilitative and long-term services and supports needed after a traumatic brain injury; yet
- Ineligible for public assistance due to income criteria, especially for couples where a spouse is injured.

The Federal TBI State Implementation Grant program has been a catalyst to assist States in breaking down these barriers through training, coordination of State policies, information and resources to better align services where possible. Since 1997, 48 States, District of Columbia and territories have received at least one grant. Currently, 19 States are implementing a 4-year grant to target specific populations through screening, training, Information & Referral services and Resource Facilitation, also known as service coordination or case management. States are targeting their efforts to juvenile and/or criminal justice systems; older adults and young children who are at high risk for a TBI due to falls; veterans and returning servicemembers; and youth in transition following secondary education.

NASHIA believes it is imperative that all States have access to resources to address this robust population, which is increasing daily due to motor vehicle crashes, falls, sports-related concussions, and military-related injuries. In a recent NASHIA survey completed by State governmental programs and State brain injury associations, survey respondents listed the following as the top three most pressing needs in their States:

- services/alternatives for individuals with behavioral issues;
- long-term services and supports; and
- post-acute rehabilitation services.

With limited State resources to address these needs, States often place people out of State or in State institutional settings. Unfortunately, many individuals, particularly those with behavioral issues, addiction, and poor judgment will find themselves homeless or in correctional facilities.

We are pleased that the program was transferred last year from the Health Resources and Services Administration to the Administration for Community Living (ACL) as we recognize the need to align resources with other Federal aging and disability programs, such as Lifespan Respite Care, Aging and Disability Resource Centers, and Assistive Technology program, in order to maximize resources. In addition, States can benefit from research conducted by the TBI Model Systems funded by the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR) also housed in the ACL.

The CDC Injury Center's TBI program helps State service delivery by developing pediatric guidelines and HEADS UP materials, which helps States with their "return to play" laws calling for education and training. As older adults are the second largest group at risk for TBI-related falls, we support the program's elderly prevention program.

Our members also support funding for data to help with injury prevention and planning for service delivery. Therefore, NASHIA supports an additional \$5 million for the Centers for Disease Control and Prevention's (CDC) National Center for Injury Prevention and Control to establish and oversee a national concussion surveillance system to accurately determine the incidence of concussions, particularly among children and youth. With the requested appropriations, CDC will launch a national surveillance system on concussions, making the agency fully responsive to the recommendations issued in a 2013 report by the National Academies of Sciences, Engineering, and Medicine (formerly known as the Institute of Medicine, or the IOM). The project will also collect information regarding prevalence of TBI among all ages, regardless of cause. This data will greatly assist States as they target their resources to better meet the needs.

In closing, over the past 30 years, States have initiated efforts to develop capacity for offering such services as information and referral, service coordination, rehabilitation, in-home support, personal care, counseling, transportation, housing, vocational and other support services for persons with TBI and their families. These services, however, vary in size and scope across the country and even within a State, creating a patchwork of services. Without Federal focus to help States leverage resources and to bring partners together, individuals with traumatic brain injury will again face large disability and healthcare systems designed for other populations. We strongly urge you to reject the President's proposal to eliminate this important program.

[This statement was submitted by Susan L. Vaughn, Director of Public Policy, National Association of State Head Injury Administrators.]

PREPARED STATEMENT OF THE NATIONAL CAMPAIGN TO PREVENT TEEN AND
UNPLANNED PREGNANCY

Dear Chairman Blunt, Ranking Member Murray, and members of the Subcommittee:

My name is Rachel Fey, Director of Public Policy at The National Campaign to Prevent Teen and Unplanned Pregnancy (The National Campaign). On behalf of our bipartisan organization, I would like to express appreciation for maintaining funding for programs that reduce teen and unplanned pregnancy in fiscal year 2017 appropriations. I respectfully request the following funding levels within the fiscal year 2018 Labor, Health and Human Services and Education (LHHS) appropriations bill: \$110 million for the Teen Pregnancy Prevention Program (TPP) Program in the Office of Adolescent Health at HHS and \$327 million for the Title X Family Planning Program in the Health Resources and Services Administration (HRSA) at HHS. Pregnancy planning is directly linked to a wide array of benefits for women, men, children, and society. These benefits include fewer unplanned pregnancies and thus less abortion, more educational and economic opportunities, improved maternal and infant health, greater family wellbeing and reduced public spending. The public understands these benefits and their connection to preventing unplanned pregnancy. The vast majority (84 percent) believe that when young women have the power to decide if and when to get pregnant, this has an impact on their educational and economic opportunities.¹

Teen Pregnancy Prevention Program

We request that funding for the TPP Program be restored to \$110 million—its original funding level. This competitive grant program was funded at \$101 million in the fiscal year 2017 continuing resolution and omnibus appropriations bill. Grants support a broad array of evidence-based programs. With more than 40 evidence-based models, including those that focus on abstinence alone, both abstinence and contraception, and parent-child communication, communities have the flexibility to choose an approach that reflects their needs and values. In addition to replicating programs with strong evidence, the TPP Program is also committed to using innovation and evaluation to continue learning what works best for particular settings and populations, expanding options for communities, and strengthening outcomes.

The current 5-year grants were awarded in fiscal year 2015. Over the 5-year project period—contingent on continued appropriations—these grants are expected to serve 1.2 million teens, and will focus intensely on the most at-risk youth. The TPP Program has been lauded by independent experts as a high quality example of evidence-based policymaking. It is one of the few government programs that both

¹<https://thenationalcampaign.org/resource/survey-says-april-2016>.

uses evidence as criteria for funding decisions and continues to rigorously evaluate its efforts and results.

In recent years, several efforts were made to reallocate funding from the evidence-based TPP Program to abstinence-only (also referred to as sexual risk avoidance) programs without a strong standard of evidence. More recently, the President's fiscal year 2018 budget proposed eliminating the TPP Program entirely. The TPP Program supports abstinence-only program models that meet the rigorous evaluation criteria required by HHS. Furthermore, there are several evidence-based program models that address both abstinence and contraception that have resulted in participating teens waiting longer to have sex. For these reasons, The National Campaign believes Federal dollars should focus on results rather than on any particular ideology. Redirecting funding from a program that focuses on what works to one that focuses on content is not an effective use of public funds. The public strongly supports this approach. Eighty-five percent of adults (including 75 percent of Republicans and 89 percent of Democrats) support maintaining Federal funding for the TPP Program.²

Since the TPP Program began, the teen birth rate has declined 41 percent from 2010 to 2016, a drop more than twice as large as the decline in any previous 6-year period. While many factors contribute to this success, it is clear that the pace of progress has accelerated dramatically since the Federal commitment to evidence-based teen pregnancy prevention began in 2010.

Despite this progress, there are still more than 550,000 teen pregnancies per year. This means that roughly 1 in 4 girls in this country will become pregnant before the age of 20—and there are disparities by race/ethnicity, age, and geography. In addition, youth in foster care have rates twice as high as youth not in care. The TPP Program addresses these disparities by targeting funds to youth and communities with the greatest needs.

At a time when the U.S. needs to become more competitive in the global economy, our high teen pregnancy rates stand in the way of progress, as young parents have less opportunity to receive the education and skills they need to compete. For example, 30 percent of teen girls who have dropped out of high school cite pregnancy/parenthood as a key reason, and fewer than 2 percent of those who have a child before age 18 attain a college degree by age 30. However, the unprecedented declines over the past two decades show that progress is possible.

The estimated savings in 2010 alone due to the substantial decline in the teen birth rate between 1991 and 2010 was \$12 billion. Yet, teen childbearing costs taxpayers at least \$9.4 billion annually.³ Accordingly, the TPP Program is a sound investment. The program represents just .06 percent of the total LHHS appropriations for fiscal year 2017. We encourage you to allocate at least \$110 million for the TPP Program and maintain current evidence standards. This will enable competitive grants around the country to continue providing a wide variety of evidence-based programs to the most at-risk youth and grow our knowledge of what works, while maintaining the progress we have made on this issue as a nation.

Title X Family Planning Program

We request \$327 million in funding for the Title X program for fiscal year 2018. 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.⁴ 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 2014, Title X—funded clinics helped women avert 904,000 unintended pregnancies, 439,000 unplanned births, and 326,000 abortions. Despite the significant return on investment, the current \$286.5 million funding level for fiscal year 2017 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. In 2015, 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. Recent research conducted by The National Campaign shows that nearly 20 million American women live in contraceptive

² <https://thenationalcampaign.org/resource/survey-says-january-2017>.

³ <http://thenationalcampaign.org/why-it-matters/public-cost>.

⁴ <https://thenationalcampaign.org/resource/saving-tax-dollars-and-reducing-abortion-what-you-need-know-about-title-x-family-planning>.

deserts—defined by their lack of reasonable access to public healthcare sites offering the full range of contraceptive methods.⁵

For the first time in decades, unplanned pregnancy is declining in the U.S. Abortion is also at its lowest levels since Roe v. Wade. Notably this is the case in both States that have passed significant restrictions on abortion and in States that have not, leading researchers to attribute the decline mainly to less unplanned pregnancy driven by greater use of effective contraception. The President’s fiscal year 2018 budget proposed maintaining the current funding level for Title X, while it also blocked funding from going to qualified providers of contraceptive care. We request that Congress support this funding level, but reject carving out high quality providers, which would exacerbate existing gaps in contraceptive access. The last thing we should do is weaken an already fragile family planning safety-net by not strongly supporting the Title X program. The public certainly agrees—75 percent of adults (including 66 percent of Republicans and 84 percent of Democrats) favor continuing the Title X program.⁶ In fact, 81 percent (including 74 percent of Republicans and 86 percent of Democrats) agree that those who oppose abortion should be strong supporters of birth control. By providing contraceptive education and services, Title X enables low-income women who wish to avoid an unplanned pregnancy to take personal responsibility. In doing so Title X also saves money and reduces abortion. Therefore, we strongly urge you to support the program.

In closing, we recognize that Congress faces tough budget decisions, but making these modest yet strategic investments in teen and unplanned pregnancy prevention reduces public spending and abortion while improving economic competitiveness and the health and wellbeing of families. Thank you for considering this testimony.

Sincerely,

[This statement was submitted by Rachel Fey, Director of Public Policy, National Campaign to Prevent Teen and Unplanned Pregnancy.]

PREPARED STATEMENT OF THE NATIONAL COALITION OF STD DIRECTORS
 CDC’S DIVISION OF STD PREVENTION FUNDING HISTORY

Fiscal Year	(\$ millions)
Funding:	
Request:	
2018	* 187.3
Level:	
2017	152.3
2016	157.3
2015	157.3
2014	157.7
2013	154.9
2012	163

*A requested increase of \$35 million.

On behalf of the members of the National Coalition of STD Directors (NCSA), I am requesting an additional \$35 million for the Division of STD Prevention in fiscal year 2018 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). NCSA members represent sexually transmitted disease (STD) programs in health departments in all fifty States, seven cities/counties, and eight U.S. territories.

STDs remain a major epidemic in the United States. Each year, there are nearly 20 million new cases of STDs, approximately half of which go undiagnosed and untreated. These new STDs cases cost the U.S. healthcare system \$16 billion every year—and impact individuals even more in immediate and life-long health consequences, including infertility and a higher risk of certain cancers. In addition, having an STD increases the likelihood of contracting HIV, and in turn, having HIV also increases the chances of contracting and spreading STDs. Untreated STDs increase the risk of both acquiring and transmitting HIV.

CDC’s Division of STD Prevention (DSTDP) guides national efforts to prevent and control STDs. DSTDP invests most of its Federal funding in State, territorial, and

⁵ <https://thenationalcampaign.org/deserts>.

⁶ <http://thenationalcampaign.org/resource/survey-says-january-2017>.

large city or county health departments that carry out on-the-ground efforts to control STDs. State, territorial, and local public health STD programs are the backbone of our national STD infrastructure, not only monitoring and controlling STD epidemics, but responding to emergency outbreaks of all kinds, from Ebola to food-borne illnesses to flu. However, the current public health infrastructure has been continually strained by budget reductions at the Federal, State, and local levels and is currently not sufficiently prepared for the reality of rising rates of STDs, particularly syphilis, and other outbreaks.

In 2015, the new STD infection rates in the United States reached a 20-year high and those rates are expected to rise further when new statistics are reported in 2016. 2015 was the fourth year in a row of double digit increases in reported rates of primary and secondary syphilis, the most infectious stage of syphilis, and rates of congenital syphilis (transmission of syphilis from a woman to a fetus) have risen 43 percent in the last 3 years. In addition, there are currently increasing levels of resistance by the gonorrhea bacterium to the only remaining drugs for treatment. The rise in STD rates also threatens to undo progress made in HIV prevention.

Investing in Prevention Works

Evidence shows that adequate investment in preventive efforts work. According to recent CDC data, cases of HIV fell by more than 18 percent from 2008 to 2014. This progress was made due to tremendous advancements in treatment and prevention efforts such as ART and PrEP, AND sustained and increased funding to the CDC Division of HIV/AIDS Prevention (DHAP). This encouraging trend illustrates that with proper investment in prevention, progress can be made to combat these epidemics.

This kind of Federal investment works to address the curable STDs as well. In the late 1990s, CDC launched a syphilis elimination plan. This plan brought new money into the STD prevention field to enhance existing programs and develop new strategies to combat the disease. Evaluation of that program showed that this increased funding resulted in notably lower syphilis rates than expected in subsequent years. The progress made in the STD and HIV Prevention fields is imperiled by future proposed cuts.

STD Prevention is HIV Prevention

More and more, STD prevention is viewed as integral to HIV prevention and detection. It's known that people who test positive for an STD, particularly syphilis and gonorrhea, are more likely to also test positive for HIV or to get HIV in the future. Furthermore Disease Intervention Specialists (DIS)—the boots-on-the-ground STD prevention workers—are on the frontline of fighting the STD epidemic and are often key entry points for individuals to access STD and HIV testing. It is their job to track down those at high-risk in the community and make sure they get the care that they need. DIS often facilitate screening for STDs and HIV that otherwise might not happen. Coordinated efforts between HIV and STD programs are integral for identifying and stopping the spread of infection, linking individuals to care, and for preventing these more serious and often avoidable health consequences.

An exciting new study released this month shows that use and adherence to CDC PrEP recommendations for STD screening can result in reductions in STD amongst men who have sex with men, a population who bear a huge burden of STD and HIV infection.

Prevention Means Health Care Savings

Slashing prevention budgets to “save” money is short-sighted and misguided. CDC has estimated that for every dollar spent on STD prevention, \$1.88 in healthcare costs is saved. STDs and HIV are often asymptomatic and do not rear their heads until it is too late. Undiscovered STDs and HIV can result in more serious health consequences resulting in need for intensive healthcare treatment, infertility, and even death. These extreme and avoidable negative health results cost the healthcare system billions of dollars annually. The most recent data shows that STDs cost the U.S. healthcare system upwards of \$16 billion dollars and cost individuals even more in immediate and life-long health consequences.

Increasing Syphilis Rates, Including Congenital Syphilis

Additional funding is needed to address our syphilis epidemic and to ensure the needs of hard to reach populations are addressed. In 2015, for the fourth year in a row, reported cases of primary and secondary syphilis increased by double digits.

Between 2012 and 2014, congenital syphilis, which can be a disabling, and often life-threatening infection for infants, increased by 38 percent to the highest rate in almost 15 years. In 2015, rates of congenital syphilis increased another 6 percent.

While syphilis is primarily an STD, it may be passed on by an infected woman during pregnancy. Each and every single case of congenital syphilis is a failure of our healthcare system and it is the role of STD programs across the country to find the cracks that women are falling through to prevent these heartbreaking and preventable cases. Passing on the infection during gestation or at birth may lead to serious health problems including premature birth, stillbirth, and in some cases, death shortly after birth. Sadly, untreated syphilis in pregnant women results in infant death in up to 40 percent of cases. Untreated infants who survive will often develop problems in multiple organs, including the brain, eyes, ears, heart, skin, teeth, and bones.

Strained Public Health Infrastructure

Responding to these ever-increasing STDs is a strained public health infrastructure. Despite ever-increasing STD rates, the STD program at the Federal Government has not seen increased funding since 2003. In that time, Federal investments in STD prevention have been stagnant or decreasing. In fact, the real buying power of Federal funding has plummeted 38 percent. State, territorial, and local health departments across the country that spearhead STD prevention and control have charged forward with the work, but the weight of the work is being overburdened by a lack of national investment in these efforts and in public health.

According to Trust for America's Health, combined Federal, State and local public health spending is currently below pre-recession levels. Adjusting for inflation, public health spending was 10 percent lower in 2013 than in 2009. At the same time, State and local investments, largely as a result of the recession budget crunch, have equally collapsed. At the height of the recession, the National Association of County and City Health Officials (NACCHO) reports that up to 45 percent of local health departments reported budget cuts and one in four is still affected by budget cuts today. Since 2008, 51,700 jobs have been lost at local health departments. As a result, when it comes to STDs, we are in the midst of true genuine crisis.

A New Response is Needed

Due to these infrastructure losses, our STD public health infrastructure is in a state of crisis and additional resources are needed to combat our growing STD epidemics. In supporting STD surveillance, prevention and control activities, an increase of \$35 million would focus on the following initiatives:

- Syphilis elimination with a special emphasis on congenital syphilis
- Emergency response staffing
- Gonorrhea disease reduction
- Program science and evaluation
- Increased use of technology to reach populations most at risk.

The Future of STDs

At a time when STDs rates are continuing to climb, a reduction in funding for STD prevention will only result in more congenital syphilis, more undiagnosed chlamydia and gonorrhea, and ultimately, more cost to the healthcare system. The \$5 million cut in fiscal year 2017 and the proposed \$22.3 million cut in fiscal year 2018 will devastate efforts to fight against babies being born with Congenital Syphilis, to combat drug-resistant Gonorrhea, and prevent and slow the skyrocketing rates of Syphilis.

Until adequate funding is put in place for STD prevention, STD rates will continue to increase at an alarming rate. We ask that you support NCSD's \$187.3 million fiscal year 2018 funding request for the Division of STD Prevention.

[This statement was submitted by David C. Harvey, Executive Director, National Coalition of STD Directors.]

PREPARED STATEMENT OF THE NATIONAL CONGRESS OF AMERICAN INDIANS

The National Congress of American Indians (NCAI) is the intergovernmental body for American Indian and Alaska Native tribal governments. NCAI is the oldest and largest national tribal organization in the United States that is dedicated to protecting the rights of tribal governments to achieve self-determination and self-sufficiency. For over 60 years tribal governments have come together as a representative congress through NCAI to consider issues of critical importance to tribal governments and endorse consensus policy positions. NCAI appreciates the opportunity to offer the following testimony on tribal programs in the Departments of Labor, Education, and Health and Human Services.

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Substance Abuse Mental Health Services Administration.—NCAI appreciates the funding provided for Tribal Behavioral Health Grants in the fiscal year 2017 appropriations bill. NCAI requests continued funding of at least \$30 million, which includes \$15 million in the Mental Health appropriation and \$15 million in the Substance Abuse Prevention appropriation. These funds are essential in the promotion of mental health and prevent substance activities for high-risk American Indian/Alaska Native (AI/AN) youth and their families.

Administration for Community Living (ACL).—Native American Nutrition and Supportive Services: NCAI recommends \$31 million for this program. This program provides nutrition and other direct supportive services to American Indian, Alaska Native, and Native Hawaiian elders. These programs help to reduce the need for costly nursing home care by supporting adult day care, meal delivery and transportation.

Head Start.—Head Start funds provide early education to over 24,000 Native children. This vital program combines education, health, and family services to model traditional Native education, which accounts for its success rate. NCAI recommends the Subcommittee maintain funding for Head Start, which includes Indian Head Start. Head Start has been and continues to play an instrumental role in Native education.

Low-Income Home Energy Assistance Program (LIHEAP).—NCAI requests \$4.7 billion for LIHEAP, with \$51 million allocated to tribes and tribal organizations. LIHEAP helps low-income households and seniors with their energy bills, providing vital assistance during both the cold winter and hot summer months.

LIHEAP households are among the most vulnerable in the country. According to the National Energy Assistance Director's Association (NEADA), nearly 90 percent of LIHEAP recipients have at least one household member who is a child, elderly, or disabled. For these households, LIHEAP funding has been a lifeline during challenging economic times. Access to affordable home energy is not a luxury—it is a matter of health and safety.

Funding for LIHEAP has declined more than 30 percent in recent years and the number of households eligible for assistance continues to exceed available funding. About 1.3 million poor households have lost access to critical LIHEAP assistance and struggle to pay for the basic necessity of home energy in addition to other essentials like food and medicine.

Funding has declined by almost \$1.7 billion since fiscal year 2010, yet energy costs have remained high, reducing the purchasing power of LIHEAP assistance. Recipients have seen their average LIHEAP grant reduced by about \$107 since 2010, from \$520 in fiscal year 2010 to \$413 in fiscal year 2015. The average LIHEAP grant is estimated to cover less than half of the average home heating costs for a household this winter, meaning that many low-income families and seniors will have fewer resources available to meet other basic needs.

DEPARTMENT OF LABOR

Senior Community Service Employment Program (SCSEP).—This program is the only Federal job training program focused exclusively on helping older Americans return to the workforce and through the program, low-income jobseekers, 55 years old or older, update their skills and contribute to their communities through paid, on-the-job training at schools, hospitals, senior centers, tribal facilities and other non-profit or public facilities. NCAI urges Congress to maintain funding for the Senior Community Service Employment Program (SCSEP) at \$435 million.

Division of Indian and Native American Programs (DINAP).—NCAI requests \$60.5 million for this program. Reducing the education and employment disparity between Native people and other groups requires a concentrated effort that provides specific assistance to enhance education and employment opportunities, creates pathways to careers and skilled employment, and prepares and maintains a pathway for Native people to join the Nation's middle class. The Workforce Innovation and Opportunity Act (WIOA) Section 166 program serves the training and employment needs of over 30,000 American Indians and Alaska Natives through a network of 175 grantees funded under the Comprehensive Service Program (Adult), the Supplemental Youth Service Program (Youth), and the Indian Employment and Training and Related Services Demonstration Act of 1992, Public Law 102-477. As the only Federal employment and job training program that serves American Indians and Alaska Natives who reside both on and off reservations, it is imperative that funding levels be maintained for the WIOA Section 166 program. Native citizens living on remote reservations or in Alaska Native villages experience great difficulties accessing the State and local workforce. In these areas, the WIOA Section 166 pro-

gram is the sole employment and training provider. Since the reauthorization of DINAP through WIOA in 2014, funding of this program has not been adjusted to account for the drastic changes in the economic environment and growth in population since the 2000 Census. Meanwhile, based on the most recent Census, the American Indian and Alaska Native population grew 27 percent between 2000 and 2010 compared to 9 percent for the general population. Accordingly, the Federal Government should increase funding for DINAP and WIOA commensurate with this expanded need. Such increases should be based not only on the significantly expanded size of the service population, but also increases in the cost of services such as tuition for post-secondary educational institutions.

U.S. DEPARTMENT OF EDUCATION

The Every Student Succeeds Act (ESSA) reauthorized education programs and included several tribal provisions: providing greater tribal consultation requirements between State Education Agencies (SEAs), Local Education Agencies (LEAs), and tribes; greater technical assistance and outreach by the Secretary of Education to LEAs or BIE schools in applying for Title VI grants; newly established language immersion programs in schools; and requires the Secretary of Education to conduct studies and reports to Congress on Native language instruction and youth suicides.

Opposing Eliminations in the President's Budget

The President's fiscal year 2018 budget eliminates funding for the Alaska Native Education Program and the Native Hawaiian Education Program. The Alaska Native Education Program is an essential program that funds the development of curricula and education programs to address the unique educational needs of Alaska Native students, as well as the development and operation of student enrichment programs in science and mathematics. There are 56 school districts in Alaska and approximately 24 percent of the students attending school in Alaska are Alaska Natives. Language and cultural immersion schools in Alaska have been successful in teaching and offering education curriculum increasing the fluency of Alaskan Native languages. There are currently 20 Alaskan Native languages spoken in Alaska.

The Native Hawaiian Education Program empowers innovative culturally appropriate programs to enhance the quality of education for Native Hawaiians. These programs strengthen the Native Hawaiian culture and improve educational attainment, both of which are correlated with positive economic outcomes. NCAI recommends the Subcommittee fund the Alaska Native Education Equity Assistance Program at \$31.4 million and the Native Hawaiian Education Program at \$32.4 million for fiscal year 2018

Other Department of Education Fiscal Year 2018 Request

- State-Tribal Education Partnership Program (STEP)*.—NCAI recommends \$5 million for STEP. Native education researchers, experts, and advocates have long been calling for Native control of Native education. Collaboration between tribal education agencies and local and State educational agencies is crucial to develop the tribal capacity to assume the roles, responsibilities, and accountability of Native education departments and to increase tribal self-governance over Native education.
- Impact Aid, Title VII*.—NCAI supports \$2 billion for Impact Aid. 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 enrolled in public schools, Impact Aid provides essential funding for schools serving Native students.
- Indian Education Formula Grants*.—NCAI requests \$198 million for Indian Education Grants. This 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.
- ESSA Title VI, Part A, Subpart 3, Language Immersion Grants*.—Native language funding is critically important to tribes and Native communities across the country, as recognized by the authorization in ESSA of Native language immersion funding. Further, the research supporting Native language funding is clear and the investment in the National Activities fund a will support the critical building block of Native languages for our students. NCAI requests \$5 million for these grants.
- ESSA Title VI, Part A, Subpart 2, Special Programs to Improve Educational Opportunities for Native Students*.—NCAI requests Congress provide \$37 million for the Special Programs and Projects to Improve Educational Opportunities for Indian Children. This program addresses the critical issues of teacher short-

ages, evidence-based work at the State and local level, and locally driven strategies to empower Native youth.

—*Tribal Colleges and Universities (TCUs) HEA Title III.*—NCAI supports \$30 million in discretionary funding and \$30 million in mandatory funding for TCUs. The nation's 37 TCUs serve Native and non-Native students in some of the most impoverished areas in the nation.

—*Perkins.*—Tribally Controlled Post-Secondary Career and Technical Institutions: NCAI requests \$10 million for tribally controlled postsecondary career and technical institutions program funds under the Carl Perkins Career and Technical Education Improvement Act. Section 117 of the Carl Perkins Career and Technical Education Improvement Act authorizes funding for operations at tribally controlled postsecondary career and technical institutions.

—*Native American-Serving, non-Tribal Institutions (Higher Education Act Title III-F).*—As the primary Federal funding for non-tribal, Native-serving institutions of higher education, the current funding levels are insufficient. NCAI request the funding for this program at \$10 million, with nearly 100 institutions potentially qualifying as Native-serving, non-tribal institutions, this strains the small amount of available funding.

NCAI appreciates the opportunity to share these recommendations with the Subcommittee. The needs in Indian Country are great and we thank this Subcommittee for working to honor the Federal Indian trust responsibility. Please contact Gwen Salt (gsalt@ncai.org) or Amber Ebarb (aebarb@ncai.org) if you have any questions about this testimony.

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 2018 Appropriation. NCSSMA respectfully requests that Congress provide fiscal year 2018 administrative funding for the Social Security Administration's (SSA) Limitation on Administrative Expenses (LAE) account, which ensures the agency can meet its multitude of public service responsibilities. We are concerned that the President's budget request of \$12.457 billion for SSA's LAE account may not be sufficient to maintain service to the public while addressing stewardship responsibilities and making much-needed Information Technology (IT) and systems upgrades. The agency must have the resources necessary to improve and modernize customer service including its IT infrastructure, enhance program integrity efforts, deter and detect fraud and errors, fund the inflationary growth in fixed costs, and continue to address the high volumes of initial claims and post-entitlement work.

Social Security is an excellent investment of taxpayer dollars that serves the American public well. In fiscal year 2016, SSA paid over \$960 billion to a monthly average of approximately 68 million beneficiaries and recipients. These payments kept 22 million people out of poverty. During the year, SSA served over 42 million visitors in over 1,200 field offices, handled 37 million calls on the National 800 Number and processed over 8.4 million claims for benefits. At the same time, SSA is also an extremely efficient agency, with administrative expenses representing only 1.3 percent of benefit outlays.

COMMUNITY-BASED SERVICE

Adequate 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. Budget constraints from fiscal year 2011 to fiscal year 2013 saw reductions in SSA's staffing levels and accompanying erosion in service levels. With improved budgets for fiscal years 2014 through 2016, SSA's permanent staffing increased, resulting in improved services. For fiscal year 2017 to date, field office wait times have remained steady compared to the prior fiscal year; however, the agency is continuing to see a significant number of customers leaving without service and phone answer rates dropping almost two percent. With the continued attrition, suspension of hiring since early Summer 2016 and the limited hiring SSA will be doing in fiscal year 2017, staffing losses will remain a factor and we can expect to see further decline in services. The following are examples of why it is vital that SSA receive adequate resources to provide excellent service in its field offices:

The parents of a terminally ill 20-month old baby visited the field office to apply for benefits. The young parents were overwhelmed with the responsibility of caring for their son who had Stage 4 bone cancer. During the interview, the

claims specialist noticed that the couple did not seem to have any source of emotional or family support, and referred them to a local support group for the families of critically ill children. The technician took the extra time to listen to the fears, hopes, and concerns of the couple. They said that the Social Security office was the only place besides the hospital where they could talk about the reality of their son's situation without feeling as if they were making people uncomfortable. The interview concluded with hugs and tears.—*North Flint, Michigan Manager*

A majority of customers within our service area, including the Wind River Reservation, lack Internet service. Further, their phone plans lack enough minutes to conduct business by phone. Before we open the doors, we have a line waiting outside every day. When we ask why they wait, they usually share they prefer face to face.—*Riverton, Wyoming Operations Supervisor*

The personal touch our field offices provide is extremely critical in serving our most fragile customers who are often mentally ill. Recently, a mentally disabled client, well known to the staff of the office, was in danger of benefits stopping for failing to respond during a medical review. Fortunately, we were able to get the needed information from the customer and avoided a cessation of a much-needed benefit. These kinds of personal interactions happen in all offices every day and form a crucial safety net for the clients who need us the most.—*Cañon City, Colorado Manager*

Field offices build trust in government overall since we are one of few agencies with a community connection. The personal interaction comforts our customers and significantly reduces stress in that person's life. This is especially true with the mentally disabled and elderly individuals who may not have other positive, face-to-face interactions in their own home or daily lives.—*South Jordan, Utah Manager*

One of the field office's primary functions is to help people in their time of need. We provide some means to a solution for almost any customer who walks through our doors. I can think of no other organization that offers this level of service to its customers. Allowing field service to deteriorate will only serve to cement the commonly held opinion that the government is an unfeeling, bureaucratic machine. I often receive comments from customers who had expected to encounter so many obstacles to obtaining service, but are surprised by a prompt, courteous, and empathetic staff. These are my proudest moments as a leader. Regrettably, the neediest in society are those who really pay the price for reductions in service.—*St. Louis, Missouri Operations Supervisor*

Local House and Senate Congressional staff act as a liaison, bringing forward customer concerns and the most complex casework. Field managers directly serve the constituent and work with Congressional aides to remedy their issues providing local community-based service.—*Kansas City Region Manager*

While we understand the budget constraints facing legislators, when SSA's administrative resource needs are unmet, it results in deterioration in key service areas and stewardship workloads as reflected in the chart below. SSA continues to experience an increase in visitors to field offices as members of the baby boom generation retire or become disabled. Over fiscal year 2016, the agency saw an increase of about 2 million field office visitors from the previous year. Nearly 3.9 million actions are currently pending in the agency's payment centers, and over 1.1 million people are waiting for a hearing decision, with the average processing time at a record-setting 616 days in April 2017.

If SSA's administrative funding is not adequate, these backlogs will increase and public service levels will degrade further.

SSA RESOURCES WITH KEY WORKLOAD SERVICE DELIVERY PERFORMANCE						
	FY 2013 Actual	FY 2014 Actual	FY 2015 Actual	FY 2016 Actual	FY 2017 Enacted	
SSA's Enacted LAE Funding (\$ Millions)	\$11,046	\$11,697	\$11,806	\$12,162	\$12,482 ¹	
All Employees on Staff (Field Office and Teleservice Centers)	31,601	33,622	33,710	32,859	31,366 ²	
Field Office	Visitors	43,232,130	40,770,320	40,666,463	42,661,023	24,418,310 ²
	Left Without Service	2,409,700	2,147,048	1,955,818	2,048,054	1,176,579 ²
	Wait Time (Minutes)	26.5	30	27.9	28.2	27.7 ²
	Wait Time Over 60 Min.	*	14.3%	12.4%	12.5%	12.0% ²
	Calls Answered	21,559,595	20,087,064	21,322,995	20,715,568	11,811,621 ²
	Calls Unanswered	7,378,392	10,032,981	6,941,152	5,090,701	3,230,687 ²
	Phone Answer Rate	74.3%	67.2%	75.3%	80.3%	78.5% ²
	SSI Redeterminations	2,634,183	2,627,518	2,266,992	2,530,446	~2,500,000
	Medical CDRs	428,568	525,875	799,013	853,754	~ 870,000
	Work CDRs	252,992	247,215	247,772	285,133	101,550 ²

*FY data not available to NCSSMA

¹Includes \$90 million in funds available through September 30, 2018, for activities to address the Office of Disability Adjudication and Review Hearing backlog. This figure also includes \$1.819 billion in dedicated program integrity funding to remain available through March 31, 2018.

²Processed in Field Offices/TSCs as of April 28, 2017.

~Projected for FY 2017

PROGRAM INTEGRITY INITIATIVES

Program integrity initiatives save taxpayer dollars and help reduce the Federal budget and deficit. The two most cost-effective tools to reduce improper payments are Medical Continuing Disability Reviews (CDRs) and SSI Redeterminations. SSA's current estimates indicate that medical CDRs conducted in fiscal year 2017 will yield a return of investment (ROI) of about \$8 on average in net Federal program savings over 10 years per \$1 budgeted for dedicated program integrity funding, including Old-Age, Survivors, and Disability Insurance (OASDI), SSI, Medicare and Medicaid program effects. SSA estimates also indicate that non-medical redeterminations conducted in fiscal year 2017 will yield a ROI of about \$3 on average of net Federal program savings over 10 years per \$1 budgeted for dedicated program integrity funding, including SSI and Medicaid program effects.

In fiscal year 2017, the \$1.819 billion for dedicated program integrity funding, which remains available through March 31, 2018, will allow SSA to complete 850,000 Medical CDRs and over 2.5 million SSI Redeterminations. We appreciate that the fiscal year 2018 President's budget request includes \$1.735 billion for dedicated program integrity funding.

Program integrity efforts must always be carefully balanced with SSA's mission to provide service to the American public. To process the Medical CDRs and SSI Redeterminations, the field offices and Disability Determination Services (DDS) will need to have adequate staffing levels or there will be delays in processing initial disability claims and reconsiderations and degradation of other services field offices provide. The same SSA field office employees who take initial claims, answer telephone calls, and develop and adjudicate benefit claims, also process program integrity workloads.

FUNDING FOR FISCAL YEAR 2018

Adequate resources, including staffing, are critical to SSA's front-line components who respond to increased requests for services for assistance from the American public due in large part to the aging of the baby boom generation and in fulfilling the agency's stewardship responsibilities. Sufficient resource allocations in fiscal year 2018 must provide for the work years needed to increase deficit-reducing program integrity work, as well as address the massive hearings backlog, increases in other workloads, visitors, and telephone calls in field offices and to the National 800 Number.

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. The fiscal year 2018 budget request invests over \$100 million to support SSA's IT modernization efforts. SSA must modernize its computer language, and database infrastructure including moving its data to the cloud and improving bandwidth. SSA's database systems are over 40 years old and include more than 60 million lines of COBOL coding. Failing to adequately address and fund SSA's IT

needs, increases the risk for significant service disruptions and reduced system performance and production. NCSSMA estimates, based on its own surveys and the actual cost of employee time, that without sufficient resources, SSA will continue to experience about \$200 million a year in lost employee productivity.

According to SSA's fiscal year 2018 Congressional Justification, SSA also projects an increase of \$329 million in payroll expenses from fiscal year 2017 to fiscal year 2018. These payroll expenses include: increases due to periodic step increases, health benefits, career ladder promotions, and new employees hired under the Federal Employees Retirement System (FERS). Total inflationary cost increases are projected to be \$378 million. The \$378 million figure also includes mandatory non-payroll costs such as higher costs of rent, lease renewals, security, and guard services. It also includes mandatory growth in State DDS costs, such as pay raises and the cost of medical evidence.

Social Security serves as the largest and most vital component of the social safety net of America. It is a promise between generations that has kept millions of people above the poverty line in their old age and disability-prone years, providing critical resources for housing, food, and medicine. Every application, inquiry, and visitor matters to us. The American public expects and deserves SSA's assistance.

CONCLUSION

NCSSMA respectfully requests that Congress provide fiscal year 2018 administrative funding for the SSA LAE account, which ensures the agency can meet its multitude of public service responsibilities. SSA must have the resources necessary to provide quality service to the American public, enhance program integrity efforts that reduce improper payments and save taxpayer dollars, invest in IT initiatives that will improve quality and efficiency while continuing 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 in ensuring 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 COUNCIL OF STATE DIRECTORS OF ADULT EDUCATION

The National Council of State Directors of Adult Education (NCSDAE) appreciates the opportunity to submit testimony for the Record regarding the funding level for Adult Education programs in fiscal year 2018.

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. 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 standardized assessments, transitioning students to postsecondary education, employment or job training, the attainment of a high diploma or its equivalent, and earnings outcomes.

NCSDAE supports funding Adult Education in fiscal year 2018 at the level authorized in the Workforce Innovation and Opportunity Act (WIOA), \$649.3 million. 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. WIOA 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 cannot succeed unless Congress supports it adequately.

Federally funded Adult Education programs serve only a small fraction of adults in the United States with limited English, math, or reading skills. Federal funding and enrollment have declined from over \$700 million and 2.8 million students in 2001, to 1.5 million learners and \$582 million in 2016. Adult Education State

Grants have been essentially flat-funded since fiscal year 2002; a reduction of more than 25 percent in real terms while enrollment has declined by 44 percent, most sharply among those who most need Adult Education and workforce skills services. Demand for services across the country far exceeds supply.

Some adults enrolled in Adult Education are seeking their high school diploma or equivalent, but a large number of American adults who have earned a high school diploma still struggle with basic skills. The problem is large and growing:

- More than 36 million Americans can't read or write at the most basic level.
- More than 60 million Americans lack the basic math skills necessary to operate a cash register or understand a bus schedule as well as the credentials and skills necessary to succeed in post-secondary education.
- Every year, one in three young adults drops out of high school.

Without access to Adult Education programs, undereducated, under-prepared adults cannot qualify for jobs with family sustaining incomes that require not only a high school equivalency, but also some college—preferably a one or 2 year certificate in a high demand occupation.

The Federal investment in Adult Education is important to our economy because the U.S. is increasingly losing the skills race to many of its economic competitors. 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." While other nations show consistent progress in enhancing the education levels of their adult populations the competency levels of U.S. adults have not made similar progress. The international Survey of Adult Skills (OECD, 2013) found that our average performance in literacy and numeracy was significantly lower than the international average. Proportionately, the U.S. has more working-age adults with low literacy skills than seven other industrialized nations.

We must invest in Adult Education because the jobs of the future will require postsecondary education. According to 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. 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.

We cannot depend on a robust economy to solve this problem. A stronger economy will bring people back into the workforce but it won't train them. According to Alan Daley's "Overcoming the Skills Shortage," "More than 75 percent of manufacturers report moderate to severe skill shortages and up to 11 percent revenue losses from increased production cost and sales losses due to those shortages. Service industries are hardest hit. Thirty-three percent of all small businesses say they cannot identify candidates qualified for job openings. And 43 percent of small business owners say unfilled jobs are impeding their growth or expansion." Employers can teach job skills but aren't qualified to teach basic skills and soft skills. That is a role for the Adult Education system.

Significant underinvestment in Adult Education and workforce skills development is eroding America's global competitiveness and our economic growth. 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 invest in Adult Education.

High schools alone cannot provide business and industry the workers they need. Most of America's workforce of tomorrow is already in today's workforce. They are beyond the reach of the high schools and postsecondary education. Adult Education is the best way to re-engage them.

There are generational impacts to not investing in Adult Education. By neglecting the adults who need services, we affect their children as well. Education levels have more of an effect on earnings over a 40-year span in the workforce than any other demographic factor. Almost 60 percent of children whose parents don't have a college education live in low-income families, and are less likely themselves to get a good education and qualify for family-sustaining jobs. Mothers and fathers who learn basic skills are better equipped to help their children succeed. 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 premiums grow with more intensive participation. Finally, children whose parents are involved with them in family literacy activities score 10 points higher on standardized reading tests. Adult

Education and family literacy are the best available weapons against intergenerational low literacy.

Further, 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 even more the demand for adult English-language programs for adults.

Adult Education is a good investment. 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 investment in Adult Education is cost-effective. 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.

Data from the Longitudinal Study of Adult Learning (LSAL), which recorded the educational and workforce experiences of a random sample of high school dropouts between 1998 and 2007, show that sustained participation in Adult Education increases the earnings of students. Using propensity score matching to control for observed differences between individuals who enrolled in Adult Education and those who did not, one study found that participating in Adult Education for 100 or more hours netted students an average annual income increase of \$6,635 (in 2007 dollars), nearly one half of standard deviation of students' 2007 incomes.

According to "The Return on Investment from Adult Education and Training," a 2011 policy paper issued by the McGraw-Hill Research Foundation in conjunction with NCSDAE, "A preemptive focus on Adult Education actually saves governments money by reducing societal healthcare, public assistance, and incarceration costs. Adult Education also . . . expands the Nation's available pool of human capital . . . and at a far lower cost per learner when compared to either K-12 or higher education."

Low literacy levels 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 be living in poverty than high school graduates. They are three times more likely to be unemployed than adults with college degrees. Experts estimate that low literacy costs the US more than \$225 billion in lost tax revenue, reduced productivity, crime, and poor health. Investing in Adult Education can improve health outcomes, reduce poverty, and reduce recidivism.

FISCAL YEAR 2018 FUNDING REQUEST

Other nations are boosting the educational levels of their young and working age adults at a faster rate than the U.S. They are showing consistent progress while the U.S. is losing ground. Adult Education is a gateway to a job and a career. It is a hand up, not a hand out. Its impact can last for generations. Properly funding the Adult Education system would yield substantial economic benefits, adding to GDP growth, personal incomes, and increased tax revenues.

In sum, we ask the Subcommittee to remember that Adult Education is a path from low-income jobs and dead-end futures to family sustaining jobs and post-secondary education. In an increasingly competitive world we must empower individuals, families, and communities with the educational opportunities they need. We cannot afford to waste the talents of millions of Americans who cannot read, perform basic math, use a computer, or solve problems creatively. Adult Education works: The number of adults without a high school diploma or equivalent declined by 20 percent from 2000 to 2015. A person with a high school diploma or equivalent earns an average of \$9,620 more per year than a non-graduate. Adult Education funding must be increased if WIOA is to succeed.

We understand the Committee faces a challenging budgetary environment. Nevertheless, we urge you to fund Adult Education at the level authorized in WIOA so that the ambitious goals of that law may be realized. We must invest adequately in our Adult Education system to remain economically competitive.

[This statement was submitted by Beverly Smith, Chair, and Patricia Tyler, Executive Director, National Council of State Directors of Adult Education.]

PREPARED STATEMENT OF THE NATIONAL ENERGY AND UTILITY AFFORDABILITY COALITION

The National Energy and Utility Affordability Coalition (NEUAC) urges you to protect and increase funding for the Low Income Home Energy Assistance Program

(LIHEAP) in order to serve America's most vulnerable families with crisis utility assistance. LIHEAP is the cornerstone of America's energy safety net program. Since 1981, LIHEAP has assisted low-income families, those on a fixed income, veterans, and seniors to ease energy burdens. LIHEAP is federally administered by the U.S. Department of Health and Human Services, Administration of Children and Families, Office of Community Service and presently is funded at \$3.39 billion.

More than 35 million households are eligible for assistance through LIHEAP, and yet the need surpasses the funds available. Only one in every five eligible households receives assistance, or around 6 million homes, leaving four out of every five eligible households potentially to remain in crisis. (National and State by State fact sheets about LIHEAP can be found at <http://neuac.org/wp-content/uploads/2017/02/FINAL-FY18-LAD-State-Sheets.pdf>.)

Federal eligibility rules governing LIHEAP require that household income may not exceed 150 percent of the Federal poverty level or 60 percent of the State's median income. Under the fiscal year 2017 guideline, a family of three would qualify if they made less than \$30,240 annually.¹ However, most LIHEAP recipients fall well below that requirement; according to HHS the typical family receiving assistance in fiscal year 2014 had a median income of just \$17,000.² Energy burdens for these families can reach 20 percent or more of their pay.

Families who rely on LIHEAP are the most vulnerable among us. State LIHEAP administrators report that more than 70 percent of LIHEAP recipient households had at least one vulnerable person—that is a senior age 60 or older, a child age 5 and younger, or an individual with a disability.³

LIHEAP is not an entitlement, it must come before Congress every year and no one is assured of assistance, not even households in crisis. Since 2009, LIHEAP funding has been reduced by one third, but the need has not fallen by a similar measure.

For information and news stories from around the country demonstrating the urgent need for LIHEAP, please see the following or go to www.SaveLIHEAP.org:

Parkersburg, WV and Mid-Ohio Valley 2/26/17

[Http://www.newsandsentinel.com/news/community-news/2017/02/united-way-funds-boost-organizations-throughout-mid-ohio-valley/](http://www.newsandsentinel.com/news/community-news/2017/02/united-way-funds-boost-organizations-throughout-mid-ohio-valley/).

“(United Way Alliance and 2–1–1) Interim Director Stacy Decicco said “we were getting on average 46 calls a week for assistance and 75 percent of those calls were utility assistance related.”

Lehigh Valley, PA 12/29/16

[Http://www.mcall.com/business/energy/mc-puc-winter-heating-crisis-20161229-story.html](http://www.mcall.com/business/energy/mc-puc-winter-heating-crisis-20161229-story.html).

“ . . . the current number of households without heat-related utility service is 4 percent higher than the average from 2011 to 2014, according to the (Pennsylvania) PUC's annual Cold Weather Survey.”

Bend, OR 2/13/17

[Http://www.neighborimpact.org/events/neighborimpacts-energy-assistance-program-reduces-services-program-hit-hard-by-weather-and-funding](http://www.neighborimpact.org/events/neighborimpacts-energy-assistance-program-reduces-services-program-hit-hard-by-weather-and-funding).

“Our program has been hit hard this season due to the weather. Between October 1, 2016 and February 8, 2017 we have served 5,226 people in our Energy Assistance program,” said Joyce Cranston, Energy Assistance Program manager at NeighborImpact. “ . . . We are trying to keep up, but the need for assistance has far outpaced the funding we have available.”

Milwaukee, WI 1/8/17

[Http://fox6now.com/2017/01/08/i-needed-it-community-advocates-sees-15-increase-in-those-needing-energy-assistance-this-winter/](http://fox6now.com/2017/01/08/i-needed-it-community-advocates-sees-15-increase-in-those-needing-energy-assistance-this-winter/).

“Community Advocates sees 15 percent increase in those needing energy assistance this winter.”

Little Rock, AR 7/5/16

[Http://www.arkansasmatters.com/news/local-news/dozens-apply-for-liheap-utility-assistance-at-state-fairgrounds](http://www.arkansasmatters.com/news/local-news/dozens-apply-for-liheap-utility-assistance-at-state-fairgrounds).

¹ LIHEAP IM 2016–02 <https://www.acf.hhs.gov/ocs/resource/liheap-im-2016-02-hhs-poverty-guidelines-for-optional-use-in-ffy-2016>.

² HHS fiscal year 2017 Budget Justification; https://www.acf.hhs.gov/sites/default/files/olab/final_cj_2017_print.pdf.

³ NEADA 2014 LIHEAP Household Report <http://neada.org/wp-content/uploads/2015/06/State-Table-FY14-Households-Served.pdf>.

“I was laid off, and I’ve got a friend living with me who’s disabled,” applicant, Jamie Brown said. “He’s got COPD so I’m really hoping they’re going to help us with our electric bill.”

Thank you for the opportunity to express the views of the National Energy and Utility Affordability Coalition on this important matter. We thank you for consideration of our request to increase funding for LIHEAP in fiscal year 2018.

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NEUAC is a national, broad-based, diverse coalition with the mission to heighten awareness of the energy needs of limited-income Americans. NEUAC members—including non-profits, fuel funds, energy providers, charitable organizations, tribes, and many other—are working to reduce the energy burden of vulnerable households through education, policy improvements and strategic partnerships.

[This statement was submitted by Katrina Metzler, Executive Director, National Energy and Utility Affordability Coalition.]

PREPARED STATEMENT OF THE NATIONAL ENERGY ASSISTANCE DIRECTORS’
ASSOCIATION

The members of the National Energy Assistance Directors’ Association (NEADA), representing the state directors of the Low Income Home Energy Assistance Program (LIHEAP) would like to first take this opportunity to thank the members of the Subcommittee for considering our funding request for fiscal year 2018. For fiscal year 2018 we are requesting the Committee restore program funding to the fiscal year 2011 level of \$4.7 billion.

The funding request would allow states to restore program services to the level provided in fiscal year 2011 including increasing the number of households served from 6.1 million to 7.0 million and restoring the purchasing power of the average annual grant to about 62 percent of the cost of home heating from approximately \$458 to \$560. We understand that there are significant budget pressures this year and we want to emphasize that while \$4.7 billion is the funding level that we believe is needed, there is absolutely no room to cut the current funding level LIHEAP without harming millions of very vulnerable households.

The average cost of home heating has remained unaffordable for millions of low-income households this winter across the country with an average annual price of \$783, representing an increase of 8.1 percent or \$58 more than the comparable cost of home heating last year. According to the US Energy Information Administration, the average home heating cost this winter for those using propane was \$1,448, heating oil \$1,227, electricity \$902 and natural gas \$577.

The Administration’s Budget, if enacted, would eliminate all funding for LIHEAP beginning in fiscal year 2018. The practical result would be that millions of low income families would not be able to afford their home energy bills and would face having to choose between heating and cooling their homes and the purchase of other vital necessities including food and medicine.

The Administration’s Budget states that LIHEAP is unable to demonstrate strong performance outcomes. NEADA strongly disagrees with that characterization of the program. LIHEAP has developed and implemented a comprehensive performance measures program that was implemented beginning in fiscal year 2016. HHS requires states to submit an annual report containing data on targeting households that pay the highest energy costs in proportion to their income, restoring energy services to families that have been shut-off due to lack of payment, and prevention of loss of energy services.

An analysis of preliminary data for fiscal year 2016 received from 30 states reported that LIHEAP:

- restored energy services for 217,542 families, approximately 7.8 percent of the total households served in those states. These are households that had been disconnected from service, had run out of delivered fuels, or whose heating or cooling appliances had become inoperable.
- prevented disconnection for 840,925 households, 30.0 percent of the total households served in those states. These households were at immediate risk of losing energy services, having either received a disconnect or past due notice, about to run out of delivered fuel, or having energy equipment in need of repair or replacement.

The Administration’s Budget further states in support of their proposal that the more than six million households currently receiving energy assistance will be able to maintain energy service because, utility companies as well as state and local gov-

ernments, provide significant heating and cooling assistance and the majority of states prohibit utilities from discontinuing heating during the winter months.

Replacing LIHEAP with a patchwork of state, local and utility assistance would take us back to the days when many poor families used their stoves to heat their homes and suffered the shut-off of energy services when they were unable to pay the bill. These pressures are made worse during periods of price spikes due to global events or extreme weather conditions that make home energy unaffordable. These programs are not a substitute for LIHEAP, rather they provide supplementary assistance.

LIHEAP's impact in many cases goes beyond providing bill payment assistance by playing a crucial role in maintaining family stability and improving health outcomes for vulnerable populations. It enables elderly citizens to live independently and ensures that young children have safe, warm homes to live in. Although the circumstances that lead each client to seek LIHEAP assistance are different, LIHEAP links these stories by enabling people to cope with difficult circumstances with dignity.

LIHEAP is the primary source of heating and cooling assistance for some of the poorest families in the United States. In fiscal year 2017, the number of households receiving heating and cooling assistance is expected to remain at about 6.1 million or about 19 percent of eligible households, with an average annual grant size of about \$458. In addition, 70 percent of recipient households have at least one vulnerable and at-risk member who is elderly or disabled, or have a child under the age of six.

LIHEAP's impact in many cases goes beyond providing bill payment assistance by playing a crucial role in maintaining family stability and improving health outcomes for vulnerable populations. It enables elderly citizens to live independently and ensures that young children have safe, warm homes to live in. Although the circumstances that lead each client to seek LIHEAP assistance are different, LIHEAP links these stories by enabling people to cope with difficult circumstances with dignity.

Energy Prices and their Impact on Low Income Households

Energy prices fall hardest on lower income households. In fiscal year 2014, the average energy burden for low-income households was 10 percent of income, almost four times more than the rate for non-low income households (2.4 percent). Of even greater concern about one-third of lower income households have energy burdens greater than 15 percent of income and one in six have an energy burden greater than 25 percent of income. Source: fiscal year 2014 Home Energy Notebook, Administration for Children and Families.

At the same time, LIHEAP is in a period of transition. Along with the Administration for Children and Families, the Department that oversees the program, LIHEAP offices are working to enhance current program integrity measures including developing modernized web-based intake systems, and instituting external verification of applicant-submitted data. In addition, they are implementing nationwide performance measures that will give Congress and the public a clear picture of the effectiveness of LIHEAP in helping low income households and have recently made public a portal to analyze the data they have collected. NEADA believes these efforts will lead to a more responsive and more cost-effective program.

The following are several examples of households receiving LIHEAP assistance:

Alabama: A single mother in Alabama supporting three children on minimum wage was often forced to decide whether to pay utility bills or rent. She received LIHEAP to help pay her bill and was enrolled in an energy education class to help manage her energy usage. In addition to the LIHEAP benefit, she was able to bring down her energy bill from about \$570 a month to \$495 month, a savings of \$75, as a result of the class.

California: A young mother of three lived in an older all-electric home and had their electricity shut off due to a past-due bill of about \$800. She worked full time making minimum wage and her husband worked as a seasonal laborer. With no electricity, the family could not heat their home, access hot water, or operate appliances. LIHEAP was able to assist the family by paying their past due bill to get the electricity turned back on. She was also referred to the County's Weatherization Program, which assists families in making their homes more energy efficient.

Connecticut: A single mother of two facing the challenges of being homeless came to the state for help. Through Connecticut's connected services, she received a housing subsidy, \$505 in LIHEAP funds, and was enrolled in the utility company's Matching Payment Program.

Georgia: A 77 year-old disabled senior living on SSI was facing shut-off due to unaffordable winter energy bills. During the winter months every year her heating

bills peaked as the result of having to maintain a consistent home heating temperature due to her disability and other illnesses. Her gas bill was in danger of disconnection with a balance of \$612 and an additional past due portion of \$355. With the senior meeting the eligibility requirement for both the LIHEAP maximum benefit \$350 and Home Energy Assistance Team program funds of \$350 the program was able to successfully assist this senior to bring her home heating bill current which resulted in the senior maintaining home heating throughout the remainder of winter.

While visiting the home of a senior citizen to take a LIHEAP application, the Program Coordinator noticed the oven and top burners of her stove were on, as well as that she was wearing a heavy over wrap. During the intake process it was discovered that her home heating furnace was not working. Based on her income she received the maximum LIHEAP benefit of \$350 and was referred to the Weatherization Assistance Program (WAP) to have her heating source evaluated. The Weatherization Program Coordinator came out and confirmed that the furnace needed to be replaced thereby increasing the senior's household's well-being, comfort and safety.

Idaho: A 90 year-old woman in rural Idaho was referred by LIHEAP to Weatherization after she indicated that she had a broken furnace. Weatherization staff found that she was using a coffee can to carry wood pellets from an outdoor shed to a pellet stove in her living room, because she was not able to carry an entire bag. With no other backup heat source, she would have to leave her home if the unreliable stove broke. Because of the referral from LIHEAP, the Weatherization program was able to install a new high efficiency furnace and weatherize her home. This saved her money on her monthly heating bill and allowed her to stay in her home.

Illinois: A single man who had been living in a tent was able to afford an apartment for the first time in years when he discovered he had an old bill with the utility and would not be able to get utilities in his new home. LIHEAP was able to get him connected and help him get up-to-date on his bills.

Oklahoma: A young single woman with medical issues was working part time as a cashier and taking care of her elderly grandmother. She was able to use LIHEAP to maintain service while she was between jobs, preventing her and her mother from entering a shelter. She was also able to use LIHEAP emergency assistance to prevent disconnect of her electricity when her new salary was not enough to cover the bill.

Pennsylvania: A disabled cancer patient lost her home through foreclosure but was still in the residence pending eviction. Her furnace was shut down for safety reasons after the state weatherization team discovered it was leaking carbon monoxide. The property was acquired by an out-of-state corporation that refused to allow the weatherization team to repair the furnace. The state LIHEAP office was able to use LIHEAP weatherization funds to provide space heaters for the woman until she was able to make other living arrangements, saving her from making the choice of living in a house made hazardous from carbon monoxide or in freezing temperatures.

Tennessee: A woman who is bed ridden and paralyzed from the waist down had to cut back on other necessities to pay her medical bills. At the beginning of last winter, she saved energy by only turning on the lights when her nurse came to visit. She also kept her thermostat on 60 degrees and asked her nurse to layer her clothing and put extra blankets on her before she left. Since receiving LIHEAP, she has been able to leave a light on at night to make her feel more secure and to keep the home at a comfortable temperature.

Wyoming: An elderly woman was facing eviction because she was in arrears on her utility bill. Her monthly social security income was not sufficient to cover her utility bill, cancer treatments, and travel costs to receive treatment. LIHEAP helped her out with her bill, ensuring she could stay in her home. "We might not be able to eat very well or pay for medicines, but at least we can be warm in our own homes with the help of LIHEAP".

NEADA strongly urges the Congress to reject the Administration's proposal and instead increase funding to \$4.7 billion for this vital program to ensure the country's most vulnerable families can heat and cool their homes in the coming year.

We appreciate the opportunity to submit testimony on behalf of the State directors of the Low Income Home Energy Assistance Program.

PREPARED STATEMENT OF THE NATIONAL FAMILY PLANNING & REPRODUCTIVE
HEALTH ASSOCIATION

SUMMARY

Requesting \$327 million in funding for fiscal year 2018 for the national family planning program (Title X of the Public Health Service Act).

My name is Clare Coleman; I'm 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 Federal Public Health Service Act, the only federally funded, dedicated family planning program for the low-income and uninsured. These cornerstones of the nation's public health safety net are essential resources for those providing access to high-quality services in communities across the country. As the committee works on the fiscal year (FY) 2018 appropriations bill, NFPRHA respectfully requests that you make a critical investment in Title X by including \$327 million, which 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 as well as hospitals, family planning councils, Planned Parenthoods, federally qualified health centers, and other private nonprofit organizations. These diverse provider networks are essential to helping ensure that millions of poor and low-income individuals as well as those who are underinsured or uninsured receive access to high-quality family planning and other preventive health services in all 50 states, the District of Columbia, and US territories. Any effort to limit participation by highly qualified providers is detrimental to patient access and public health.

An analysis published in the American Journal of Public Health in January 2016 found that in order for all low-income, uninsured women of reproductive age to access family planning services, the program would need to be supported with approximately \$737 million. The fiscal year 2017 appropriations process provided only \$286.5 million, a fraction of what is needed to serve low-income, uninsured women across the country. It's also important to note that the Title X program also supports men, so the resource needs identified in the analysis are extremely conservative.

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. More importantly, Title X-funded health centers, because of the quality and specialty care they provide, remain in demand for individuals regardless of their payer source.

Furthermore, if Congress fundamentally alters the structure and financing of Medicaid, as is proposed in the version of the American Health Care Act currently under consideration in the Senate and in President Trump's fiscal year 18 budget request, these changes will compound the demands being placed on the Title X safety net. The proposals will inevitably shift costs to states, forcing them to make choices about program eligibility, benefits, and provider payments in order to adapt to new funding constraints. Medicaid beneficiaries will also likely face new barriers to coverage, such as premiums and other cost-sharing requirements.

Likewise, last year's Zika virus outbreak highlighted the importance of the publicly funded family planning safety net and the need for robust Title X funding. The CDC-confirmed causal linkage between babies born with microcephaly and pregnant women infected with the Zika virus reinforced the simple concept that in a time of public health emergency, women will turn to Title X-funded providers for thorough counseling, risk assessment, and access to family planning services. While the public health threat has largely dissipated in the colder weather when mosquitos carrying the virus cannot thrive, public health experts expect and policymakers should prepare for the Zika virus to continue to spread domestically as warm weather returns.

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). During the same period, approximately 1.1 million

patients were lost from the program. These findings are very disturbing given that four in ten women who access care at a Title X-funded health center say that it is their only source of care. In fiscal year 2018, the financial picture looks no less dire, especially because thus far there is not an agreement in place to provide budgetary relief from the sequester.

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 increasing service efficiency and which provide a significant return on investment. Title X has long set the standard for high-quality family planning and sexual health service provision and recently doubled down on its efforts to lead the field by advancing best practices for clinical care. In April 2014, the program issued “Providing Quality Family Planning Services—Recommendations of CDC and the U.S. Office of Population Affairs,” that outlines the most up-to-date clinical recommendations for all providers of family planning care, including Title X-funded providers, to help define patient-centered, high-quality care in a family planning visit. Such efforts reinforce the network’s dual role as safety-net providers and centers of excellence for family planning and sexual healthcare.

Millions of low-income women and men depend on the Title X program for affordable access to family planning and preventive health 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 making a significant investment in the nation’s family planning safety net and requests funding for Title X at \$327 million in fiscal year 2018.

[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 National Head Start Association (NHSA), thank you for the opportunity to submit written testimony regarding funding for Head Start and Early Head Start (collectively Head Start) in fiscal year 2018. For more than 50 years, Head Start has created opportunities for disadvantaged children and families to succeed by providing the highest quality early childhood care and education including health, nutrition, parent engagement, family support, and child development services. NHSA is grateful for the Subcommittee’s tradition of strong bipartisan support for early childhood care and education in general and for Head Start specifically. NHSA and the Head Start community stand ready to work with Congress to continue to deliver great care and support to children and families. Head Start remains at the forefront of early childhood education innovation in rural, Native American, and urban communities, based on proven, data-driven solutions. As decisions are made on funding for fiscal year 2018, the Head Start community respectfully requests that the Subcommittee allocate \$9,818,643,596 for Head Start—an increase of \$565,548,596 over fiscal year 2017.

Understanding today’s fiscal climate, we do not make this request lightly. Any increase for Head Start will be exceptionally difficult unless current budget caps for non-defense discretionary spending are raised and the Labor, Health and Human Services, Education Subcommittee receives a strong 302(b) allocation. We urge the full Committee, the Congress, and the Administration to adopt and support strong funding levels for domestic priorities in fiscal year 2018.

We recommend \$9,818,643,596 for Head Start in fiscal year 2018 in order to enable Head Start programs to retain a highly effective workforce, better utilize existing data to ensure continuous improvement, implement new program performance standards, and meet the changing needs of working families across the Nation. Included in this testimony are details of what this increase would support and why it is a critical investment at this time.

The Head Start community is appreciative of being a funding priority for this Committee, and the whole of Congress. In fiscal year 2017, Congress appropriated \$9,253,095,000 for Head Start and Early Head Start—an increase of \$85,000,000 for a cost of living adjustment. This funding level built off a significant increase in fiscal year 2016 to support Head Start programs seeking to better serve working families through extended duration of services, retain the Head Start workforce, and expand much-needed services for infants and toddlers. The extended duration funds (\$294,000,000) were met with overwhelming interest by programs across the Nation—so much interest that many programs who were eligible for the funds were

forced by the U.S. Department of Health & Human Services to reduce their extension plans by as much as a third. At the Friends of Children of Mississippi Inc. Head Start and Early Head Start program, these funds provided before & after care and extended hours for 700 children in Copiah, Clarke, Humphreys, Kemper, Madison, Newton, and Rankin Counties. According to the Director of the program, Dr. Marvin Hogan, this allowed the program “to elevate their operations to another level” by better meeting the needs of working families. Dr. Hogan has had remarkable success moving Head Start families into the workforce for area employers and the extended hours for the children enabled families to remain employed.

In May, President Trump released his administration’s full fiscal year 2018 Budget Proposal and it included \$9,168,095,000 for Head Start and Early Head Start. NHTSA is disappointed that the fiscal year 2017 cost of living adjustment was not included in the President’s proposal. Head Start’s dedicated staff do a remarkable job and deserve more support. While the Budget Proposal did not take into consideration the final fiscal year 2017 Omnibus Appropriations bill, we remain confident that Congress will ensure that these funds, as well as Head Start’s position as the premier early childhood care and education program in the United States, will extend into fiscal year 2018 and beyond.

In addition to maintaining the fiscal year 2017 increase in fiscal year 2018, the Head Start community has two main priorities for the coming fiscal year: retaining highly-effective staff and better meeting the needs of children and families through the implementation of the new Program Performance Standards. They are each described below:

Supporting Quality Workforce Retention: Within the sum provided, NHTSA recommends allocating \$193,789,995 (including \$13,440,000 for Early Head Start—Child Care Partnership grantees) in fiscal year 2018 for Workforce Investments through a cost-of-living adjustment, per the Consumer Price Index-Urban. Because of non-competitive salaries, nearly every Head Start provider struggles to retain quality staff. Furthermore, high staff turnover rates directly impact quality of services to young children. Investing in workforce quality is the most important and pressing need for programs across the country. In Vermont, six different Head Start programs, in both rural and urban settings, all reported that they are “hemorrhaging direct service staff, especially qualified, licensed teachers.” They agreed that the biggest challenge in attracting new qualified staff is low pay; in their area, an employee can make significantly better wages getting a position in the K–12 system. The Head Start community strongly encourages Congress to stand with our Nation’s most vulnerable families by helping Head Start organizations recruit and retain quality early childhood educators.

Supporting A High Quality System: Within the overall sum, NHTSA recommends that \$396,758,601 be allocated for Quality Improvement Funding (QIF) without restrictions in fiscal year 2018.¹ As outlined in the 2007 Head Start Act, these funds may be used for increasing duration of services to better support working families, staff training, improving community-wide coordination, enhancing classroom environments, and strengthening transportation safety. These funds would allow programs to flexibly prioritize funding based on their needs and avoid cutting access as they implement the recently released Head Start Program Performance Standards. For example, at the Lummi Nation Head Start program in Bellingham, Washington, the program has two priorities—more facilities to accommodate growth/expansion of hours and mental health professionals to provide more direct support for struggling children in the classroom.

Much has changed in Head Start world over the last year. Most significantly, on September 1st, 2016, the Head Start Program Performance Standards were updated for the first time in decades. The new Standards were notably streamlined, going from eleven to four sections, and strengthened by increasing the focus on data, continuous improvement, and local flexibility. The Head Start community has met the new Standards with appreciation for the long-awaited and much-needed changes.

Three independent research reports have also come out documenting the Head Start advantage. These reports detail that Head Start not only gives students better outcomes at the end of their time in the program, but that these results persist through life. The advantages last through high school, college, and even into parenthood for certain groups of students.^{2,3,4} These outcomes include higher test scores,

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.

²Bauer, L. and D. W. Schanzenbach, (2016) The Long-Term Impact of the Head Start Program. The Hamilton Project, the Brookings Institution. Retrieved from: http://www.hamiltonproject.org/assets/files/long_term_impact_of_head_start_program.pdf.

less chronic absenteeism,⁵ higher graduation rates, and better parenting skills.⁶ The groups that particularly benefited from Head Start were Hispanic and African-American children, children who qualify for free lunch, and children whose mothers did not finish high school.⁷ Unique program features—such as paying teachers on a scale comparable to the public schools, offering full-day services, and using data to inform continuous quality improvement—can also be tied to better outcomes for children.⁸ These new studies reinforce Head Start's extensive body of prior research that has proven that when disadvantaged children receive high-quality birth-to-five education, such as the combination of Early Head Start and Head Start, the return on investment can be as high as 13 percent annually, or \$7.30 for every dollar spent.⁹ These savings are generated through increased earnings, employment, and family stability;¹⁰ as well as decreased welfare dependency,¹¹ healthcare costs,¹² crime costs,¹³ grade retention,¹⁴ and special education.¹⁵ Head Start ensures children from the most disadvantaged communities receive the nurturing, engaging, and healthy education necessary for an equal opportunity to succeed in life.

In closing, the Head Start community does understand the pressures the Subcommittee faces in fiscal year 2018, and we are grateful for the commitment shown by Congress to keep early learning, and Head Start in particular, a priority. We urge the Subcommittee to strengthen Head Start and Early Head Start in fiscal year 2018 through investments that will improve workforce retention, support continuous quality improvement and the implementation of new Standards, and better support working families across the Nation.

[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 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 2018 budget recommendations for child welfare and children's mental health programs administered by the Department of Health and Human Services (DHHS). Our full recommenda-

³Phillips, D., W. Gormley, & S. Anderson. (2016). The Effects of Tulsa's CAP Head Start Program on Middle-School Academic Outcomes and Progress. *Developmental Psychology*, 52, 1247–1261. Retrieved from: <https://georgetown.app.box.com/s/q43pgptmz2m6h3zjcosk93ucnh1k4o9e>.

⁴Montaloux, C. (2016) Revisiting the impact of Head Start. Institute for Research on Labor and Employment, University of California Berkeley. Retrieved from: <http://irle.berkeley.edu/files/2016/IRLE-Revisiting-the-impact-of-Head-Start.pdf>.

⁵Phillips, Gormley, and Anderson (2016).

⁶Bauer and Schanzenbach (2016).

⁷Ibid.

⁸Phillips, Gormley, and Anderson (2016).

⁹Garcia, J.L., J.J. Heckman, D.E. Leaf, and M.J. Prados (2016). The Life-cycle Benefits of an Influential Early Childhood Program. Human Capital and Economic Opportunity Global Working Group, University of Chicago. Chicago, IL. (2016–035). Retrieved from: https://econresearch.uchicago.edu/sites/econresearch.uchicago.edu/files/Garcia_Heckman_Leaf_etal_2016_life-cycle-benefits-ecp_r1.pdf.

¹⁰Benefits and Costs of Head Start. Social Policy Report. 21 (3: 4); Deming, D. (2009). Early childhood intervention and life-cycle skill development: Evidence from Head Start. *American Economic Journal: Applied Economics*, 1(3): 111–134; Meier, J. (2003, June 20). Interim Report. Kindergarten Readiness Study: Head Start Success. Preschool Service Department, San Bernardino County, California; Deming, D. (2009, July). Early childhood intervention and life-cycle skill development: Evidence from Head Start, p. 112.

¹¹Meier, J. (2003, June 20). Kindergarten Readiness Study: Head Start Success. Interim Report. Preschool Services Department of San Bernardino County.

¹²Frisvold, D. (2006, February). Head Start participation and childhood obesity. Vanderbilt University Working Paper No. 06–WG01; Currie, J. and Thomas, D. (1995, June). Does Head Start Make a Difference? *The American Economic Review*, 85 (3): 360; Anderson, K.H., Foster, J.E., & Frisvold, D.E. (2009). Investing in health: The long-term impact of Head Start on smoking. *Economic Inquiry*, 48 (3), 587–602.

¹³Americans too high: Pew study; Garces, E., Thomas, D. and Currie, J. (2002, September). Longer-term effects of Head Start. *American Economic Review*, 92 (4): 999–1012.

¹⁴Over Head Start: What the Research Shows.; Garces, E., Thomas, D. and Currie, J. (2002, September). Longer-Term Effects of Head Start. *American Economic Review*, 92 (4): 999–1012.

¹⁵NHSA Public Policy and Research Department analysis of data from a Montgomery County Public Schools evaluation. See Zhao, H. & Modarresi, S. (2010, April). Evaluating lasting effects of full-day prekindergarten program on school readiness, academic performance, and special education services. Office of Shared Accountability, Montgomery County Public Schools.

tions appear in the charts below with our priority recommendations described in more detail underneath the charts.

Child Welfare

Agency	Program	Fiscal year 2017 enacted	Fiscal year 2017 recommended
DHHS ACF/CB	Promoting Safe and Stable Families-Discretionary (tribal) Tribal Court Improvement Program	\$59.7m (\$1.8m) (\$1.0m)	\$70m (\$21m) (\$1.0m)
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 (\$500k)
DHHS ACF/CB	Child Welfare Services (tribal)	\$268.7m (\$6.3m)	\$280m (~\$7.1m)
DHHS HRSA	Maternal Infant & Early Childhood Home Visiting Program (tribal)	\$400m (\$12m)	\$400m (\$12m)

PRIORITY RECOMMENDATIONS

Promoting Safe and Stable Families recommendation (Title IV-B, Subpart 2—Discretionary Portion):

Increase discretionary funding to \$70 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 continue tribal court improvement funding at \$1 million.

The Promoting Safe and Stable Families Program provides funds to tribes for coordinated child welfare services that include family preservation, family support, family reunification, and adoption support services. This program has a mandatory capped entitlement appropriation as well as a discretionary appropriation. There is a 3 percent set-aside for tribes under each program. All tribes with approved plans are eligible for a portion of the set-aside that is equal to the proportion of their member children compared to the total number of member children for all tribes with approved plans. Based on this formula, tribes who would qualify for less than \$10,000 are not eligible to receive any funding. This means that many tribes, typically those tribes who 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

The Promoting Safe and Stable Families Program offers support for those culturally based services that tribes already have experience with, such as parenting classes, home-visiting services, respite care for caregivers of children, and other services that safely preserve families, but cannot expand based upon low levels of funding. This program is vital to the tribes and tribal consortia that depend on it to support their efforts to prevent the unnecessary removal of AI/AN children from their homes. Yet because of the funding levels, hundreds of tribes are ineligible for this formula grant. Increasing this program to \$70 million (still \$130 million below

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.

the authorized appropriation) could help dozens of new tribes access this funding and augment the programming of the tribes and consortia currently funded.

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 court with their child welfare system 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 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.

Children's Mental Health

Agency	Program	Fiscal year 2017 enacted	Fiscal year 2018 recommended
DHHS SAMHSA	Programs of Regional and National Significance— Children and Family Programs (includes Circles of Care)	\$6.4m	\$8.5m (Reserve \$6.5m for Circles of Care)
DHHS SAMHSA	Children's Mental Health Services Program— Systems of Care	\$117m	\$124m
DHHS SAMHSA	GLS State/Tribal Youth Suicide Prevention	\$35.4m	\$40.5m
DHHS SAMHSA	GLS Campus Suicide Prevention Program	\$6.5m	\$9.1m
DHHS SAMHSA	AI/AN Suicide Prevention	\$2.9m	\$3.2m
DHHS SAMHSA	Tribal Behavioral Health Grant (divided between substance abuse prevention and mental health services)	\$30m	\$50m

³ U.S. Department of Justice, Office of Justice Programs, Office of Juvenile Justice and Delinquency Prevention. (2014). Attorney General's Advisory Committee on American Indian/Alaska Native Children Exposed to Violence: Ending violence so children can thrive (p. 81). Retrieved from www.justice.gov/sites/default/files/defendingchildhood/pages/attachments/2014/11/18/finalaianreport.pdf.

Children's Mental Health—Continued

Agency	Program	Fiscal year 2017 enacted	Fiscal year 2018 recommended
DHHS SAMHSA	Project LAUNCH	\$34.5m	\$34.5m

Programs of Regional and National Significance Children and Family Programs (includes Circles of Care):

Ensure that \$6 million under this line item continues to be reserved specifically for the tribal and urban Indian community Circles of Care program.

The Children and Family Programs in the Substance Abuse and Mental Health Services Administration (SAMHSA) budget represents funds allocated to support the 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 Native 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 allows 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.⁴

Of the 31 total graduated Circles of Care grantees, 12 have obtained direct funding to implement their system change efforts through the Child Mental Health Initiative (CMHI) Program (which funds system of care grants), and four others have partnered with other CMHI-system of care 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.

Programs of Regional and National Significance, Tribal Behavioral Health Program: Increase funding for the Tribal Behavioral Health program to \$50 million.

In the fiscal year 2016 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 2018 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.⁵ Although these statistics are troubling, with adequate resources tribes are best able to serve these young people and help them heal before they reach adulthood.

There is growing evidence that Native youth who are culturally and spiritually engaged are more resilient than their peers. Research has revealed that 34 percent of Native adolescents . . . preferred to seek mental or substance abuse services from a cultural or religious oriented service provider. In other research, American

⁴American Psychiatric Association. (2010). Mental health disparities factsheet: American Indians and Alaska Natives (p. 4).

⁵U.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.

Indian caregivers preferred cultural treatments (e.g., sweat lodge, prayer) for their children and found the traditional-based ceremonies more effective than standard or typical behavioral health treatment.⁶

Children's Mental Health Initiative (Systems of Care):

Increase funding to \$124 million to allow for the continued support of the current cohorts of 4-year Systems of Care Expansion Implementation Grants, 6-year Children's Mental Health Initiative Systems of Care Grants, and new grantees in fiscal year 2018.

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 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, 17 tribal communities are funded under the Children's Mental Health Initiative.

Evaluation studies of Systems 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.⁷

PREPARED STATEMENT OF THE NATIONAL INDIAN HEAD START
DIRECTORS ASSOCIATION

Thank you Chairman Blunt, Ranking Member Murray, and members of the Committee for this opportunity to submit written testimony regarding the critical topic of Federal funding for American Indian/Alaska Native (AI/AN) Head Start and Early Head Start Programs. My name is Lee Turney and I am the President of the National Indian Head Start Directors Association (NIHSDA), the official voice of AI/AN Head Start programs for almost 40 years. Our organization thanks you for your dedicated work and sustained investment in improving early childhood education in Indian Country. However, much work remains to be done in ensuring a more promising future for all of our children through access to quality Head Start and Early Head Start programs in their home communities.

Introduction.—Indian Head Start has been an integral part of Head Start since the program began in 1965. It is currently the most successful Federal program focused on addressing the complex needs of Native youth and families in early childhood education. It does this through a highly effective program model that focuses on the whole individual—through education, health, language, and culture—as well as on the family and wider community, to create a vibrant and safe learning environment for our Native children.

Despite the critical services that such programs provide to tribal communities, only about 16 percent of the age-eligible Native child population is enrolled in Indian Head Start; and of the 567 federally recognized tribes, only about 188 have Head Start programs. This means approximately 379 tribes do not have Head Start available for their children. Of those that do, many face significant hurdles in providing adequate classroom facilities, meeting the Federal in-kind contribution requirement, and overcoming culturally inappropriate evaluation metrics. Strengthening and expanding programs is, therefore, paramount to Indian Head Start's continued success in meeting the needs of Native children, families, and communities.

Federal Trust Responsibility to Indian Tribes.—The United States Constitution, treaties, Federal statutes, executive orders, Supreme Court precedent, and other agreements establish the Federal Government's trust responsibility to protect the

⁶Novins, D. K., & Bess, G. (2011). 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* (pp. 189–204). Santa Barbara, CA: SABC-CLIO, LLC.

⁷Stroul, 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.

interests of Indian tribes and communities. They also set forth the Federal Government's recognition of Indian tribes as sovereign nations with inherent powers of self-governance over their communities and tribal members. Indian Head Start programs help fulfill these unique obligations to Indian tribes by reinforcing the Federal Government's commitment to work with tribes on a government-to-government basis. For example, the Head Start Act requires annual consultations with tribal governments operating Indian Head Start programs. It also ensures that funds flow directly from the Federal Government to the tribes.

Tribal programs have traditionally had difficulty securing funds that must first pass through the States. NIHSDA is, therefore, strongly opposed to the use of block granting for program funds because it would give States almost full control over Head Start and severely impair the ability of Indian Head Start programs to provide critical life services to AI/AN children, families, and communities. NIHSDA recently joined with 64 national, State, and regional Head Start associations in voicing its concerns regarding the block grant funding proposal set forth in the Head Start Improvement Act of 2017 (S.185 and H.R. 1921, respectively). Block granting inhibits the ability of Head Start programs to meet local needs and infringes on tribal sovereignty. NIHSDA urges Congress to honor its trust obligations to Indian tribes by providing adequate funding for Indian Head Start programs in fiscal year 2018 on a direct government-to-government basis.

Base Funding Head Start and Early Head Start Programs.—Together with the National Head Start Association and the Migrant and Seasonal Head Start Association, NIHSDA would like to express its appreciation for Congress' commitment to expanding access to meaningful early childhood education opportunities for America's most vulnerable children through Head Start and Early Head Start programs. To enable our programs to continue to serve the dire and ever-increasing needs of working and low-income families, NIHSDA recommends funding Head Start and Early Head Start at \$10,171,763,201 in fiscal year 2018. Within this amount, NIHSDA recommends \$396,758,601 be allocated for Quality Improvement funding to support the implementation of the new performance standards. These funds should be provided without restriction so that programs can apply the funds to 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 \$184,280,600 be allocated for Workforce Investments through a cost of living adjustment. Recruiting and training qualified teachers is a persistent challenge for Indian 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.

NIHSDA further recommends that no less than three (3) percent of funds appropriated to Head Start in fiscal year 2018 be set aside for American Indian and Alaska Native programs. Section 6(a)(4)(D)(ii) of the Head Start reauthorization act of 2007 provides for special expansion funds of not less than three (3) percent for Indian Head Start programs and not less than four-and-a-half (4.5) percent for Migrant and Seasonal Head Start programs, with the option of an additional percentage increase at the Secretary's discretion. The set-aside funds are paramount to Indian Head Start's continued success in meeting the needs of Native children, families, and communities.

Exempt Indian Head Start from Federal Budget Cuts and Sequestration.—NIHSDA is deeply concerned by the drastic reductions in discretionary, non-Federal spending set forth in President Trump's fiscal year 2018 budget proposal, particularly in regards to the Department of Health and Human Services (HHS). The fiscal year 2018 budget proposes to reduce HHS spending by \$15.1 billion, which translates to a 17.9 percent decrease from the 2017 annualized CR level. This drastic cut poses an immediate and unacceptable risk to our children and families, who depend on the HHS for early childhood care and education, medical services, public health programs, and other social services that provide our communities with the tools they need in meeting life's challenges. In addition to harming families, the proposed reduction would detrimentally impact the AI/AN Head Start workforce with the loss of countless jobs—which translates into indirect negative effects on local economies and tribal communities through lost purchasing power and applicable tax revenues. Cuts in Federal funding should not present yet another barrier to the well-being and success of our children and families.

Native children face serious disparities in education, health, and safety. An average of 28 percent of American Indian and 22 percent of Alaska Native families live in poverty, although the rate can climb to as high as 60 percent in some communities. An untold number of Native children and families live in deep poverty, which

is commonly defined as having cash income below half of one's poverty threshold. The high school graduation rate hovers at around 50 percent in many Native communities. Suicide is the second leading cause of death for Native youth aged 15–24 years old. Underlying psychological issues of historical trauma, social despair, and cultural loss affect Native youth, families, and communities as a whole. By engaging Native children through a unique combination of mainstream and culturally appropriate classroom practices, Indian Head Start may be the best Federal program in place that actually addresses the complex needs of Native children who, on a daily basis, must deal with the conditions herein described.

The ability of Indian Head Start to provide these essential services to Native youth is severely hindered by the chronic underfunding of Head Start and annual budget cuts due to sequestration under the Budget Control Act of 2011 (Public Law 112–25). When across-the-board sequestration occurred in 2013, other low-income programs, such as the Child Care Entitlement to States and the Children's Health Insurance Program, were exempt from the full effect of funding restrictions—but not Head Start. The disruption in Federal funds, coupled with the detrimental effects of the diversion of priority program funds in 2007, has translated into immediate and long-lasting negative effects for our programs through decreased funds for teacher training, classroom expansion, cost of living increases, facilities maintenance, and other educational services.

To ensure all needy children have access to quality Indian Head Start programs, NIHSDA urges Congress to exempt Indian Head Start from any cuts to the HHS budget, as well as from reduced funding due to sequestration.

Protection of Special Expansion Funds.—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 HHS, 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 out of the set aside programs to expand the funding of mainstream Head Start programs. Congress's set aside had effectively been reduced to 8–9 percent by unilateral and undisclosed administrative action and, necessarily, the funding of the priority programs had been reduced as well.

To address this irregularity and to assure that the Indian Head Start program could make up some financial ground, the 2007 Act provided for special Indian Head Start expansion funds. 42 U.S.C. §9835. The formula is very complicated and difficult to parse, however, it essentially provided that Indian Head Start would receive increases of up to \$10 million per year for fiscal year 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 other programs to make up for the unseen losses in Indian Head Start programs). Because of flat funding in fiscal year 2008 and fiscal year 2010, Indian Head Start only received special expansion funds in fiscal year 2009. As a result, there has never been real mitigation of Indian Head Start's losses arising from the earlier diversion of priority program funds. NIHSDA requests that HHS appropriated funds include a clarification that Indian Head Start expansion funds are reserved for the exclusive, flexible use of priority programs and not mainstream Head Start programs.

Unique Challenges Facing Indian Head Start 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. These programs desperately need facilities and quality improvement funds for staff training and development, staff retention, improved classroom facilities, increased services, and other program needs. As stated, the current Head Start Act includes provisions for special expansion funds for Indian Head Start, but these funds have only been triggered once under the Act. NIHSDA urges Congress to provide increased funding for Indian Head Start in fiscal year 2018 so that our programs can continue to fulfill their critical role in developing Native youth resiliency and strengthening Native families and communities.

Stand Strong for Head Start.—We believe that an investment in Head Start is an investment in the promise of our Nation's future. NIHSDA, therefore, urges Congress to stand strong for early childhood education throughout the fiscal year 2018 budget process. Head Start and Early Head Start programs provide low-income students—as well as their families and communities—with access to essential educational support services that help lay the foundation for success in later life. Moreover, investing in Indian Head Start helps fulfill the unique obligations of the Federal trust responsibility to Indian tribes by reinforcing the Federal Government's

commitment to work with tribes on a government-to-government basis in meeting the needs of Native communities.

Thank you for the opportunity to submit testimony on behalf of this critical issue. NIHSDA has developed a wealth of knowledge regarding early childhood education in Indian Country and welcomes the opportunity to work with Congress on addressing the complex needs of our children and families going forward. Please do not hesitate to contact us for any additional information.

[This statement was submitted by Lee Turney, President, National Indian Head Start Directors Association.]

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 success of the existing programs at the CDC National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), \$2.165 billion for NIDDK, and increases for the HRSA Division of Transplantation (DoT) and Bureau of Primary care to fight kidney disease.

ABOUT CKD

CKD is a condition characterized by a gradual loss of kidney function over time. CKD impacts 26 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). Kidney disease can be detected through a simple blood and urine test, yet can go undetected until very advanced because kidney disease often has no symptoms. When kidney disease progresses, it may lead to kidney failure, which requires dialysis or a kidney transplant to maintain life. African Americans develop ESRD at a rate of 4 to 1 compared to Whites and Hispanic Americans developing it at a rate of 2 to 1.

THE IMPORTANCE OF EARLY DETECTION OF CKD

Astonishingly, 90 percent of individuals with CKD are unaware they have it.¹ Because CKD is often asymptomatic it goes undetected without laboratory testing. Some people are not diagnosed until they have reached end-stage renal disease (ESRD) and must begin dialysis immediately.

Over 675,000 Americans have ESRD; over 475,000 receive dialysis at least 3 times per week to replace kidney function and 200,000 Americans live with a kidney transplant. Complicating the cost and human toll is the fact that it is a disease multiplier, with patients very likely to be diagnosed with cardiovascular disease. Medicare spends more than \$100 billion annually on the care of people with CKD, including \$87,000 per dialysis patient and \$32,500 for a transplant patient.

Cost-effective early identification and treatment options exist which can slow the progression of kidney disease, delay complications, and prevent or delay kidney failure. Intervention at the earliest stage is vital to improving outcomes, lowering healthcare costs, and improving patient experience, yet in a recent clinical study only 12 percent of primary care clinicians were properly detecting CKD in their patients with diabetes who are at the highest risk of kidney disease.² There often is a misconception that once someone is diagnosed with CKD, there must be a referral to a nephrologist. However, it is not necessary in most instances for referral to a nephrologist in early stages.

THE CKD INTERCEPT INITIATIVE

NKF's CKD Intercept initiative aims to transform 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. In support of this effort, NKF is advocating for Congress to enact legislation 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

¹Tuot DS, Plantinga LC, Hsu CY, et al. Chronic kidney disease awareness among individuals with clinical markers of kidney dysfunction. *Clin J Am Soc Nephrol.* Aug 2011;6(8):1838-1844.

²Szczech LA, et al. Primary Care Detection of Chronic Kidney Disease in Adults with Type 2 Diabetes: The ADD-CKD Study (Awareness, Detection and Drug Therapy in Type 2 Diabetes and Chronic Kidney Disease), *PLOS One* November 26, 2014.

healthcare team. In addition, this legislation 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.

While progression of CKD can lead to ESRD, CKD patients are at a greater risk of death, cardiovascular events and adverse drug events. In a most recent study conducted by The Johns Hopkins University, testing for kidney disease—in those with the disease—may be a stronger risk predictor of heart attack and stroke than tobacco use, blood pressure, or high cholesterol.³ Testing for kidney disease in at-risk populations provides the opportunity for interventions to foster awareness, foster adherence to medications and control risk factors.

With the continued support of Congress, NKF is confident a feasible detection, surveillance and treatment pilot can be advanced as a vital step to improve outcomes and lower the costs of kidney disease.

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. We encourage the Committee to sustain funding for the project in fiscal year 2018. We also urge the committee to increase funding for NCCDPHP overall and to use increased funds to promote quality improvement in CKD detection and care among healthcare payers and practitioners.

NIH NIDDK

NKF supports the Friends of NIDDK request of \$2.165 billion for the Institute in fiscal year 2018. Medicare spent over \$100 billion in 2014 caring for patients with kidney disease, \$70 billion of which was for individuals who do not have kidney failure, yet NIH funding for kidney disease research is only about \$600 million annually. Patients deserve better and we cannot allow these opportunities to slip away.

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 fiscal year 2017 efforts, 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 people in underserved communities who otherwise would have little or no access to care. 1 in 13 Americans receives care at participating health clinics. Community Health Centers can serve as a first line of detection and care for people at risk and with CKD who have not been diagnosed. Specifically, 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 risk of progression and cardiovascular complications and CKD diagnosis. This move would align with Healthy People 2020 objectives related to CKD detection and provide a critical data source for CKD surveillance.

HRSA DOT

NKF urges the Committee to increase funding for organ donation and transplantation programs. Activities supported by DoT include initiatives to increase the number of donor organs, and the National Donor Assistance Program which helps individuals obtain a transplant by assisting living organ donors with expenses such

³Matsushita, Kunihiro, Estimated glomerular filtration rate and albuminuria for prediction of cardiovascular outcomes: a collaborative meta-analysis of individual participant data, *Lancet Diabetes Endocrinol*. Published online May 29, 2015, [http://dx.doi.org/10.1016/S2213-8587\(15\)00040-6](http://dx.doi.org/10.1016/S2213-8587(15)00040-6).

as travel and subsistence that are not reimbursed by insurance, a health benefit program, or any other State or Federal program.

This year NKF launched the “The Big Ask/The Big Give” campaign. This initiative, promotes and supports awareness of living kidney donation. It is designed for both those waiting for a kidney transplant who have trouble asking somebody to consider donation (The Big Ask) and potential kidney donors (The Big Give). The Big Ask/The Big Give provides the necessary education and platform to take the misconceptions and confusion out of what can be a very complex process. The program is offered nationwide to transplant centers, dialysis centers and nephrology practices.

To better understand and develop solutions to the high rate of deceased organs that are donated, but never used—NKF will host the Organ Discard Conference in May, which will bring together the transplant community, researchers, and government agencies to address this phenomenon that if rectified could increase the number of transplants performed in the U.S.

Thank you for your consideration of our funding requests for fiscal year 2018.

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 urges the subcommittee to fund the Health Resources and Services Administration’s (HRSA) Title VIII nursing workforce development programs at \$244 million in fiscal year 2018.

NURSING EDUCATION

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). Unfortunately, Federal funding for nursing education is inconsistent with the healthcare reality facing our Nation today.

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. Infrastructure development for all program levels is critical to advancing the science of nursing education. This will increase the pool of nurses and nurse educators. Insufficient investment in the nursing workforce is shortsighted and further jeopardizes access to and the quality of the Nation’s market-driven healthcare delivery system. Policies must be implemented, to develop accurate and replicable models for projecting workforce capacity and to evaluate education, preparation, and workforce activities to increase retention in the nursing profession.

THE NURSE AND NURSE EDUCATOR WORKFORCE

Health inequities, inflated costs, and poor healthcare outcomes are intensifying because of today’s shortfall of appropriately prepared licensed vocational/practical nurses (LVNs/LPNs), registered nurses (RNs), advanced practice registered nurses (APRNs), and nurse faculty. A high quality-nursing workforce equals high quality care for the Nation. With 4.8 million active, licensed RNs/LVNs/LPNs, nurses are the primary professionals delivering quality healthcare in the Nation (NCSBN 2017). According to the Bureau of Labor Statistics (BLS), the RN workforce is projected to grow by 16 percent from 2014 to 2024, resulting in 1,088,400 job openings due to growth and replacement needs. The BLS also estimates the LVN/LPN workforce will grow by 16.3 percent resulting in 322,200 job openings and the APRN workforce will grow by 31 percent with 93,600 job openings during the same period.

This increase is fueled by an expanded 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. The situation is further affected by the needed replacement of some 439,300 jobs vacated by RNs, 117,300 vacated by LPNs/LVNs, and 53,400 vacated by APRNs who will leave

the profession and/or retire by 2024. The BLS projects a need of 19 percent more faculty members to meet the expected increase in demand. In addition, with 12,200 current faculty members expected to retire, 25,400 new nursing instructors will be needed by 2024 (BLS 2015).

The nursing shortage continues to outpace the level of resources allocated by various levels of government to help alleviate it. Funding for nursing education is inconsistent with the healthcare reality facing our Nation today. A strong nursing workforce is essential to a health policy that provides high-value care for every dollar invested in capacity building.

EQUALLY PRESSING IS LACK OF DIVERSITY

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 28 percent of the student population and males only 15 percent of pre-licensure RN students (NLN 2014). 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.

TITLE VIII FEDERAL FUNDING REALITY

Today's undersupply of appropriately prepared nurses and nurse faculty, as well as the projected loss of experienced nurses over the next decade, does not bode well for our Nation. The Title VIII nursing workforce development programs are a comprehensive system of capacity-building strategies that 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. Information from HRSA's Title VIII programs listed below provides a perspective on current Federal investments.

The *Advanced Nursing Education* (ANE) program supports infrastructure grants to schools of nursing for advanced practice programs preparing nurse-midwives, nurse anesthetists, nurse practitioners, clinical nurse specialists, nurse administrators, nurse educators, public health nurses, or other advanced level nurses. In academic year 2014–2015, ANE program grantees trained 8,735 nursing students and produced 2,148 graduates. In addition, 30 percent of students trained were underrepresented minorities and/or from disadvantaged backgrounds.

Nursing Workforce Diversity (NWD) grants increase educational opportunities for individuals from disadvantaged backgrounds (including racial and ethnic minorities underrepresented in nursing) through scholarship or stipend support, pre-entry preparation, and retention activities. In academic year 2014–2015, the number of nursing program students trained was 4,400.

Nurse Education, Practice, Quality, and Retention Grants (NEPQR) address the critical nursing shortage via projects to expand the nursing pipeline, promote career mobility, provide continuing education, and support retention. The NEPQR program funded the Veterans' Bachelor of Science in Nursing (VBSN) program and made awards to 17 schools. Four hundred seventy-two veterans were enrolled in BSN degree programs and 82 graduated with a BSN degree. It is estimated that 33 percent of participating veterans were underrepresented minorities in the field of nursing, and 24 percent reported coming from a financially and/or educationally disadvantaged background.

The *Nurse Faculty Loan Program* (NFLP) supports the establishment and operation of a loan fund at participating schools of nursing to assist nurses in completing their graduate education to become qualified nurse faculty. In academic year 2014–2015, the NFLP supported 2,399 students pursuing faculty preparation. Twenty percent of students who received a loan reported coming from a disadvantaged

background and nearly 25 percent of students are considered underrepresented minorities in their prospective professions.

The *NURSE Corps Scholarship and Loan Repayment Program* (NURSE Corps) offers to individuals, who are enrolled or accepted for enrollment as full-time or part-time nursing students, the opportunity to apply for funds. The NURSE Corps repays up to 85 percent of nursing student loans in return for at least 3 years of practice in a designated nursing shortage area. In fiscal year 2015, the NURSE Corps loan repayment program made 590 loan repayment awards and 319 continuation awards. The NURSE Corps scholarship program made 257 new scholarship awards and 12 continuation awards during the same time period.

The NLN urges the subcommittee to fund the Title VIII nursing workforce development programs at \$244 million in fiscal year 2018.

[This statement was submitted by Anne R. Bavier, Ph.D, RN, FAAN, President, and Beverly Malone, Ph.D, 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 2020 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 2020 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 2020 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 114-669 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 Congress in bill and/or report language to continue 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 in-

crease 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.

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.

National Black Programming Consortium (NBPC) 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.

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.

Stephen Gong, Center for Asian American Media

Sandie Viquez Pedlow, Latino Public Broadcasting

Leslie Fields-Cruz, National Black Programming Consortium

Leanne Ka'ulani Ferrer, Pacific Islanders in Communications

Shirley K. Sneve, Vision Maker Media

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 2018:

- At least \$2 billion increase over fiscal year 2017 level for the National Institutes of Health (NIH);
- \$8.3 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 (Public Law 114–255);
- \$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 over our recommended fiscal year 2017 funding level of \$13.067 billion for the Social Security Administration's (SSA) administrative budget;
- \$364 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. Most people with MS are diagnosed between the ages of 20 and 50, with at least two to three times more women than men being diagnosed with the disease. The Society addresses the challenges of each person affected by MS. To accomplish this, we fund cutting-edge research, drive change through advocacy, facilitate professional education, collaborate with MS organizations around the world, and provide programs and services designed to help people with MS and their families live their best lives.

The Society is disappointed with the President's fiscal year 2018 budget proposal, "A New Foundation For American Greatness" as it leaves behind those living with disabilities, illness, or chronic diseases like MS. At a time when there is so much excitement around fulfilling the promises included in the bipartisan 21st Century Cures law, the President's budget proposal would set back research and innovation and prevent people with MS from receiving the coverage and services they need to live their best lives. We urge the Committee to reject these proposed cuts and instead, adequately fund research and programs 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.

The Society regards research as a public-private partnership and dedicates a sizeable amount of money to MS research annually. In 2016, the Society invested over \$40 million in MS research projects- nearly half of the NIH's investment of \$92.85 million in MS research projects, that year. We work closely with the NIH and fund research that is complementary to what the Agency is funding; therefore, we rely on Congress to provide consistent and sustained investments to the Agency in order to cultivate an environment that is optimal for scientific discovery. Due to cuts to NIH's overall budget and investments that have not kept pace with biomedical inflation, NIH spending on MS-related research has decreased by more than \$20 million since fiscal year 2011.

The NIH is a fundamental partner in our 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 FDA. 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 Precision Medicine Initiative will improve our understanding of the anatomy and connectivity of the brain and ultimately aid researchers in the development of novel endpoints and biomarkers. The Society urges Congress to provide at least a \$2 billion increase for the NIH in fiscal year 2018.

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 2018.

CENTERS FOR MEDICARE & MEDICAID SERVICES

Medicare: It is estimated that over 20 percent of the MS population relies on Medicare as its primary insurer. The majority of these individuals are under the age of 65 and receive the Medicare benefit as a result of their disability. Of particular importance to the MS community are: having 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 without arbitrary coverage limits or documentation requirements; 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. The most recently available data (2007) reveals that the average annual direct and indirect (e.g. lost wages) cost for someone with MS in the U.S. is approximately \$69,000. After years of paying to manage their disease, some people with MS have spent the vast majority 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

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 over our recommended funding level of \$13.067 billion for fiscal year 2017 for the SSA’s administrative budget so that it can continue efforts to reduce hearings and disability backlogs, pay monthly benefits in a timely manner, and determine post-entitlement issues in a timely manner.

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

AHRQ (Agency for Healthcare Research and Quality) is a small agency that is revolutionizing the healthcare system based on healthcare costs and quality. The Agency 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 such as this are vital in ensuring that the healthcare community has science and evidence-based information to aid in consultations on treatment decisions. AHRQ’s budget was cut by \$30 million in fiscal year 2016, which significantly impacted the Agency’s ability to collect healthcare spending data, and patient safety research projects that prevent, mitigate, and decrease the number of medical errors, patient safety risks and hazards, and quality gaps. 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 \$365 million for the Agency in fiscal year 2018.

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 industries have valid and trustworthy data on health outcomes, clinical effectiveness, and appropriateness of different medical treatments by evaluating existing studies and conducting its own.

In July 2016, PCORI approved \$20 million to fund four comparative effectiveness research studies that will assess several therapies used to treat multiple sclerosis and its symptoms. These comparative effectiveness 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. In November 2016, PCORI approved an additional \$30 million to fund comparative effectiveness clinical trials that will determine the relative effectiveness of different MS treatment protocols. 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. We recommend that Congress fully fund PCORI’s work for fiscal year 2018 and ensure that the Institute has reliable and sustainable funding to continue its work in the future.

CENTERS FOR DISEASE CONTROL AND PREVENTION

The Centers for Disease Control and Prevention (CDC) is tasked with protecting public health and safety through the control and prevention of disease, injury, and disability. While most public attention has focused its work on infectious disease, the CDC performs vital work on food borne pathogens, environmental health, occupational safety and health, health promotion, injury prevention, surveillance programs for non-infectious diseases and educational activities designed to improve the health of Americans.

Unfortunately, budgetary cuts and public health emergencies have left the Agency unable to collect data to track the incidence and prevalence of diseases like MS. There has been no national prevalence studies conducted for MS since the mid-1970’s, and no accurate estimates are available for researchers to utilize when developing their studies. The 21st Century Cures Act (Public Law 114–255) authorized the creation of the National Neurological Conditions Surveillance System (NNCSS) within the Agency—but Congress must provide funding for it. Information collected by this system will provide a foundation for researchers in evaluating and understanding factors such as: geographic clusters of MS, variability in racial and eth-

nicity, the impact of sex and gender on disease, outcome measures and health care practices and utilization. Having strong and reliable prevalence data is critical to protecting the public health. In fiscal year 2018, we ask that Congress fund the CDC at \$8.3 billion for fiscal year 2018 inclusive of \$5 million for the NNCSS.

CONCLUSION

The National MS Society thanks the Committee for the opportunity to provide written testimony on our recommendations for fiscal year 2018 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 Appropriations Subcommittee Chairman Blunt, Ranking Member Murray, Chairman Cochran, Vice Chairman Leahy 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 \$256.25 million in Family Violence Prevention and Services Act (FVPSA), Violence Against Women Act (VAWA) and related programs administered by the U.S. Department of Health and Human Services fiscal year 2018 Budget (specific requests detailed below).

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 his or her lifetime. Female victims of rape, physical violence, or stalking by an intimate partner experienced severe impacts such as fear, concern for their safety, need for medical care, injury, need for housing services, and missing work or school.

The CDC has estimated that 854,000 women in Missouri and 1,094,000 women in Washington State have experienced rape, physical violence, or stalking by an intimate partner in their lifetime.¹ 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.² The cycle of intergenerational violence is perpetuated as children are exposed to violence. Approximately 15.5 million children are exposed to domestic violence every year.³ One study found that men exposed to physical abuse, sexual abuse and witnessing adult domestic violence as

¹ Black, M.C., Basile, K.C., Breiding, M.J., Smith, S.G., Walters, M.L., Merrick, M.T., Chen, J., & Stevens, M.R. (2011). The National Intimate Partner and Sexual Violence Survey (NISVS): 2010 Summary Report. Atlanta, GA: National Center for Injury Prevention and Control, Centers for Disease Control and Prevention.

² Bureau of Justice Statistics (2008). Homicide Trends in the U.S. from 1976–2005. U.S. Dept. of Justice.

³ McDonald, R., et al. (2006). "Estimating the Number of American Children Living in Partner-Violence Families." *Journal of Family Psychology*, 30(1), 137–142.

children were almost 4 times more likely than other men to have perpetrated domestic violence as adults.⁴

In addition to the terrible cost domestic and sexual violence has on the lives of individual victims and their families, these crimes also cost taxpayers and communities. The cost of intimate partner violence exceeds \$5.8 billion each year, \$4.1 billion of which is for direct healthcare services.⁵ Translating this into 2016 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.⁶

Despite this grim reality, we know that when a coordinated response is developed and immediate, and essential services are available, victims can escape from life-threatening violence and begin to rebuild their lives. To address unmet needs and build upon its successes, FVPSA and VAWA programs should receive increased investment in the fiscal year 2018 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 has remained the only Federal funding directly for shelter programs. Now in its 33rd year, FVPSA has made substantial progress toward ending domestic violence. Despite the progress and success brought by FVPSA, 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."⁷ 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."⁸

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, demand has increased as a result of the economic downturn, and victims with fewer personal resources become increasingly vulnerable. Since the economic crisis began, eight out of ten domestic violence shelters have reported an increase in women seeking assistance from abuse.⁹ As a result,

⁴Whitfield, 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.

⁵National 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.

⁶Bureau 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.

⁷Lyon, E. & Lane, S. (2009). *Meeting survivors' needs: A multi-State study of domestic violence shelter experiences*. Harrisburg, PA: National Resources Center on Domestic Violence.

⁸Lyon, 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.

⁹Mary Kay's Truth About Abuse Report. Mary Kay Inc. (2012).

shelters overwhelmingly report that they cannot fulfill the growing need for these services.

Each year NNEDV 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 2016, while more than 72,959 victims of domestic violence received services, over 11,991 requests for services went unmet, due to lack of funding and resources. Of those unmet requests, 66 percent were for safe housing. In 2016, domestic violence programs reported that they had laid off 1,200 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.

In 2014, domestic violence programs funded by the Family Violence Prevention & Services Act (FVPSA) provided shelter and nonresidential services to more than 1.3 million victims. 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 continue this work to prevent and end domestic violence, FVPSA funding must be increased 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. DELTA should minimally be funded 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)—\$8.25 million;
- Preventative Health and Health Services Block Grant, Rape Set-Aside—\$7 million;
- Violence against Women Health Initiative, (Office On Women's Health)—\$10 million

[This statement was submitted by Kim Gandy, President and CEO, National Network to End Domestic Violence.]

PREPARED STATEMENT OF NATIONAL PTA AND THE 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 2018 for the record. 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 support robust investments in public education and family engagement programs. 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 engagement 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. Specifically, our organizations request \$10 million in the fiscal year 2018 U.S. Department of Education budget for the Statewide Family Engagement Centers (SFECs) grant program to prepare all students for the 21st century workforce and help grow our economy.

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 House of Representatives and the Senate recognized the importance of parent and family engagement in education by including the SFECs program in their respective reauthorization bills. In fact, the SFECs program is one of the few non-categorical programs from No Child Left Behind (NCLB) that was maintained in the Every Student Succeeds Act (ESSA).

The SFECs grant program will 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. Additionally, SFECs will 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 underway, States, school districts, school leaders and parents need the resources that can be provided by SFECs to engage parents as stakeholders and effectively implement the law as Congress intended. Our organizations are aware of the fiscal pressure being placed on non-defense discretionary spending, which is why we view our request of \$10 million for SFECs as reasonable in comparison to the \$39.3 million that the former Parental Information and Resource Centers (PIRCs) received in fiscal year 2010. Therefore, National PTA and PACER Center urge the L-HHS-ED Subcommittee to pass an fiscal year 2018 L-HHS-ED appropriations bill that includes \$10 million for the Statewide Family Engagement Centers program. A modest investment of \$10 million will immensely help States and school districts to better support schools and educators in implementing effective family engagement to increase student achievement and foster greater school improvement efforts.

[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 2018 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

¹ Henderson, 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>.

² Allensworth, 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.

- 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 Medicaid 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 and reduce facility-based placements, and can improve maternal employment (Caldwell, 2007) and marriages (Harper, 2013). 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 (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 2011/12 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 (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, so 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, 35 States and the District of Columbia have received basic grants to build coordinated systems of community-based respite services. Most 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 maintained to help sustain

these innovative State efforts. States are developing long-term sustainability plans, but without Federal support, many of the grantees will be cut.

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 will allow funding of several new States and enable current and former grantees to continue their ground-breaking work to serve more families.

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 2018 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.

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[This statement was submitted by Jill Kagan, Chair, National Respite Coalition.]

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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-

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 and reduce facility-based placements, and can improve maternal employment (Caldwell, 2007) and marriages (Harper, 2013). 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 (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 2011/12 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 (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 care-

givers 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, so 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, 35 States and the District of Columbia have received basic grants to build coordinated systems of community-based respite services. Most 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 maintained to help sustain these innovative State efforts. States are developing long-term sustainability plans, but without Federal support, many of the grantees will be cut.

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 bi-

partisan 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 will allow funding of several new States and enable current and former grantees to continue their ground-breaking work to serve more families.

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 2018 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.

Complete references available on request or at https://archrespice.org/images/Lifespan_Appropriations/FY_2018/NRC_Senate_Labor-H-FY2018_OW_Testimony-w-refs.pdf.

[This statement was submitted by Jill Kagan, Chair, National Respite Coalition.]

PREPARED STATEMENT OF THE NATIONAL RURAL HEALTH ASSOCIATION

The National Rural Health Association (NRHA) is pleased to provide the Senate Subcommittee on Labor, Health and Human Services, Education and Related Agencies with a statement for the record on fiscal year 2018 funding levels for programs with a significant impact on the health of rural Americans.

NRHA is a national nonprofit membership organization with a diverse collection of 21,000 individuals and organizations who share a common interest in rural health. The Association's mission is to improve the health of rural Americans and to provide leadership on rural health issues through advocacy, communications, education and research.

NRHA is advocating support for a group of rural health program that assist rural communities in maintaining and building a strong healthcare delivery system into the future. Most importantly, these programs help increase the capacity of the rural healthcare delivery system and true safety net providers. Rural Americans, on average, are poorer, sicker and older than their urban counterparts. Programs in the rural health safety net increase access to healthcare, help communities create new health programs for those in need and train the future health professionals that will care for the 62 million rural Americans. With modest investments, these programs evaluate, study and implement quality improvement programs and health information technology systems.

Funding for the rural health safety net is more important than ever as rural America is facing a hospital closure crisis. Seventy-nine rural hospitals have closed, 10,000 rural jobs lost and 1.2 million rural patients have lost access to their nearest hospital since 2010. Even more concerning is that 673 rural hospitals are at risk of closure, meaning sustained Medicare cuts threaten the financial viability of 1 in 3 rural hospitals. The loss of these hospitals would mean 11.7 million patients would lose access to care in their community. Continued cuts to rural providers have taken their toll, forcing far too many closures. Medical deserts are appearing across rural America, leaving many of our Nation's most vulnerable populations without timely access to care.

Important Rural Health Programs Supported by NRHA are Outlined Below:

State Offices of Rural Health (SORH) provide State specific infrastructure for rural health policy. SORH is the counterpart to the Federal rural health research and policy framework. SORH forms an essential link between small rural communities and the State and Federal resources to develop long term solutions to rural health problems. These funds provide necessary capacity to States for the administration of critical rural health programs, assist in strengthening rural healthcare delivery systems, and maintaining rural health as a focal point within each State. SORH plays a key role in assisting rural health clinics, community health centers, and small, rural hospitals assess community healthcare needs. This program creates a State focus for rural health interests, brings technical assistance to rural areas, and helps frontier communities tap State and national resources available for healthcare and economic development. SORH forms an essential connection to other State agencies and local communities; allowing Federal resources to best address the unique needs of rural communities. *Request: \$12.5 million.*

Rural Health Research and Policy program forms the Federal infrastructure for rural health policy and the Federal Office of Rural Health Policy (FORHP). FORHP administrates important 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 Department of Health and Human Services (HHS) Secretary on access to care, the viability of rural hospitals, and the availability of physicians and other health professionals. These grants provide policy makers with policy-relevant research on problems facing rural communities in providing access to quality affordable care and to improving population health in rural America. By funding rural health research centers across the country, these grants produce a mix of health services research, epidemiology, public health, geography, medicine, and mental health. This program allows rural America to have a coordinated voice in HHS, in addition to providing expertise to agencies such as the Centers for Medicare and Medicaid Services. *Request: \$10.4 million.*

The *National Health Service Corps (NHSC)* plays an important role in maintaining the healthcare safety net by placing primary healthcare providers in the most underserved rural communities. NHSC is a network of 8,000 primary healthcare professionals, and 10,000 sites (September 2010). However, the demand for primary care providers far exceeds the supply, and the needs of rural communities continue to grow. Seventy-seven percent of the 2,050 rural counties in the United States are designated as primary care Health Professional Shortage Areas (HPSAs) and 60 percent of rural Americans live in a mental health professional shortage area. Rural areas have fewer than half as many primary care physicians per 100,000 people as urban areas. Rural communities must have the resources necessary to hire primary care, dental and behavioral health providers. *Request: \$337 million.*

Rural Health Outreach and Network Grants provide capital investment for planning and launching innovative projects in rural communities that will become self-sufficient. These grants are unique Federal grants in that they allow a great deal of flexibility for the community to build a program around their community's specific needs. Grant funds are awarded for communities to develop needed formal, integrated networks of providers that deliver primary and acute care services. The grants have led to successful projects including information technology networks, oral screenings, and preventative care. Due to the community nature of the grants and the focus on sustainability after the grant term has run out—85 percent of the grantees continue to deliver services a full 5 years after Federal funding ends. *Request: \$72.4 million.*

Rural Hospital Flexibility Grants fund quality improvement and emergency medical service projects at Critical Access Hospitals (CAHs). These grants allow rural communities to improve access to care, develop increased efficiencies, and improved quality of care by leveraging the services of CAHs, Emergency Medical Services (EMS), clinics, and health practitioners. These grants serve an important function in increasing information technology activities in rural America. Also funded in this line is the Small Hospital Improvement Program (SHIP), which provides grants to more than 1,500 small rural hospitals (50 beds or less) across the country to improve business operations, focus on quality improvement, and ensure compliance with health information privacy regulations. *Request: \$50.4 million.*

The Office for the Advancement of Telehealth (OAT) supports the provision of clinical services at a distance, reduces rural provider isolation, fosters integrated delivery systems through network development, and tests a broad range of telehealth applications. Long-term, telehealth promises to improve the health of millions of Americans, save money by reducing unnecessary office visits and hospital stays, and provide continuing education to isolated rural providers. OAT coordinates and promotes the use of telehealth technologies by fostering partnerships between Federal and State agencies and private sector groups. Since telehealth is still an emerging field with new approaches and technologies, continued investment in the infrastructure and development is needed. *Request: \$21 million.*

The Rural Opioid Overdose Reversal Grant helps reduce the occurrences of morbidity and mortality related to opioid overdoses in rural communities through the purchase and placement of emergency devices used to rapidly reverse the effects of opioid overdoses. The grant also helps train licensed healthcare professionals and emergency responders on the use of opioid reversals. Rural communities are struggling with prescription opioids and heroin abuse. While opioid use generally is on the rise nationwide, the rate of overdose deaths in non-metro counties is 45 percent higher than in metro counties. *Request: \$11.1 million.*

Title VII Health Professions Training Programs (with a significant rural focus):

—*Area Health Education and Centers (AHECs)* encourage and provide financial support to those training to become healthcare professionals in rural areas.

Without this experience and support in medical school, far fewer professionals would be aware of the needs of rural communities and even fewer would make the commitment to practice in rural areas. AHECs support the recruitment and retention of physicians, students, faculty and other primary care providers in rural and medically underserved areas. It has been estimated that nearly half of AHECs would shut down without Federal funding, placing future access to healthcare in rural communities at risk. *Request: \$33.5 million.*

—*Rural Physician Pipeline Grants* help medical colleges develop rural specific curriculum and to recruit students from rural communities that are likely to return to their home regions to practice. This “grow-your-own” approach is one of the best and most cost-effective ways to ensure a robust rural workforce into the future. *Request: \$5.3 million.*

—*Geriatric Programs* train health professionals in geriatrics, including funding for Geriatric Education Centers (GEC). There are currently 47 GECs nationwide that ensure access to appropriate and quality healthcare for seniors. Rural America has a disproportionate share of our Nation’s elderly and is more likely to have physician shortages than urban locations. Without this program, rural healthcare provider shortages would grow. *Request: \$42.8 million.*

The National Rural Health Association appreciates the opportunity to provide our recommendations to the Subcommittee. These programs are critical to the rural health delivery system and help maintain access to high quality care in rural communities. We greatly appreciate the support of the Subcommittee and look forward to working with Members of the Subcommittee to continue making these important investments in rural health.

[This statement was submitted by Maggie Elehwany, Vice President, Government Affairs and Policy, National Rural Health Association.]

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 2018 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 2018 I would like to request \$71,382,000 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 almost \$23 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 2018 request of \$71,382,000 in Operations would allow NTID to admit all qualified students for Fall 2018 enrollment, keep the fiscal year 2018 tuition increase relatively low, and continue to offer Grants in Aid to more students. With this funding, NTID can support new academic programs (such as degrees in Applied Science and Business Administration), maintain newly added staff (sign language interpreters and captionists) in student access services to meet unprecedented demand, continue and expand outreach efforts, and complete much needed capital and renovation projects. Consistent with NTID’s outreach mission, this funding would also allow NTID to continue its efforts on behalf of underprepared students by working with regional partners to implement intensive summer academic programs in selected high-growth, ethnically diverse areas of the country. This funding would support the NTID Southeast Regional STEM Center, which, following the grant-funded NTID DeafTEC model, aims to deliver NTID expertise to schools, students, parents and employers in a traditionally underserved geographic region.

ENROLLMENT

Truly a national program, NTID has enrolled students from all 50 States. In Fall 2016 (fiscal year 2017), NTID's enrollment was 1,300 students. NTID's enrollment history over the last 10 years is shown below:

NTID ENROLLMENTS: FISCAL YEAR 2008—FISCAL YEAR 2017

Fiscal Year	Deaf/Hard-of-Hearing Students				Hearing Students				Grand Total
	Undergrad	Grad RIT	MSSE	Sub-Total	Interpreting Program	MSHCI	MSSE	Sub-Total	
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
2008	1,103	51	31	1,185	130	N/A	28	158	1,343

(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. One of NTID's greatest strengths is our outstanding track record of assisting high-potential students to gain admission to, and graduate from, the other colleges of RIT at rates comparable to their hearing peers.

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, 271 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 93 percent have found jobs commensurate with their education level. Of our fiscal year 2015 graduates (the most recent class for which numbers are available), 94 percent were employed 1 year later, with 75 percent employed in business and industry, 16 percent in education and non-profits, and 9 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 and SSDI 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 univer-

sities. Equally important is the demonstrated impact of an NTID education on graduates' earnings. At age 50, \$58,000 is the median salary for NTID deaf and hard-of-hearing graduates with bachelor degrees and \$41,000 for those with associate degrees, compared to \$34,000 for deaf and hard-of-hearing students who withdrew from NTID and \$21,000 for deaf and hard-of-hearing graduates from other universities.

An NTID education also translates into reduced dependency on Federal transfer programs, such as SSI and SSDI. At age 40, less than 2 percent of NTID deaf and hard-of-hearing associate and bachelor degree graduates participated in the SSI program compared to 8 percent of deaf and hard-of-hearing students who withdrew from NTID. Similarly, at age 50, only 18 percent of NTID deaf and hard-of-hearing bachelor degree graduates and 28 percent of associate degree graduates participated in the SSDI program, compared to 35 percent of deaf and hard-of-hearing students who withdrew from NTID.

ACCESS SERVICES

Access services include sign language interpreting, real-time captioning, classroom notetaking services, captioned classroom video materials, and assistive listening services. NTID provides an access services system to meet the needs of a large number of deaf and hard-of-hearing students enrolled in baccalaureate and graduate degree programs in RIT's other colleges as well as students enrolled in NTID programs who take courses in the other colleges of RIT. Access services also are provided for events and activities throughout the RIT community. Historically, NTID has followed a direct instruction model for its associate-level classes, with limited need for sign language interpreters, captionists, or other access services. However, the demand for access services has grown recently as associate-level students request communication based on their preferences.

Higher enrollments have also increased the demand for access services. During fiscal year 2016, 149,046 hours of interpreting were provided—an increase of 28 percent compared to fiscal year 2010. During fiscal year 2016, 24,335 hours of real-time captioning were provided to students—a 25 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 2017, there were 551 deaf and hard-of-hearing students enrolled in baccalaureate or graduate programs at RIT, a 7 percent increase compared to fiscal year 2010, and 410 students with cochlear implants, a 50 percent increase over fiscal year 2010.

As a result, NTID's fiscal year 2018 funding request recognizes the need to invest in additional access services staff and in research on technologies that might serve as an alternative to traditional access services.

SUMMARY

It is extremely important that NTID's fiscal year 2018 funding request be granted in order that we might continue our mission to prepare deaf and hard-of-hearing people to excel in the workplace. 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/SSDI programs. NTID's employment rate is 93 percent over the past 5 years. Therefore, I ask that you please consider funding our fiscal year 2018 request of \$71,382,000 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 increased 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 enforcement advocates supports increasing the fiscal year 2018 funding level to \$25 million to allow for nationwide expansion of the NVDRS program including all 50 States, District of Columbia and U.S territories. Fiscal year 2017 NVDRS funding is \$16 million.

BACKGROUND

Each year, about 58,000 Americans die violent deaths.¹ In addition, an average of 121 people² (20 of which are military veterans³) 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 funding levels only allow the program to operate in 42 States.⁵ While NVDRS is beginning to strengthen violence and suicide prevention efforts in the 42 participating States, non-participating States continue to miss out on the benefits of this important public health surveillance program.

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

¹Centers for Disease Control and Prevention. (2015, June 18). Injury Prevention & Control: Division of Violence Prevention. Retrieved April 14, 2016, from <http://www.cdc.gov/violenceprevention/nvdrs/>.

²Americans for Suicide Prevention. (n.d.). Suicide Statistics. Retrieved April 14, 2016, from Americans for Suicide Prevention: <http://afsp.org/about-suicide/suicide-statistics/>.

³Kemp, J., & Bossarte, R. (2013, February). Suicide Report 2012. Retrieved April 14, 2016, from Department of Veterans Affairs: <http://www.va.gov/opa/docs/suicide-data-report-2012-final.pdf>.

⁴Centers for Disease Control and Prevention. (2015, June 18). National Violent Death Reporting System—An Overview. Retrieved 14 2016, April, from National Violent Death Reporting System: http://www.cdc.gov/violenceprevention/pdf/nvdrs_overview-a.pdf.

⁵Centers for Disease Control and Prevention. (2015, December 15). National Violent Death Reporting System—State Profiles. Retrieved March 7, 2017, from A CDC website: <https://www.cdc.gov/violenceprevention/nvdrs/stateprofiles.html>.

⁶U.S. Department of Health and Human Services. (2016, April 8). The U.S. Opioid Epidemic. Retrieved April 14, 2016, from U.S. Department of Health and Human Services: <http://www.hhs.gov/opioids/about-the-epidemic/>.

⁷Centers for Disease Control and Prevention. (2014, January 17). Surveillance for Violent Deaths —National Violent Death Reporting System, 16 States, 2010. Retrieved April 14, 2016, from Morbidity and Mortality Weekly Report-Surveillance Summaries/Volume 63/No.1: <http://www.cdc.gov/mmwr/pdf/ss/ss6301.pdf>.

⁸Alexander GC, F. S. (2015). The Prescription Opioid Epidemic: An Evidence-Based Approach. Baltimore: Johns Hopkins Bloomberg School of Public Health. <http://www.jhsph.edu/research/centers-and-institutes/center-for-drug-safety-and-effectiveness/opioid-epidemic-town-hall-2015/2015-prescription-opioid-epidemic-report.pdf>.

⁹Center for Disease Control and Prevention. (2013). National Violent Death Reporting System. Retrieved April 14, 2014, from A Web-based Injury Statistics Query and Reporting System (WISQARS) Database: <https://wisqars.cdc.gov:8443/nvdrs/nvdrsDisplay.jsp>.

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

At an estimated annual cost of \$25 million for full implementation, 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 2018

The 2014 Consolidated Appropriations Act recognized the public health utility of NVDRS in preventing violent deaths and increased NVDRS funding by roughly \$8 million to facilitate continued expansion of the NVDRS program. The program received an additional \$4.7 million in fiscal year 2016 for a total of \$16 million. The additional \$5 million will allow ten new States to participate in NVDRS. The time is now to complete the nation-wide expansion of NVDRS by providing an appropriation of \$25 million in fiscal year 2018 to place NVDRS in all 50 States and U.S. territories.

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 implemen-

¹⁰Smith, S. G., Fowler, K. A., & and Nolon, P. H. (March 2014). Intimate Partner Homicide and Corollary Victims in 16 States—NVDRS 2003–2009. *American Journal of Public Health*, 461–466.

¹¹Kang, H., Bullman, T. A., & Smolenski, D. J. (2015). Suicide risk among 1.3 million veterans who were on active duty during the Iraq and Afghanistan wars. *Annals of Epidemiology*, 96–100.

tation 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 2018 appropriation of \$25 million.

[This statement was submitted by Kate McFadyen, Chair, National Violence Prevention Network.]

PREPARED STATEMENT OF NEPHCURE KIDNEY INTERNATIONAL

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2018

- Provide \$36 billion for the National Institutes of Health (NIH)
 - Provide a corresponding increase to the NIH Institutes and Centers
 - Support the expansion of the FSGS/NS research portfolio at NIDDK, the Office of Rare Diseases Research (ORDR) and the National Institute on Minority Health and Health Disparities (NIMHD) by funding more research proposals for Primary Glomerular Disease
-

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. For this reason, and on behalf of the thousands of families that are significantly affected by this disease, we encourage support for expanding the research portfolio on FSGS/NS at the NIH.

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 recently initiated the Cure Glomerulonephropathy Network (Cure GN), a multicenter 5-year cohort study of glomerular disease patients. Participants will be followed longitudinally to better understand the causes of disease, response to therapy, and disease progression, with the ultimate objective to cure glomerulonephropathy. NephCure recommends that the subcommittee encourage NIDDK to continue to support CureGN as well as other primary glomerular disease program announcements.

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 encourage NIMHD to continue to study FSGS/NS, including the APOL1 gene.

Thank you for the opportunity to present the views of the FSGS/NS community. Please contact NephCure Kidney International if additional information is required.

[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 2018 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 \$23 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 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 2018 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 2018 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 2018 as was allocated in fiscal year 2017 for Impact Aid, \$1.33 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 programs operated by tribes to assist in the delivery of education services within a reservation.

The Tribe recommends \$9.6 billion for Head Start. Indian Head Start 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 \$212 million be provided for all Tribal Behavioral Health Grants under the Substance Abuse and Mental Health Services Administration to match the funds provided for in fiscal year 2017. 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 addi-

tion, 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 2017 levels.

The Tribe recommends \$60.5 million be allocated to the Department of Labor's Division of Indian and Native American Programs. The Workforce Innovation and Opportunity Act, Section 166 Indian and Native American Programs serve the training and employment needs of tribes using grantees funded 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.

Thank you for your consideration of the Tribe's requests with respect to these fiscal year 2018 appropriations.

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 requesting fiscal year 2018 funding for all programs administered by the Older Americans Act (OAA) (U.S. Department of Health and Human Services, Administration on Aging) be restored to at least fiscal year 2010 enacted levels, or a 12 percent increase. Of interest to OHA is to ensure Title III–D, Disease Prevention and Health Promotion, is restored to at least \$21,000,000 because of the cost-effectiveness that health education, health promotion, and disease prevention programs provide to the system. Since fiscal year 2012, Title III–D funding has remained stagnant at \$19,848,000. Also under Title III of the OAA, OHA recommends Title III–E, National Family Caregivers Support Program, to be fully restored to fiscal year 2010 enacted level of \$154,220,000 because of the range of critical support services the Program provides to family caregivers, who number approximately 40 million individuals. The president's fiscal year 2018 budget request maintains level funding for most OAA programs.

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 condi-

¹Administration on Aging. (2013). Aging Statistics. Retrieved from http://www.aoa.gov/Aging_Statistics/.

²Consumer Survey, National Association of Dental Plans. 2012.

tions. 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 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 2016 A State of Decay, Vol. III 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 half 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:

- Tooth loss continues to be a signal of suboptimal oral health. There are eight States with a 20 percent or more rate of edentulism, with West Virginia still notably having an older adult population that is 33.6 percent edentate.
- Communities without fluoridated water ignore opportunities for prevention. While States have increased the rates of communities with fluoridated water

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*.

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/hck10cv.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>.

since 2010, five States (10 percent) still have 60 percent or more of their residents living in communities unprotected by fluoridated water. Hawaii (89.2 percent) and New Jersey (85.4 percent) have the highest rates of unprotected citizens, representing an unnecessary public peril 70 years after Community Water Fluoridation (CWF) was introduced and since named a public health best practice.

- Persistent shortage of oral health coverage. Sixteen percent (8 States) cover no dental services through Medicaid and only four States (8 percent) cover the maximum possible dental services in Medicaid.
- Critical lack of a strategic plan to address the oral health of older adults. Eighty-four percent (42 States) lack a State Oral Health Plan that both mentions older adults and includes SMART objectives. Of the 42 States, 14 lack any type of State Oral Health Plan.
- Inadequate surveillance of the oral health condition of older adults persists. Forty-six percent (23 States) have never completed a Basic Screening Survey of older adults and have no plan to do so.

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 use funds they receive for disease prevention and health promotion activities 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

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.

proper care that these screenings could provide. Although the oral health screenings provision would not require new or additional funding under the OAA, restoring funding to at least fiscal year 2010 levels would greatly assist the Aging Network to conduct the screenings. More succinctly, 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. Therefore, OHA recommends the Subcommittee to restore fiscal year 2018 funding for all OAA programs to at least fiscal year 2010 enacted levels, or a 12 percent increase. Moreover, OHA recommends Title III–D, Disease Prevention and Health Promotion, to be restored to at least \$21,000,000 because of the cost-effectiveness that health education, health promotion, and disease prevention programs provide to the system; and Title III–E, National Family Caregivers Support Program, to be fully restored to fiscal year 2010 enacted level of \$154,220,000 because of the range of critical support services the Program provides to family caregivers.

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 THE OREGON AMERICAN FEDERATION OF STATE, COUNTY AND MUNICIPAL EMPLOYEES

Until recently, I have worked as a social worker in Clackamas County, Oregon, for Lifeworks NW, providing mental healthcare for rural young adults and youth who have serious and persistent mental illness. The Affordable Care Act, Medicaid expansion and the Substance Abuse and Mental Health Services Administration (SAMHSA) grants that improve community mental health services are a game changer in the lives of Americans with mental health and substance use disorders. A continuation of Medicaid expansion and the new demonstration program for community mental health centers is vital.

In 2015, the Medicaid expansion under the Affordable Care Act gave 14 million Americans (546,400 Oregonians) the chance to see a doctor, get medications for chronic conditions and gain access to mental healthcare. One out of three persons covered through Medicaid expansion live with mental health or substance abuse conditions. Medicaid expansion offers them the foundation to get treatment, and access services they need to build resilience and foster recovery from addiction, trauma, and a history of mental conditions that has impaired their ability to function.

Medicaid expansion is especially important because it covers single adults with mental illness who may easily fall through the cracks in our healthcare system. Mr. S. at age 19, was one of my clients who prior to Medicaid expansion would have likely fallen through the cracks in the healthcare system. He met the clinical criteria for PTSD (Post-traumatic Stress Disorder) and bipolar disorder. In addition, he suffered from a long history of profound trauma and violence, and poor foster care placements. However, his presentation as an adult would not have been severe enough to access developmentally appropriate community-based mental health services. He was not picked up by the police chronically, regularly present in the emergency room, or have persistent active suicide ideation. However, in time, without treatment, his functioning and mental health would have likely deteriorated to require a much more intense level of care, such as inpatient care, or acute care.

Because Oregon expanded Medicaid, my community mental health center has been able to offer a program designed to help young people, like Mr. S., transition from the services they receive as children to adult services. Under 18 years of age, he was able to access clinical care and supportive services 24 hours a day when needed. Once 18 years of age, he would be seen in an office outpatient setting once

every six weeks. That dramatic cliff and drop in treatment and services is fraught with negative outcomes for these young people, such as addiction, incarceration, homelessness and suicide. The TAY Program (Transition Age Youth Program) allowed me to provide Mr. S. with in-home treatment once a week. Over the course of my work with Mr. S., he developed and expanded his self-awareness and skills. He was able to begin to make healthy and developmentally appropriate self-determinations about his future. Medicaid continues to be his coverage. He would be at a tragic disadvantage in life if Congress repealed the Medicaid expansion.

As a clinician, I am passionate about mental health; it is my calling. Like Mr. S., the vast majority of my clients have suffered a long history of trauma, abuse, neglect, violence, addiction and homelessness that would scar any soul deeply. To recover and tap into their own strengths and resilience requires a level of services and integrative care that most community healthcare systems are not designed to deliver. Most community mental health centers are staffed at insufficient levels, which allow staff to provide clients with only symptom management. Community mental health centers need to be staffed to allow clinicians to engage regularly in the deeper, more transformative work that is required for mental health and addiction recovery.

I have seen indications that some structural change is possible. Four sites at Lifeworks NW plan to implement a program to deliver more integrative care, combining primary care services and mental healthcare. They will be part of Oregon's 2-year demonstration grant under the Excellence in Mental Health Act. The focus is to provide better care by increasing clinical staff, streamlining services and improving working conditions. In these locations, clients will benefit from a cohort of well-resourced professional staff not just one social worker because of criteria to establish Certified Community Behavioral Health Clinics (CCBHC). Clients will have additional support in developing basic life skills and have a better chance of overcoming the many barriers they face. For these structural changes to spread and become the norm, Medicaid expansion must remain the foundation for the SAMSHA grants to build on and further improve community mental health services.

Social workers and other behavioral health staff must have a voice in the workplace. Our work is not just a job. It is a steadfast commitment that is largely unsung. Like others in the field, our days often start early and end late. This work matters because it means something to make a community better, to help someone who has seen horrible trauma find that they already possess the courage to move forward on his or her own terms, and to support someone on the path of recovery. In fact, it means everything.

The work by every person in a community mental health center deserves respect because we are working to sustain our communities. We see how social, economic, and racial inequities affect overall mental health and well-being. I urge you not to repeal the current Medicaid expansion. I also urge you to provide SAMSHA with multiyear and mandatory funding to support additional grants to reduce community mental health center caseloads.

AFSCME is the Nation's largest and fastest growing public services employees' union with more than 1.6 million working and retired members, including 50,000 behavioral health workers. Oregon AFSCME is an affiliate of AFSCME and represents 25,000 workers, including 1,000 in the behavioral health industry.

[This statement was submitted by Lielah Ann Leighton, MSW, Oregon American Federation of State, County and Municipal Employees (Council 75 AFSCME).]

PREPARED STATEMENT OF PATH

This testimony is submitted by Carolyn Reynolds, Vice President of Policy and Advocacy, on behalf of PATH. 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 2018 funding for global health programs within the U.S. Department of Health and Human Services (HHS). PATH acknowledges the strong leadership the Subcommittee has shown in supporting HHS' work in this area, and recommends that support continue. This testimony is submitted on behalf of PATH, a leader in global health innovation. As an international nonprofit organization, PATH saves lives and improves health, especially among women and children. By mobilizing partners around the world, PATH takes innovation to scale, working alongside countries primarily in Africa and Asia to tackle their greatest health needs and threats to global health. We respectfully request that this Subcommittee ensure that there are no cuts to global health programs within HHS in fiscal year 2018, that the Centers for Disease Control and Prevention's (CDC's) Cen-

ter for Global Health (CGH) is funded at no less than fiscal year 2017 levels [\$435 million], and that no less than \$34.1 billion is allocated for the National Institutes of Health (NIH)—programs that capitalize on the agency’s technical expertise to improve human health, increase national security by minimizing the risk of future threats posed by infectious disease outbreaks and other biosecurity threats, and bolstering the ability of partner countries to contain such threats at their source.

Using Cost-Effective Strategies to Save Lives

Through relatively modest investments for global health programs, the United States has helped save millions of lives around the world and also improved the health and security of Americans. Because of these investments, many diseases that threatened the lives of millions of people only a decade ago are now in decline and are on the path to eradication. For every dollar invested in global health, there is an expected 10—to 20—fold return in economic benefit. Investing in global health allows developing nations to move toward aid independence and increase their participation in the global economy.

One key strategy for achieving HHS’ global health and security goals is immunization, with the majority of vaccine delivery activities overseen by CDC’s Global Immunization Division. CDC plays a critical role at the global, regional, and country levels by providing scientific leadership and guidance to implement evidence-based strategies to control, eliminate and eradicate vaccine-preventable diseases.

Vaccines are one of the highest-impact and most cost-effective tools to combat infectious disease threats available today. For every \$1 invested in immunization, there is a \$16 return across the lifespan of the immunized child. 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 five each year.

In addition to protecting the health of children, immunization programs further support the creation of better disease detection and health systems to help thwart other threats. These programs train staff and provide real-time disease tracking and reporting, as well as support faster and more accurate data sharing. These efforts build capacity for local health systems to plan for and respond to public health crises. As diseases do not respect borders, and travel as easily as people do within countries and across continents, bolstering local systems will help safeguard Americans by containing deadly disease outbreaks before they spread.

The Vital Role of HHS in Global Health and Security

New public health challenges in the form of infectious disease outbreaks pose direct threats to U.S. 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 impact that global health security—or a lack of it—can have on American lives. In addition to the devastating loss of life, pandemics have a disastrous effect on economies, costing up to \$60 billion a year to contain. The World Bank estimates that another global pandemic on the scale of the 1918 Spanish flu could cost the global economy as much as \$5 trillion dollars. Yet a investing a fraction of this amount, \$4.5 billion a year—or 65 cents for every resident of the planet—could prevent pandemics from occurring.

HHS plays a critical leadership role in promoting global health security, preventing emerging disease threats by supporting resilient health systems and infrastructure, building effective surveillance measures to detect diseases before they spread, and developing planned and cost-effective response systems. These actions are reinforced through HHS’s Global Health Strategy (2015–2019) that articulates the department’s international role in guiding efforts to protect health globally. For example, CDC collaborates with countries around the world and with partners such as PATH and through multiple platforms to combat outbreaks, including through activities under the Global Health Security Agenda, its Emergency Operating Centers, Field Epidemiology Training Programs, Epidemic Intelligence Service, and the Public Health Emergency Management Program. Other agencies and departments including the National Institute of Allergy and Infectious Diseases (NIAID), the Fogarty International Center, and Biomedical Advanced Research and Development Authority (BARDA) support these efforts.

As stated by Secretary Price at the World Health Assembly, “We want to emphasize today just how committed the United States is to a cooperative, transparent and effective international response to outbreaks of infectious disease . . . the United States affirms its support for the Global Health Security Agenda and is dedicated to building capacity to comply with the International Health Regulations, and to find and stop disease outbreaks around the world, whether they are naturally oc-

curing, accidental, or deliberate in nature.” Furthermore, the efficacy of these programs has been demonstrated. For example, investments in health security resulted in the reduction of outbreak response time in Cameroon from eight weeks to 24 hours. This reduction in response time is the difference between a limited outbreak and a devastating epidemic, yet these and other activities that serve as the backbone of such efforts are in large part built upon dwindling supplemental funding. These activities across HHS should be continued with non-supplemental permanent funding—now is not the time to pull back.

Fighting to Eliminate Malaria

In addition to its critical work in immunization and health security, HHS has a long history in controlling and eliminating malaria domestically and internationally. CDC plays a key role as a co-implementer of the President’s Malaria Initiative (PMI), alongside the U.S. Agency for International Development. PMI’s work to scale-up malaria interventions in partner countries is contributing to global efforts that have saved an estimated 6.8 million lives since 2000. In countries where PMI has focused its efforts, advances in malaria control have brought about social and economic benefits that include better school attendance and improved worker productivity. Research indicates that malaria-free countries have five times greater economic growth than countries with malaria. While incredible progress has been made, these gains are fragile, and investments must be sustained to prevent re-emergence of malaria in communities that have succeeded in eliminating it.

CDC’s role in combating malaria extends beyond co-implementing PMI. With evidence of growing insecticide and drug resistance, CDC’s Parasitic Diseases and Malaria program has provided malaria technical assistance globally, with a focus on monitoring, evaluation, surveillance, and operational and implementation research. CDC’s research to develop and evaluate interventions as well as forward looking approaches remain the cornerstone of current control and elimination efforts. Examples of CDC’s contributions include evaluations of the impact of improved nets, insecticides, and strategic use of antimalarial drugs; preventing malaria during pregnancy; developing more sensitive diagnostic tests; providing material to private, government, and academic researchers through its collaborating centers and partnerships; as well as field trials of promising malaria vaccines, such as RTS,S—the malaria vaccine candidate furthest along in development globally.

While CDC’s mandate has grown, its budget for malaria has remained flat. An increase in funding would allow the agency to expand the development and evaluation of new tools, increase their ability to track the spread of drug and insecticide resistance, and bolster surveillance systems that are necessary for achieving malaria elimination, and eventually eradication.

Protecting the U.S. Through Leadership in Global Health R&D

While access to existing, proven health interventions must be extended, it is also critical to support research and development (R&D) into future technologies that can prevent existing and emerging global health threats. Investments made by the U.S. Government, including through the NIH and CDC over the past three decades, have enabled many partners, including PATH, to advance innovations that have improved health and saved lives around the world. These innovations include new and improved vaccines, such as an effective, low-cost vaccine against meningitis A, which historically caused devastating outbreaks each year in Africa’s Meningitis Belt. Zero cases of meningitis A have occurred among the more than 235 million Africans vaccinated since 2010. We also leveraged U.S. support to pioneer safe injection technologies that have helped to prevent millions of blood borne infections. Thanks to a discovery made by scientists at NIH, PATH was able to develop a simple, rapid test for exposure to river blindness, a disease that affects 25 million people. This test was launched commercially last year and is an important tool in the fight to eliminate river blindness in Africa.

The promise of new global health technologies can only be realized when products are developed, tested, licensed, and scaled up for use where they are needed. Investment in these activities at NIH and CDC should continue. Furthermore, strengthened collaboration and coordination between HHS operating divisions and other U.S. agencies that fund and develop new and improved drugs, diagnostics, vaccines, and devices will be critically important. Increasing the alignment of R&D investments and global health program priorities across the U.S. Government will help maximize the impact of U.S. taxpayer dollars and ensure that promising products are supported throughout the entire development pipeline. To leverage critical U.S. investments, HHS should continue to look for innovative funding and partnership models, like those being deployed by BARDA to engage private sector expertise and investment in global health R&D.

An Investment in Health, at Home and Around the World

With continued 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 these programs, the U.S. can protect the health of Americans while ensuring that people around the world have the opportunity to lead healthy lives and reach their full potential.

[This statement was submitted by Carolyn Reynolds, Vice President, Policy and Advocacy, PATH.]

PREPARED STATEMENT OF THE PATIENT CENTERED CARE ADVOCACY GROUP, INC.

The purpose of this testimony is to express concerns about CDC's mishandling and poor management of the epidemic of Lyme disease and associated tick-borne illnesses. Specific concerns include lack of accountability and CDC's failure to comply with numerous Committee directives to improve awareness, surveillance, prevention, diagnostics, and treatment.

Lyme disease was identified in 1975 by Allen Steere when he was investigating a cluster of cases of rheumatoid arthritis in children in Lyme, Connecticut. Since then, Lyme disease has become the most common vector-borne disease in the United States, with 380,690 new cases in 2015 at an annual cost of more than \$4.1 billion. Lyme disease has been reported in all U.S. States and the number of high-risk counties has increased 320 percent over the past two decades.

Lyme disease is often called The Great Imitator because it can mimic many other diseases. It is common for patients with Lyme to be misdiagnosed with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia, psychiatric illnesses, and neurodegenerative diseases such as Multiple Sclerosis, Parkinson's, and Alzheimer's.

Cases of other tick-borne diseases, including Anaplasmosis, Babesiosis, Ehrlichiosis, Powassan virus, and Rocky Mountain spotted fever, are also increasing. Co-infection with multiple tick-borne pathogens is common and greatly complicates diagnosis and treatment. When underreporting and misdiagnosis are taken into consideration, the true economic impact of the epidemic of tick-borne diseases is likely in the tens of billions of dollars.

Unreliable diagnostic tests, treatment regimens that fail up to 36 percent of the time,¹ inaccurate surveillance, inadequate programs for prevention, and insufficient Federal funding for research have created a perfect storm of unmet medical need and patient suffering.

Almost two decades ago, in response to concerns from advocacy groups and healthcare practitioners about the urgent need to provide more attention and resources to combat this epidemic, Congress began to include strong appropriations language for tick-borne diseases. Reports for appropriations bills from fiscal year 1998 to fiscal year 2016 include more than 90 directives for Lyme disease and other tick-borne diseases, including:

- Nine directives to advance the development of more accurate tests,
- Eleven directives to develop effective programs for prevention,
- Nine directives to expand and improve surveillance,
- Five directives to correct misuse of the Lyme disease surveillance case definition, and
- Fourteen directives to include a broad range of scientific viewpoints in planning and execution.

Report language for tick-borne diseases and links to Committee reports can be viewed here: www.lymepatientadvocacy.org/Documents/CongressionalDirectivesforLymeDisease.pdf.

Unfortunately, most of these directives have not been fulfilled, and there has been minimal effort to comply. When noncompliance was brought to CDC's attention, CDC's response was to defend its noncompliance because the directives were in the report, but not in the bill itself.

CDC's failure to acknowledge, address, and more efficiently manage this epidemic has led to great and unnecessary human suffering and hardship. Therefore, it is imperative that Congress step in and provide the oversight necessary to ensure that

¹Adrion ER, Aucott J, Lemke KW, Weiner JP (2015) Health Care Costs, Utilization and Patterns of Care following Lyme Disease. *PLoS ONE* 10(2): e0116767. <https://doi.org/10.1371/journal.pone.0116767>.

CDC complies with directives for tick-borne diseases and aggressively combats what has snowballed into a serious public health crisis.

EXAMPLES OF NONCOMPLIANCE

The following examples of noncompliance are from the Senate report 107–84 for the Departments of Labor, Health and Human Services, and Education, and Related Agencies Appropriations Act for fiscal year 2002.

Develop Improved Diagnostics

“The Committee recognizes that the current state of laboratory testing for Lyme disease is very poor . . . The Committee directs CDC to work closely with the Food and Drug Administration to develop an unequivocal test for Lyme disease.”

The dismal accuracy of the CDC-sanctioned two-tier test (ELISA and Western Blot) for Lyme disease has been a point of contention for many years. This test is an indirect assay that measures the immune response but does not confirm the presence of an infection.

A recently published systematic meta-analysis of 20 years of published data² showed a mean sensitivity of only 59.5 percent for the two-tier test. These patients remain undiagnosed and untreated. Untreated Lyme disease can cause neurological and cardiac damage and, occasionally, death. By comparison, the sensitivity for the HIV/AIDS antibody test is greater than 99 percent.

Rather than advance the development and use of highly accurate direct detection tests that can confirm the presence of an infection, CDC continues to promote outdated serology tests that are based on a single strain of *Borrelia burgdorferi* (the bacterium that causes Lyme disease). In addition to being highly unreliable, the current tests do not detect most other strains and species of *Borrelia* that are known to cause disease, contributing to misdiagnosis and underreporting.

Correct Misuse of the Lyme Disease Surveillance Case Definition

“The Committee is distressed in hearing of the widespread misuse of the current Lyme disease surveillance case definition. While the CDC does state that “this surveillance case definition was developed for national reporting of Lyme disease: it is NOT appropriate for clinical diagnosis,” the definition is reportedly misused as a standard of care for healthcare reimbursement, product (test) development, medical licensing hearings, and other legal cases. The CDC is encouraged to aggressively pursue and correct the misuse of this definition. This includes issuing an alert to the public and physicians, as well as actively issuing letters to places misusing this definition.”

The case definition for Lyme disease defines how the two-tier test should be interpreted. The threshold for a positive test is 2 of 3 IgM or 5 of 10 IgG antibody “bands.” Even though several bands are highly specific for Lyme and sufficient to determine exposure, many healthcare providers mistakenly believe patients who do not meet the 2/3 or 5/10 threshold cannot have been exposed to Lyme. In addition, due to the Lyme bacteria’s ability to suppress the immune response, many patients with Lyme disease do not produce any detectable antibodies.

Fifteen years after the above directive was issued, the case definition is still widely misused by physicians as a requirement for a diagnosis and by insurance companies to deny coverage to patients with valid cases of Lyme.

Instead of complying with Committee directives and issuing alerts, officials in charge of CDC’s Lyme disease program regularly make public statements and publish articles that promote use of the two-tier test and CDC’s surveillance case definition for diagnosing Lyme disease. For example, in a September 2014 letter to the *Wall Street Journal*, Paul Mead, chief of epidemiology and surveillance for CDC’s Lyme disease program, said “The two-step testing process recommended by CDC is accurate and was developed specifically to aid in diagnosing patients suspected of having Lyme disease.”

The continued and widespread misuse of the case definition results in large numbers of patients being misdiagnosed and denied medically necessary treatment. Many who do obtain treatment are refused insurance coverage and face financial hardship from out-of-pocket expenses.

²Cook M, Puri B. Commercial test kits for detection of Lyme borreliosis: A meta-analysis of test accuracy. *International Journal of General Medicine*. 2016; Volume 9:427–440. <https://www.ncbi.nlm.nih.gov/pubmed/27920571>.

Include a Broad Range of Scientific Viewpoints

“The CDC is encouraged to include a broad range of scientific viewpoints in the process of planning and executing their efforts. This means including community-based clinicians with extensive experience in treating these patients, voluntary agencies who have advocacy in their mission, and patient advocates in planning committees, meetings, and outreach efforts.”

There is significant controversy in science, medicine, and public policy regarding Lyme disease. Two medical societies hold widely divergent views on the best approach to diagnosing and treating Lyme disease. This conflict—combined with significant shortcomings in testing accuracy—makes it difficult for patients to be properly diagnosed and receive treatment.

One medical society, the Infectious Diseases Society of America (IDSA), regards Lyme disease as “hard to catch and easy to cure” with a short course of antibiotics. IDSA claims that the Lyme bacteria cannot persist in the body after a short course of antibiotics.

In contrast, the International Lyme and Associated Diseases Society (ILADS) regards Lyme disease as often being difficult to diagnose and treat, resulting in persistent infection in many patients, which requires treatment for extended periods. ILADS recommends individualized treatment based on the severity of symptoms, presence of tick-borne co-infections, and patient response to treatment, thereby allowing the patient and healthcare provider to collaborate and reach an informed decision based on the patient’s circumstances and preferences.

Unfortunately, instead of supporting a broad range of scientific viewpoints, CDC provides preferential treatment to IDSA by endorsing and promoting IDSA’s 2006 guidelines for Lyme disease, which are not compliant with current standards and are not listed by the National Guidelines Clearinghouse (NGC). At the same time, CDC withholds information from the medical community, the insurance industry, and the general public about more current guidelines from ILADS, which are fully compliant with current standards and listed on the NGC.

IDSA emphasizes that the guidelines are voluntary, but CDC’s endorsement is effectively an official seal of approval. Therefore, many physicians feel compelled to comply, and health insurance companies are supported in refusing to cover non-IDSA-compliant care.

When treatment goes beyond the IDSA guidelines, doctors risk becoming the focus of medical board investigations. Physicians who provide patients with effective treatments not recommended by IDSA are targeted, while doctors who follow the IDSA guidelines and deny treatment to patients who are later proven to have Lyme face little or no repercussions.

Provide Reports to Congress

In the cases of directives that required reports to Congress, CDC either did not provide the reports or provided incomplete reports. An example is CDC’s failure to provide a report to the House and Senate Appropriations Committees as required by a directive in the House Report 111–220 that accompanied H.R. 3293 for fiscal year 2010.

“Tickborne Diseases.—The Committee directs the Secretary to review the coordination of efforts across HHS operating divisions with respect to tick-borne diseases to ensure that: a broad spectrum of scientific viewpoints is represented in public health policy decisions, accurate information is disseminated to the public and physicians, and actions are taken by the Department that will foster significant progress in the development and adoption of improved diagnostics for Lyme disease. The Department shall submit a report to the Committees on Appropriations of the House of Representatives and the Senate with the findings from this review not later than September 30, 2010.”

The Patient Centered Care Advocacy Group filed a FOIA request for a copy of the report and was informed by HHS that CDC was responsible for the report and did not provide it “due to the requesting Senator leaving the position.”

CDC DEFENDS NONCOMPLIANCE

In an April 2016 letter, CDC Principal Deputy Director Anne Schuchat defended CDC noncompliance with directives for Lyme disease in the Senate report 107–84 for the S. 1536 appropriations bill for fiscal year 2002. The reason she gave is because the language was in the report but not in the bill itself. Below is a quote from Schuchat’s reply:

“Although committee reports may include language that encourages agencies to work on programmatic activities, only the appropriations bill signed by the President includes directives to be carried out by Federal agencies. There were

no directives specific to Lyme disease in the fiscal year 2002 Labor, Health and Human Services, and Education appropriations bill.”
www.lymepatientadvocacy.org/Documents/Anne_Schuchat_CDC_04-28-2016.pdf.

This pattern of noncompliance along with CDC’s position that it does not need to comply is very troubling. Had CDC made reasonable efforts to comply with Committee directives, this epidemic would be under better control, and thousands of patients would not be suffering due to CDC’s failure to fulfill its mandate to help prevent and control these diseases.

REQUESTED ACTIONS

To address this situation and ensure that CDC fulfills directives in appropriations report language, we respectfully request the following actions:

- Direct CDC to provide a detailed report on efforts to fulfill directives for Lyme and other tick-borne diseases in prior appropriations language.
- Issue directives to ensure compliance with future report language.
- Direct CDC to establish a balanced set of performance indicators for Lyme disease and other high priority tick-borne diseases and hold CDC accountable for performance.

Thank you for your attention to this matter.

[This statement was submitted by Bruce Fries, President, Patient Centered Care Advocacy Group, Inc.]

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 2018 recommending that the National Institutes of Health (NIH) expand its research efforts into amyloidosis, a rare disease characterized by abnormally folded protein deposits in tissues. I also request that the report language for fiscal 2018 directs 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.

There is no known cure for amyloidosis.

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 14 years. This was due to the intensive, life-saving treatment that I have received. I continue to participate in a clinical trial that looks for ways to diagnose and treat amyloidosis.

Even for people with successful treatment, amyloidosis remains a threat. 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 and treatment that has been developed over the past 14 years.

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.

More research needs to be funded for various types of amyloidosis.

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.

I want to use my experience with this rare disease to help save the lives of others.

AMYLOIDOSIS

Amyloidosis occurs when unfolded or misfolded proteins form amyloid fibrils and are deposited in organs, such as the heart, kidney 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.

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 amyloidosis 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 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 rescue and other new drugs have increased the remission rate and long-term survival dramatically. However, this treatment can also be life threatening and more research needs to be done to provide less risky forms of treatment.

RESEARCH

Although it has been almost 14 years since my initial stem cell transplant for amyloidosis, I, like most patients, am faced with recurring amyloidosis. Fortunately, due to research, there are new forms of treatment that are options for me and patients with recurring amyloidosis. These were not available 14 years ago. This is evidence that funding through Health and Human Services can make a difference.

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

Timely diagnosis is also of great concern. 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.

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.

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 NIH, particularly the Office of Rare Diseases, participates in meetings and symposia and works closely with organizations doing research and

outreach on 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. In partnership with pharmaceutical companies, new types of treatment, RNA interference and antisense oligonucleotides that work by decreasing production of the precursor protein are now in clinical trials.
- 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. The National Institute of Aging has been supporting this work.
- 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 2018

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 to help address this deadly disease:

- First, include in the fiscal year 2018 Committee report language recommending that NIH expand its research efforts into amyloidosis, a group of rare diseases characterized by abnormally folded protein deposits in tissues.
- 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 ask for your support in helping me turn what has been my life-threatening experience into hope for others.

Thank you for your consideration.

PREPARED STATEMENT OF THE PHYSICIAN ASSISTANT EDUCATION ASSOCIATION

CODE RED—CRITICAL: CLINICAL EDUCATION SITE SHORTAGE
THREATENS PA HEALTH WORKFORCE

The Physician Assistant Education Association (PAEA), which represents the 226 accredited PA programs in the United States, is pleased to submit testimony on the fiscal year 2018 appropriations for physician assistant (PA) education programs authorized through Title VII of the Public Health Service Act. PAEA supports funding of at least \$580 million in fiscal year 2018 for health professions education programs under Title VII. PAEA also requests \$12 million of that funding to support PA programs through the HRSA Primary Care Training and Enhancement Grants Program. Title VII is the only designated Federal source for PA education and is crucial to the PA education system's ability to graduate the highly skilled PAs needed to bolster the Nation's healthcare workforce.

CODE RED—Critical: Clinical Site Shortages

The PA profession has played a key role in the U.S. healthcare system for more than 50 years. Responding to demand, the profession has grown rapidly, with more than 115,000 graduates now practicing in every medical and surgical specialty and setting. The PA profession stands ready to produce more graduates, to help fill projected shortages of clinicians. However, efforts to increase the number of PA graduates must contend with a shortage of clinical training sites, a phenomenon experienced throughout the health professions and particularly acute in primary care disciplines.

The shortage of clinical sites is a direct result of the projected shortages of providers in recent years. As the health professions education system has moved to increase graduates, the rising numbers of clinicians in training put pressure on avail-

able clinical sites. Simultaneously, practicing clinicians face new productivity and documentation demands, forcing some to reduce their commitment to education.

Competition for clinical sites has also led to a new and compounding issue—PA programs paying for sites. More than a third (35.4 percent) of PA programs now report paying for some or all sites, an increase of 14 percentage points since 2012.¹ PAEA data also show that an astounding 94.8 percent of program directors are moderately or very concerned about clinical site opportunities, and that almost half of them (46.7 percent) report that the need to pay for sites has negatively impacted their plans to increase enrollment.¹ Payments for supervised clinical rotations also increase costs for students through new fees and increased tuition. Federal assistance can help break this cycle.

Background on the PA Profession and Education Model

PAs are licensed healthcare professionals educated in general medicine who have consistently proven to be effective members of the healthcare team. PAs provide a broad range of medical and therapeutic services to diverse rural and urban populations and have prescriptive authority in all 50 States.

PA education programs average 27 months in length, comprised of a year of classroom studies and a year or more devoted to clinical rotations. The 2,000 hours of clinical training that PA students undergo is second only to that of physicians in time devoted to training with patients. Their advanced medical training allows PAs to practice with significant autonomy, often serving as the sole medical provider in remote and underserved areas. The PA practice model is, by design, a team-based approach to patient-centered care, in which PAs work in partnership with physicians and other health professionals.

Need for Increased Title VII Funding

The unmet need for primary care services in the United States is well documented and expected to grow as the population ages. The PA profession was created specifically to address a shortage of primary care physicians more than 50 years ago. This commitment remains today as PAs address the new challenges our Nation faces in primary care and other specialties. However, even with the current output of more than 8,000 PA graduates each year, clinician shortages continue to persist, particularly in rural and underserved communities. Title VII, as the single direct funding source for PA programs, plays a crucial role in developing and supporting our members' ability to produce the next generation of PAs. Zeroing out funding to primary care medicine would damage programs' ability to develop innovative curricula and support clinical placement of students in rural and underserved communities. As Congress considers healthcare reform, ensuring an uninterrupted pipeline of healthcare providers should be a high priority for patients and the overall health of our Nation.

In academic year 2014–2015, Title VII grantees educated 4,390 PA students. About 29 percent of PA students reported a disadvantaged background, and 13 percent came from a rural background. Training sites for Title VII funded programs were located primarily in medically underserved communities (60 percent), primary care settings (58 percent), and/or rural settings (19 percent).²

More than 2,000 healthcare professionals trained alongside PA students while participating in interprofessional team-based care across all training sites affiliated with the Title VII grantee program. Grantees provided 135 courses and training activities to PA students during the 2014–2015 academic year as part of an effort to improve primary care curriculum into PA training. Lastly, 364 PA faculty members were trained through the faculty development activities funded by the Title VII program, and 29 faculty members completed structured faculty programs.³

In addition, Title VII funding enhances clinical training and education, helps PA programs to recruit applicants from disadvantaged and minority backgrounds, and supports innovative programs to ensure a diverse, well-trained health professional team. Title VII was strengthened in 2010 when Congress enacted a 15 percent specific allocation in the appropriations process for PA programs. This funding has enhanced capabilities to train future PAs, to creatively expand care to the underserved, and to develop a more diverse PA workforce. For example, one of our PA

¹Physician Assistant Education Association, *By the Numbers: Program Report 31*, Washington, DC: PAEA, 2016. doi:10.17538/PS31.2016.

²Department of Health and Human Services, fiscal year 2017 Health Resources and Services Administration for Children and Families, *Justification of Estimates for Appropriations Committees*. https://www.acf.hhs.gov/sites/default/files/olab/final_cj_2017_print.pdf.

³Department of Health and Human Services, fiscal year 2017 Health Resources and Services Administration for Children and Families, *Justification of Estimates for Appropriations Committees*. https://www.acf.hhs.gov/sites/default/files/olab/final_cj_2017_print.pdf.

programs uses a HRSA grant to operate a mobile health vehicle to provide health education and initial health screenings to local underserved patients.⁴

Finally, Federal support of clinicians who precept PAs and other healthcare professionals is a promising strategy for relieving the clinical site crisis. This support would have the additional benefit of promoting interprofessional education and practice.

Enhancing Diversity

The quality of patient care is enhanced when clinicians reflect America's changing demographics. PA programs are committed to attracting students from underrepresented groups and disadvantaged backgrounds, as well as experienced military veterans. Studies show that health professionals from underserved areas are three to five times more likely to return to underserved areas.^{5,6,7} Increased education costs may have a negative impact on the diversity of the PA applicant pool and reduce the number of graduates who practice primary care.

To leverage the efforts of PA programs and increase workforce diversity in the PA profession, PAEA supports funding for the Health Careers Opportunity Program (HCOP) and increased funding for the Scholarships for Disadvantaged Students and the National Health Service Corps (NHSC). These programs are vital to our Nation's health and provide a clear path for students who might not otherwise consider a PA career. While the NHSC has received additional funding, these other vital programs have been zeroed out in the President's fiscal year 2018 budget. Eliminating these programs will have an adverse impact on disadvantaged students who want to serve their fellow citizens by becoming primary care providers.

Recommendations on Fiscal Year 2018 Funding

The Physician Assistant Education Association, along with our colleagues in the health professions community, requests that the Senate Appropriations Committee support funding for Title VII health professions programs at a minimum of \$580 million for fiscal year 2018. This level of funding is crucial to educate and maintain highly skilled primary care practitioners, particularly those from diverse backgrounds and veterans, who are more likely to practice in medically underserved areas and serve vulnerable populations. We also ask for the continuation of the 15 percent allocation for PA education programs in the Primary Care Medicine cluster and request funding of \$12 million, which will allow support for the expanding number of PA programs.

We thank the subcommittee members for their support of the PA profession, continued commitment to finding solutions, and the current challenges we face in securing and maintaining quality clinical education sites.

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), Institute of Education Sciences (IES), and Bureau of Labor Statistics (BLS). These agencies are important to the members of the Population Association of America (PAA) and Association of Population Centers (APC) because they provide direct and indirect support to population scientists and the field of population, or demographic, research overall. In fiscal year 2018, we urge the Subcommittee to adopt the following funding recommendations: \$36.1 billion, \$2 billion above the final fiscal year 2017 enacted funding level for the NIH, including funds for targeted initiatives authorized by the 21st Century Cures Act; \$170 million for the NCHS; \$670 million for the IES; and, \$640.9 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

⁴PAEA Education Forum, October 15–19, 2014: Encouraging a Primary Care Career Using a Mobile Health Vehicle, Lorraine Cashin, MPS, PA–C, Mercy College; Brian Baker, Mercy College.

⁵Phillips RL, Dodoo MS, Petterson S, et al. Specialty and Geographic Distribution of the Physician Workforce: What Influences Medical Student and Resident Choices? Washington DC: The Josiah Macy, Jr. Foundation and The Robert Graham Center; 2009.

⁶Hyer RL, Bazemore AW, Bowman RC, Zhang X, Petterson S, Phillips RL. Rural origins and choosing family medicine predict future rural practice. *Am Fam Physician*. 2007;76(2):207.

⁷Talley RC. Graduate medical education and rural healthcare. *Acad Med*. 1990;65: 522–525.

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

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, three major research center programs that the Division supports, the Roybal Centers for Translational Research, Resource Centers for Minority Aging Research, and Centers on the Demography and Economics of Aging, as well as the Health and Retirement Survey (a longitudinal study that has collected data, including biomarkers, from more than 27,000 Americans over the age of 50 since 1992, establishing itself as a unique, accessible data source), will be eligible for funding renewal. With additional support in fiscal year 2018, the Institute can support these programs while also contributing to the NIA's efforts to address the scourge of Alzheimer's disease. The BSR division is also eager to support and expand its data collection efforts consistent with recommendations contained in a 2016 report issued by outside experts, including PAA members, regarding the Institute's data infrastructure. As members of the Friends of NIA, PAA and APC an additional \$500 million in fiscal year 2018 to support trans-NIH aging research.

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 National Longitudinal Study of Adolescent Health (Add Health), tracing the effects of childhood and adolescent exposures on later health. The Add Health study received a 2016 Golden Goose Award, recognizing its significant and unique scientific contributions.

In addition to supporting individual research grants and surveys, NICHD supports the Population Dynamics Centers Research Infrastructure Program. With additional funding in fiscal year 2018, 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 a funding increase in fiscal year 2018 that is proportionate to the \$2 billion increase over fiscal year 2017 for NIH.

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, such as the National Health Interview Survey (NHIS) and National Survey of Family Growth, to help data users understand the population's health, influences on health, and health outcomes.

In recent years, NCHS has made noteworthy progress toward modernizing the NVSS, moving many States from paper-based to electronic filing of birth and death statistics and expediting the release of these data to the user community. However, persistent flat funding levels in recent years, and the loss of funds from the Prevention and Public Health Fund (PPHF), are hampering the agency's ability to enact additional innovations and make necessary survey redesigns and system improvements. PAA and APC are concerned that funding for NCHS, as a component of the Centers for Disease Control (CDC), will be further constrained if the PPHF is eliminated altogether. The fund currently comprises 16 percent of the CDC budget.

As members of the Friends of NCHS, PAA and APC request that NCHS receive \$170 million in budget authority in fiscal year 2018. NCHS could use this additional money to support ongoing implementation of electronic death records nationwide and to implement necessary technical innovations to its core surveys, including a redesign of the NHIS.

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. The agency also supports the National Longitudinal Studies program and the American Time Use Survey, which are invaluable datasets that inform how complex factors, such as changes in work status, income, and education, interact to affect outcomes.

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 no less than the agency's fiscal year 2017 request, \$640.9 million, in fiscal year 2018. This funding would allow BLS to support its core programs and surveys and to conduct other postponed activities, including development of a supplemental statistical poverty measure—an initiative currently stalled under the existing CR.

INSTITUTE OF EDUCATION SCIENCES

PAA and APC support \$670 million for the IES in fiscal year 2018, an amount that accounts for inflation since the last appropriation (in 2016), plus four-percent growth over the same period. IES is the independent and nonpartisan statistics, research, and evaluation arm of the U.S. Department of Education charged with providing and disseminating rigorous scientific evidence on which to ground education policy and practice. Adequate funding for all IES programs in fiscal year 2018 will enable the Institute to best support important research, data collection and statistical analysis, and dissemination. This work contributes to a growing evidence base that informs effective and efficient educational practice and policy across the Nation.

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 and Association of Population Centers.]

PREPARED STATEMENT OF PREVENT BLINDNESS

Prevent Blindness, the Nation's leading non-profit, voluntary organization committed to preventing blindness and preserving sight, appreciates the opportunity to submit testimony to the Subcommittee and respectfully requests the following allocations and support in fiscal year 2018 to promote eye health and prevent eye disease and vision loss in the U.S.:

- \$3,300,000 to expand current vision and eye health efforts at the Vision Health Initiative of the Centers for Disease Control and Prevention (CDC).
- \$3,500,000 to the Health Resources and Services Administration (HRSA)'s Maternal and Child Health Bureau (MCHB) to establish children's vision and eye health programs in 10 States, and a technical assistance coordinating center.
- \$3,294,000 for the Glaucoma Project at CDC to allow the program to continue improving glaucoma screening, referral, and treatment for populations that experience the greatest disparity in access to glaucoma care.

INTRODUCTION AND OVERVIEW

The National Academies of Sciences, Engineering, and Medicine (NASEM) recently issued the report: "Making Eye Health a Population Health Imperative: Vision for Tomorrow." Importantly, the report recognizes that, for too long, vision and eye health have not received the attention and investment they warrant given their importance to public health. 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, nearly 25 percent of all school-aged children. Vision problems are a leading cause of impaired health in childhood and reduces a child's ability to learn and capacity to positively contribute to society. Recent research shows that the economic burden of vision loss and eye disorders is \$145 billion each year, and, without increased attention, could rise to as much as \$717 billion by the year 2050 given our Nation's rapidly-aging population.

Good vision is an integral component to health and well-being. It 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. Alarming, while half of all incidents of blindness can be prevented through education, early detection, and treatment, the National Eye Institute (NEI) at the National Institutes of Health (NIH) reports that “the number of Americans with age-related eye disease and its consequential vision impairment is expected to double within the next three decades.”¹

To curtail the increasing incidence of vision loss in America, and its accompanying economic burden, Prevent Blindness is requesting sustained and meaningful Federal funding for programs that work to prevent eye disease, vision loss, and blindness and ultimately promote eye health. In a time of significant fiscal constraints, we recognize the challenges facing the Subcommittee and urge you to consider the ramifications of decreased investment in vision and eye health. Vision loss is often preventable, but without the necessary funding to better understand eye conditions, treatment options, and development of public health systems and infrastructure to disseminate good science and prevention strategies millions of Americans face significant impacts to their independence, health, and economic livelihoods.

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 with public, private and nonprofit partners to create an effective public health approach to vision loss prevention and eye health promotion. For example, the CDC has successfully developed model programs that 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 the CDC has in addressing the challenges that exist for vision and eye health. The NASEM report 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;
- 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, and
- Develop a coordinated public health surveillance system to monitor eye and vision health in the U.S.

The President’s fiscal year 2018 budget proposal, A New Foundation for American Greatness, includes drastic cuts that threaten the CDC’s recognized role in addressing our Nation’s collective vision and eye health. If enacted, these cuts would severely impact the ability for States to respond to the consequence of vision loss from the most severe chronic illnesses. We urge the Senate to consider the downstream impacts that preventable vision loss and eye disease would have on Americans whose livelihoods depend on their ability to see.

INVESTING IN THE VISION OF OUR NATION’S MOST VALUABLE RESOURCE: CHILDREN

Early detection and intervention for vision problems are incorporated into national goals and healthcare standards. The Healthy People 2020 initiative includes the following objectives for vision:

- “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 vision loss and/or cause problems socially, academically, and developmentally. Studies have demonstrated that optical correction of significant refractive error may be re-

¹“Vision Problems in the U.S.: Prevalence of Adult Vision Impairment and Age-Related Eye Disease in America,” Prevent Blindness America and the National Eye Institute, 2008.

lated to improved child development and school readiness.^{2,3,4} Yet only 52 percent of children ages 3 through 5 are screened for vision problems,⁵ and only one-third of all children receive eye care services before the age of six.⁶ 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 addition to acknowledging the important—yet underfunded—role of the CDC’s VHI, the NASEM report committee acknowledged the HRSA-funded quality improvement work led by the Prevent Blindness-established National Center for Children’s Vision and Eye Health (the Center) as a leading example of the importance of continuous quality improvement among diverse stakeholders in advancing eye health in the U.S. In 2009, Prevent Blindness established the Center to be 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. 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. 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 of all ages;
- Advance State-based performance improvement systems and screening guidelines
- Promote family education and engagement in their child’s vision health, and
- Provide technical assistance to States in the implementation of strategies for vision screening, establishing quality improvement measures, and promote State-to-State sharing of promising practices.

Strong funding will allow MCHB to assist States in developing children’s vision screening and eye health programs and 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 a technical assistance center allowing it to identify and develop resources as a part of vision health outreach and awareness.

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 2018 funding for the CDC Vision Health Initiative, CDC Glaucoma Project, and the MCHB. 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. We are happy to be a resource to Subcommittee members and your staff. We very much appreciate the Subcommittee’s attention to—and consideration of—our requests.

ADDENDUM

Americans care about increasing preventative funding for eye care. The See Now online campaign ran from March through June in support of these requests, garnering 67,786 signatures from Americans who want to see our government take action to save the sight of millions. For many, access to preventative eye care has been life changing. Here are some of their stories:

“If my ophthalmologist had not caught my cataracts I would have been blind by the time I was 5 years old”—*Kylie Glass*

“What if I never received that treatment? Would I have ever gotten good grades in school to help me pursue my career in optometry? Would I have ever been able to read the chalkboard in the classroom?”—*Stephanie Golon*

²Ibironke JO, F. D. (2011). Child Development and Refractive Errors in Preschool Children. *Optometry and Vision Science*, 252–8.

³Roch-Levecq AC, B. B. (2008). Ametropia, preschoolers’ cognitive abilities, and effects of spectacle correction. *Arch Ophthalmol*, 187–98.

⁴Atkinson J, A. S. (2002). Infant vision screening predicts failures on motor and cognitive tests up to school age. *Strabismus*, 187–98.

⁵O’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.

⁶“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.

“I was amazed to discover that one of my eyes was showing signs of this disease. I had no idea! I am “only” 59 years old and in very good health. I am pretty knowledgeable in health matters, yet it took this chance encounter at a meeting to get this early diagnosis.”—*Richard Wittburg*

“When they told me that Akeem had vision problems, I was shocked! How did I not know that my son had vision problems? We took him to all his checkups, and he passed everyone, but they had not caught this.”—*Rocco, Akeem’s father*

[This statement was submitted by Hugh Parry, President & CEO, Prevent Blindness.]

PREPARED STATEMENT OF THE PULMONARY HYPERTENSION ASSOCIATION
THE ASSOCIATION’S FISCAL YEAR 2018 L–HHS APPROPRIATIONS RECOMMENDATIONS

-
- \$7.48 billion in discretionary budget authority for the Health Resources and Services Administration (HRSA).
 - \$7.8 billion in program level funding for the Centers for Disease Control and Prevention (CDC).
 - \$500,000 for a pulmonary hypertension awareness and early diagnosis campaign at CDC.
 - At least \$36 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 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 2018 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. It affects people of all ages, races and ethnic backgrounds. 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. There is no cure. 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. In addition, types of PH can overlap in a single individual, leading to poorer prognosis. The reasons for this are unknown and also present opportunity for future study.

ABOUT THE ASSOCIATION

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 275 patient support groups; a robust national continuing medical education program; a PH clinical program accreditation initiative; and a national observational patient registry. For thirteen consecutive years, PHA has received the highest rating—four stars—for fiscal accountability and transparency from Charity Navigator, placing it in the top half of 1 percent of all rated charities.

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. Federal organ transplantation activities are coordinated through HRSA. To ensure HRSA can expand its important mission and continue to make improvements in donor lists and donor-matching please provide HRSA with \$7.84 billion in discretionary budget authority in fiscal year 2018.

CENTERS FOR DISEASE CONTROL AND PREVENTION

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 PH. When individuals are diagnosed with PH quickly and begin appropriate therapy, their prognosis and life-expectancy improve dramatically. However, 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 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.

In this regard, we hope the Subcommittee will provide \$500,000 for a PH early diagnosis campaign at CDC. Such an effort would serve to complement PHA's own programs that support education, awareness, and epidemiological activities to promote early and accurate diagnosis of PH. Improving awareness and recognition of PH would not only save lives, but would reduce Federal healthcare costs related to emergency room visits and hospitalization. In addition, in order for such a program to flourish, CDC needs consistent and incremental increases in funding.

NATIONAL INSTITUTES OF HEALTH

Please provide NIH with meaningful increases—including at least \$36 billion in program funding in fiscal year 2018—to facilitate expansion of the PH research portfolio so we can continue to improve diagnosis and treatment. The Office of Rare Diseases Research (ORDR), located within NCATS, supports and coordinates rare disease research and provides information on rare diseases to patients, their families, healthcare providers, researchers and the public. In collaboration with other NIH institutes, ORDR funds rare diseases research primarily through the Rare Diseases Clinical Research Network (RDCRN), which supports clinical studies, investigator training, pilot projects, and access to information on rare diseases. Most recently, 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.

THE PATIENT PERSPECTIVE

The stories of two families impacted by PH help to illustrate the urgent need for increased research, public awareness and accurate diagnosis. Christen White Cranford lived with PAH symptoms for at least 2 years before diagnosis. When she spoke with her primary care physician about her fatigue and shortness of breath, the doctor told her to lose weight. It was not until she fainted—a symptom of severe PH—that she finally received an accurate diagnosis. It then took another 9 months for her to be connected with a physician truly experienced in treating the rare condition and by then, her condition was very advanced. Christen died in 2002 at the age of 22. In 1998, when their daughter Emily was five, Jack and Marcia Stibbs noticed that she could not keep up with the other children in the neighborhood. She seemed to lack the energy and strength to run and play. This condition worsened to the point where she would have to stop and rest after coming down the steps in the morning. Emily was diagnosed with PAH later that year. She is now 24 years old and a graduate of Vanderbilt University.

As these stories illustrate, prompt, effective diagnosis of pulmonary hypertension can mean the difference between life and death. Thank you again for your consider-

ation of the PH community's priorities as you develop the fiscal year 2018 L-HHS Appropriations bill.

[This statement was submitted by Mr. Brad A. Wong, President and CEO, Pulmonary Hypertension Association.]

PREPARED STATEMENT OF SHIELA RAMSEY

Department of Education Funding for Ronald E. McNair Post-Baccalaureate Achievement Program

\$43 million is the estimated amount of taxes a cohort of 4,000 McNair scholars will contribute in a year to the government and they will no longer need governmental assistance for themselves like their families needed. It doesn't seem like a large amount when compared to the spending, but if that's the case then the \$35 million a year the McNair program costs the United States is not a large amount. Given that McNair Scholars contribute more than that amount there is absolutely no need to cut the program.

I was raised by a single mom who became a mother at 16 and worked as a fast food cashier my whole life to provide for my brother and me. By all means one would assume my fate would be similar. However, I chose to attend college for a degree in geology. I will not deny that I struggled greatly my first years of college. I often contemplated dropping out, but after encouragement from a professor I applied to be a McNair Scholar. I had no intention of graduate school until I was accepted into the program, but here I am now about to start a master's program. This would not have been possible without the McNair Program and other TRIO programs. I would not have even finished my undergraduate degree without the programs. I would have been back to the life I started in. I would have been back to needing the governments help just to get by, but now I am able to help others that grew up like me accomplish what I have accomplished and more.

PREPARED STATEMENT OF THE REFUGEE COUNCIL USA

On behalf of the twenty-four member organizations of Refugee Council USA (RCUSA)¹ dedicated to refugee protection, assistance and welcome, 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 2018. RCUSA recommends fiscal year 2018 funding levels of \$1.693 billion for the Department of Health and Human Services' Refugee and Entrant Assistance (REA) account. This reflects a continuance of the funding provided in the fiscal year 2017 omnibus appropriations bill with the sole exception of a recommended increase in funding for trafficking victim's services, given the 771 percent increase in identified victims in need of trauma-informed services since 2002 based on the 2002 ORR report to Congress and the 2016 TIP report.

RCUSA is deeply concerned about the 31 percent proposed cuts to programs that help refugees learn English, find jobs, and successfully integrate in the United States. These cuts will not only diminish the prospects of recently arrived refugees and other populations from achieving economic self-sufficiency, but will shift the costs from the Federal Government to States, localities, and community organizations. These cuts are justified on faulty assumptions that the account will only serve 98,000 individuals through these programs—which has not been the case since 2007. In addition, the administration signals in this budget a continued focus on a refugee admissions level of 50,000 for fiscal year 2018, which would represent an abdication of US leadership in a time of global crisis but also a rejection of sound national security, foreign policy, and economic goals; it would also keep US families needlessly separated and rejects the will of the American people. RCUSA recommends at least 75,000 refugees are resettled in 2018.

¹Members: Amnesty International, Asylum Access, Boat People SOS, Center for Applied Linguistics, Center for Migration Studies, Center for Victims of Torture, Church World Service, Episcopal Migration Ministries, Ethiopian Community Development Council, HIAS, Human Rights First, International Catholic Migration Commission, International Rescue Committee, International Refugee Assistance Project, Jesuit Refugee Service, Jubilee Campaign, Lutheran Immigration and Refugee Service, Refuge Point, Refugee Center Online, SEARAC, US Conference of Catholic Bishops, US Committee for Refugees and Immigrants, Upwardly Global, and World Relief.

The REA account in the LHHS appropriations bill funds the Office of Refugee Resettlement (ORR). 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, roughly 200,000 people each year rebuild their lives and contribute to American communities across the country. In fiscal year 2016 alone, ORR served over 270,000 people.

Today, the number of forcibly displaced persons around the world exceeds 65 million, the largest number in recorded history. Among them are over 25 million refugees. The United States has long been a leader in protecting and defending liberty and justice through its support of refugees and others who are victims of persecution and violence. Robust funding is critical for these programs that uplift human dignity, combat oppression and extremism, and advance our Nation's values and security.

The U.S. is one of roughly 30 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 to the United States. 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 9 voluntary nonprofit resettlement agencies that have signed a Cooperative Agreement with the State Department and have local affiliates in over 300 sites in communities throughout the country. Six of the nine voluntary agency networks are faith-based, and harness the energy of many churches, synagogues and other faith communities to help welcome the 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 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 without needing to access Federal or State assistance programs. The program leverages public funds with private donations at a 2:1 ratio, with nongovernmental agencies working hand-in-hand with local communities to match Federal Government contributions with private resources. In fiscal year 2016, over 82 percent of refugees who participated in this program obtained employment by the end of the 180-day service period, a major factor in achieving self-sufficiency.

Refugee Cash and Medical Assistance (CMA).—CMA provides time-limited 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 are among the most vulnerable of refugees. They have lost or been separated from their parents and families and have often suffered greatly not only in their home country but also in host countries, that is, 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 United States.

Refugee Social Services (RSS)

RSS supports initial employability services and other services that address initial barriers to employment such as social adjustment, interpretation and translation, day care for children, and citizenship and naturalization. It is provided to States and non-profit organizations through a mix of formula funding and discretionary

grants so that programs can be based on local need tailored to local situations. Highlights:

School Impact.—School Impact funding, provided through a formula in the RSS program, supports impacted school districts with the funds necessary for activities that will lead to the effective integration and education of vulnerable, newly arrived children. Services include English as a Second Language instruction, after-school tutorials, programs that encourage high school completion and full participation in school activities, after-school and/or summer clubs and activities, parental involvement programs, bilingual/bicultural counselors, interpreter services and other important programs.

Preferred Communities.—The USRAP resettles refugees who are in urgent need of protection, such as women heads of households, victims of torture, those with significant physical or mental health vulnerabilities, and refugees from protracted refugee situations. Such refugees need further support toward integration and self-sufficiency, and the Preferred Communities program provides funding for Intensive Case Management that provides such effective support.

Additional discretionary, competitive grants include: Microenterprise Development (fostering the creation of refugee-owned businesses); Refugee Family Child Care (promoting women's employment through -owned childcare businesses); Individual Development Accounts (increasing the asset-building of refugees via matching savings.); Refugee Agricultural Partnership (RAPP) (promoting access to healthy food and cultural connection through garden programs); and Ethnic Community Self Help.

Targeted Assistance Program (TAG)

Unlike RSS, which focuses on initially arrived refugees and is available to all States, TAG funding provides support to States with particularly high refugee arrivals, including via secondary migration, and services to refugees requiring longer term employment support. For example, it provides employment services harder to employ refugees to prevent long-term dependence on State cash assistance. 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 transition into higher paying jobs. ORR provides funding through formula funds to States that qualify and through discretionary grants.

RCUSA is strongly concerned with the proposed 21 percent cuts to these programs that 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. RCUSA notes that the administration proposes both merging RSS and TAG despite their distinct goals, and is concerned that change combined with the reduced proposed funding raises the potential to end the critical and differential functions of these two programs. RCUSA also notes that the proposed budget would change the formula allocation so that funds are based upon 12, rather than 24, month arrivals—subjecting State funds to greater variation and reducing the ability of States to do budget planning.

Refugee Health Promotion (RHP)

This program provides critical resources through competitive grants to States that allow them to address critical mental and emotional health needs that are not supported through existing funding sources, such as RMA, which covers solely coordination of initial domestic medical screenings and up to 8 months of transitional medical assistance for refugees ineligible for Medicaid. RMA does not cover the costs of: 1) Addressing mental health needs and integrating such needs into each refugee's comprehensive plan for integration and self-sufficiency; nor 2) Developing educational resources for health and mental healthcare providers, for resettlement case managers, and for refugees. RHP fills this critical gap. Health providers estimate that eliminating this small, but critical funding, would ultimately lead to greater costs by reducing early communicable disease interventions, increasing emergency room visits due to less preventive health education, and diminished workplace productivity due to decreased management of chronic conditions or behavioral health issues. Given its importance both to the self-sufficiency success of refugees and to the States that welcome them, RCUSA strongly opposes the proposed RHP elimination.

Survivors of Trafficking

Since the passage of the Trafficking Victims Protection Act in 2000, victims of human trafficking have received medical and psychological treatment, housing, access to educational programs, life skills development, and other assistance through HHS-funded programs carried out by NGO. This program also funds public awareness, training, and coalition building to raise awareness about human trafficking

among law enforcement, social services, medical staff, and other potential first responders, in addition to other to other faith-based and community groups. These grants are crucial to providing victims, including children, integrative aid and services once they have been identified as a victim of trafficking. An increase of \$19.2 million is requested to serve trafficking survivors, given the 771 percent increase in the number of victims identified and certified in need of trauma-informed specialized services from fiscal year 2002–2015, based on the 2002 ORR report to Congress and the 2016 TIP report.

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. In fiscal year 2015, ORR's Survivor of Torture program provided grants to 34 direct service rehabilitation programs and one technical assistance provider in 22 States and in Washington D.C. An estimated 9,000 survivors and their families from 125 countries benefited from these services.

Unaccompanied Children (UCs)

In fiscal year 2016 the Office of Refugee Resettlement served an all-time high of 59,140 children. ORR's services include holistic, child-centered care for unaccompanied children (UCs) while in Federal custody and ensures their safety upon family reunification or placement in the community. 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. Some children who are deemed asylees, victims of human trafficking, or other children qualified for special protection because of other serious vulnerabilities, may also qualify to be protected under the unaccompanied refugee minor program. The fiscal year 2017 December Continuing Resolution also authorized up to \$500 million to care for increased numbers of unaccompanied children. RCUSA urges that such funds be available for all ORR populations.

Summary of RCUSA fiscal year 2018 funding recommendations:

Program Areas	Fiscal Year		
	2017 Enacted Funding	2018 President's Request	2018 RCUSA Request
Transitional & Medical Services	\$490,000,000	\$320,000,000	\$490,000,000
Social Services	155,000,000	159,000,000	155,000,000
Targeted Assistance	47,601,000		47,601,000
Refugee Health Promotion	4,600,000	0	4,600,000
Subtotal of Resettlement Services	697,201,000	479,000,000	697,201,000
Foreign-Born Trafficking Victims	13,000,000	13,000,000	19,000,000
Domestic Trafficking Victims	5,755,000	5,755,000	19,000,000
Torture Survivor Assistance	10,735,000	10,735,000	10,735,000
Unaccompanied Children	948,000,000	948,000,000	948,000,000
Total—All REA Activities	\$1,674,691,000	\$1,457,000,000	\$1,693,936,000

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 2018 appropriations under the jurisdiction of the Subcommittee on Labor, Health and Human Services, Education, and Related Agencies. We request an increase of \$2 billion for the National Institutes of Health, \$7.8 billion for the Centers for Disease Control and Prevention, and \$364 million for the Agency for Healthcare Research and Quality.

The National Institutes of Health (NIH) 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. In 2016, NIH sponsored over 5,000 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 Undiagnosed Diseases Program at the National Human Genome Research Institute provides hope for patients who seek answers for deadly and debilitating conditions that have evaded diagnosis. The National Institute of Nursing Research taps into the unique insights of the nursing community to confront critical challenges in health and healthcare, and the National Center for Complementary and Integrative Health supports research to advance promising areas of medicine and healthcare outside the traditional biomedical arena. Because much of these non-traditional approaches lack intellectual property protection, potentially beneficial solutions are too often not explored. NIH helps address this gap in the research and development pipeline. 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 \$2 billion in fiscal year 2018, and to supplement that increase by releasing the fiscal year 2018 funding targeted for specific national research initiatives under the 21st Century Cures Innovation Fund. 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 (CDC) 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 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 \$7.8 billion in fiscal year 2018 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, 30 percent is wasted on medical errors, unnecessary services, excessive administrative costs and inefficient delivery. 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. Nearly 20 percent of

Medicare patients face readmission within 30 days of discharge. AHRQ-funded research identified treatment gaps and helped discharged patients receive proper outpatient treatment and follow up appointments, decreasing readmission rates by up to 50 percent.

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 \$364 million in fiscal year 2018.

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 ISABEL J. RODRIGUEZ

Good afternoon, I am an Afro-Latina in my third year as an undergraduate at Portland State University majoring in physics and minoring in mathematics. I am a 2016 McNair scholar, 2016 Oregon NASA Space Grant Consortium scholar, LSAMP scholar, and a member of the TRIO program. I aspire to become a researcher in the field of astrophysics, and this summer I will begin the process of applying to Ph.D. programs.

I am also a former college dropout. Nearly 10 years ago, I entered the university system without a firm grasp of what I wanted. As a result, my first encounter with higher education quickly revealed my unpreparedness for the experience and I dropped out at the earliest opportunity. In the years that followed, I learned about the things that peaked my curiosity, about the person I wanted to become. It was not long before I yearned to return to academia, this time with a different set of values in hand.

Becoming a part of a community within the university that shared a common set of core values including academic excellence, integrity, and hard work, was critical for sustaining my success in this new setting as well as for introducing me to opportunities I would have never considered. Portland State University's LSAMP community has been the main driver in shaping my path, and its Director has been both an important mentor and my strongest advocate. Thanks to this connection, I am now a member of the University's Honors College, a Ronald E. McNair scholar, a student leader within the LSAMP STEM Public Outreach Community (SPOC), as well as a peer mentor with the BUILD EXITO program. The research I have been involved as part of the McNair program has led me to become an Oregon NASA Space Grant scholar, and introduced me to my first professional conference presentation. While exploring professional and academic opportunities are important aspects of my undergraduate experience, I believe that it would not be complete without giving back. My role as a peer mentor has allowed me to play a small part in guiding a diverse group of students through some of their undergraduate experience.

I aspire to earn a Ph.D. in astrophysics, a field that, like many in STEM, suffers from a lack of diversity. As a scientist, I believe it is important to play the role of an educator, a communicator, and as a minority, this role implies visibility—an integral component to the recruitment and retention of a diverse workforce. I also want to dedicate my efforts to science policy work in the service of science literacy as well as equity and inclusion. The ability to understand the fundamental concepts that shape our world, the ability to think critically and solve problems, the ability to elect leaders who value rationality over the suppression of uncomfortable ideas—all of these things are going to help ensure that our future leads to progress, not stagnation.

It is with these principles in hand that I ask for the government's continued support of programs like the Louis Stokes Alliance for Minority Participation, the Ronald E. McNair program, and TRIO. They are important—not just for their end goal of diversifying the sciences, but for giving students the opportunity to feel like they belong in the spaces that their passions and curiosities have led them.

Sincerely.

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 2018 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 \$174 million be provided for the polio eradication activities of the CDC to support essential polio eradication strategies and innovations outlined in the Polio Eradication and Endgame Strategic Plan.

The United States is the leading public sector donor to the Global Polio Eradication Initiative. The 325,000 members of Rotary clubs in the US appreciate the United States' generous support and longstanding leadership. Rotary, including matching funds from the Gates Foundation, has contributed more than US\$1.6 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 US leadership remains vital to achieve the goal of a polio free world and ensure that the investment in polio eradication infrastructure and resources lives on to benefit other health efforts.

PROGRESS IN THE GLOBAL PROGRAM TO ERADICATE POLIO

Since the launch of the GPEI in 1988, eradication efforts have led to more than a 99 percent decrease in cases. Thanks to this committee's funding for the polio eradication activities of the CDC, 2016 saw the fewest children afflicted by polio in history, with only 37 cases confirmed globally. Transmission of the wild polio virus is limited to a few areas of just three countries—Pakistan, Afghanistan and Nigeria. The detection in July 2016 of wild polio in Nigeria after 2 years was a sobering reminder that polio is a difficult disease to eradicate, especially in areas with humanitarian crises and faltering health systems. 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. The GPEI works to reach more than 450 million in some 60 countries which are either endemic or at-risk for polio outbreaks.

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 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 this crippling disease. CDC has used the Congressional support to make the following significant programmatic contributions:

- Provided \$55 million to the World Health Organization for surveillance, technical staff and operational costs related to immunization activities, primarily in Africa.
- Provided \$13.8 million to UNICEF for approximately 57.4 million doses of oral polio vaccine, 5 million doses of inactivated polio vaccine, and \$12 million for operational costs for National Immunization Days (NIDs) in 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.
- Supported rapid detection and response to wild poliovirus (WPV) transmission in Borno, Nigeria, which had largely been under control of Boko Haram for 2 years.
- Established several important benchmarks based on best practices developed in India and Nigeria to streamline decisionmaking and accountability

- at the local level, and ultimately improve the performance and efficiency of polio programs.
- Fostered program quality improvements through the establishment of Emergency Operations Centers in Pakistan and Nigeria and related use of CDC-developed management dashboards.
 - Worked with the Pakistan Ministry of Health, WHO and USAID's mission in Islamabad, to train 65 national epidemiologists from CDC's Field Epidemiology Training Program (FETP) and deploy them to the highest risk districts to help improve the quality of surveillance and immunization activities, and strengthen routine immunization systems.
 - CDC's National STOP program for Nigeria trained 219 staff in the highest risk states to stop transmission of wild polio. Nigeria's polio legacy planning will transition those workers to build lasting improvements in Nigeria's immunization system.
 - Led efforts to coordinate the switch from trivalent oral polio vaccine to bivalent vaccine, and also supported the introduction of inactivated polio vaccine.
 - Trained 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.
 - Provided the largest volume of operational (poliovirus isolation) and technologically sophisticated (genetic sequencing of polio viruses) lab support to 145 laboratories of the global polio laboratory network.
 - Provided 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.
 - CDC's Stop Transmission of Polio (STOP) program trains and deploys public health professionals to improve vaccine-preventable disease surveillance and to help plan, implement, and evaluate vaccination campaigns. STOP places staff resources in countries of higher-risk for poliovirus transmission to support critical national immunization functions. STOP has trained and deployed more than 1,800 public health professionals to work on polio surveillance, data management, campaign planning and implementation, program management, and communications in high-risk countries. In 2016, the STOP program sent 435 professionals on assignments to 35 countries.
 - Led the efforts to raise awareness of the importance and urgency of stakeholder planning to ensure that key polio-related assets will be leveraged to benefit other public health priorities.

FISCAL YEAR 2018 BUDGET REQUEST

We respectfully request \$174 million in fiscal year 2018 for the polio eradication activities of CDC, the same as the fiscal year 2017 level. With Congress' continued support for polio eradication in fiscal year 2018, 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.

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 145 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 \$13 billion already invested in eradication. Success will ensure that the significant investment made by the US, Rotary International, and many other countries and entities, is protected in perpetuity.

PREPARED STATEMENT OF THE RYAN WHITE MEDICAL PROVIDERS COALITION

My name is Dr. Ernie-Paul Barrette, and I am the Medical Director of the Primary Care Medicine Clinic at Barnes Jewish Hospital, and in July, I will become the Director of the Ryan White HIV/AIDS clinic at Washington University in St. Louis, Missouri. I write to submit testimony on behalf of the Ryan White Medical Providers Coalition (RWMPC) of the HIV Medicine Association (HIVMA), of which I am a member.

RWMPC is a national coalition of medical providers and administrators who work in healthcare agencies supported by the Ryan White HIV/AIDS Program funded by the HIV/AIDS Bureau (HAB) in the Health Resources and Services Administration (HRSA). I thank the Subcommittee for funding the Ryan White Program, and in particular the Part C program which supports direct HIV medical care and treatment, in fiscal year 2017 with \$201.1 million. And while I am very grateful for this support, I am disappointed that Congress cut the Part C Program by \$4 million in fiscal year 2017, because there is great need for HIV medical care and treatment in St. Louis and throughout our Nation. And while I understand that budgets are tight, I request \$225.1 million in fiscal year 2018—a \$24 million increase—including restoration of the \$4 million cut to the Ryan White Part C program in fiscal year 2017.

While I know that this would be a great deal of funding, it is in fact well below the estimated need. The Ryan White clinic at Washington University is the largest HIV clinic in the St. Louis region, which accounts for 51 percent of newly diagnosed cases in the State. In 2016, the Ryan White clinic at Washington University experienced a 2.1 percent increase in HIV patients, serving over 1800 patients that year. Unfortunately, our Ryan White Part C funding has remained flat since 2013, and during that time our patient load has increased by 6 percent. Since becoming a Ryan White Part C grantee in 2007, our clinic has experienced an 80 percent increase in HIV/AIDS patients served per year, indicating the great need for these HIV medical care services in the St. Louis region. The fiscal year 2017 cut to our Part C funding this year may jeopardize the level of care we are able to provide to patients.

For example, Part C funding at our clinic supports nurses who are an integral part of our clinical team. Without full Part C funding this year, it is very possible we will have to cut back our nursing staff, and this would make it less feasible to serve so many patients. Ryan White clinical care uses a team approach, involving a variety of medical and other professionals who manage the comprehensive range of patient HIV care needs, from primary HIV care, to mental health and substance use treatment, lab services, medication adherence, dental care, and support services needed to remain in care, such as transportation. Reducing our nursing staff would make it much less likely that we would be able to manage the large and increasing volume of patients and their complex medical needs. Additionally, the Part C clinic has aggressively re-engaged individuals living with HIV who have been lost from care, and are working hard to link newly diagnosed patients to HIV care and treatment. These populations are more likely to be uninsured and thus will rely primarily on medical services supported by the Ryan White Part C program. Given the pressures to expand and maintain access to HIV care and treatment to improve both individual and public health outcomes in St. Louis and nationwide, I urge members of the Subcommittee to restore the \$4 million cut to the Ryan White Part C program and fully fund Part C in fiscal year 2018 at \$225.1 million.

Washington University has been a major provider of HIV primary care and supportive services for people living with HIV/AIDS since the late 1980s, and has completed 10 successful years as the Ryan White Part C grantee for the City of St. Louis and its six surrounding counties (St. Louis, Franklin, Jefferson, Lincoln, St. Charles, and Warren). A comprehensive range of services is available for HIV/AIDS patients at the Washington University Infectious Diseases Clinic, where the Ryan White Part C program is operated in coordination with its sister program, Project ARK, the region's Ryan White Part D grantee since 1995.

Washington University also has had the distinct honor of being selected three times as a HRSA Special Projects of National Significance (SPNS) grantee (1994–1999; 2010–2012; 2016–present). Our SPNS projects have focused on creating a comprehensive model of care for women living with HIV/AIDS (1994–1999); integrating hepatitis C treatment within HIV clinical care for persons with HIV/HCV co-infection (2010–2012); and using technology to improve engagement and retention in care among youth and young adults living with HIV (2016–present). Unfortunately, the fiscal year 2018 Trump Administration budget proposes to cut this important program that helps to identify innovative, replicable models of care to improve the

treatment of HIV nationwide. I urge members of the Subcommittee to fully fund the SPNS program in fiscal year 2018 at \$25 million.

Additionally, I urge Subcommittee members to fully fund the AIDS Education and Training Centers (Part F) in fiscal year 2018 at \$33.6 million. Unfortunately, the Trump Administration budget also proposes to eliminate this program, which provides continuing education, training, and technical assistance on HIV care and treatment issues to Ryan White Program providers, including clinicians and AIDS Service Organizations. Ensuring that HIV clinics, AIDS Service Organizations, and the HIV workforce overall are highly trained is a key factor to reducing HIV/AIDS nationwide and ultimately achieving an AIDS-free generation.

Ryan White Part C Programs Support Comprehensive, Expert, and Effective HIV Care

Ryan White Part C directly funds comprehensive and effective HIV care and treatment—services that are responsible for the dramatic decrease in AIDS-related mortality and morbidity over the last decade. The Ryan White Part C Program has supported the development of expert HIV care and treatment programs that achieve key outcomes that improve both individual and public health by helping prevent the transmission of HIV. In 2011, a ground-breaking clinical trial—named the “scientific breakthrough of the year” by Science magazine—found that HIV treatment not only saves the lives of people living with HIV, but also reduces HIV transmission risk to near zero—proving that HIV treatment is also HIV prevention.

Ryan White Part C directly funds 346 community health centers and clinics that provide comprehensive medical care in 49 States, Puerto Rico and the District of Columbia. The program targets the most vulnerable communities, including people of color, women, and low-income populations. Ryan White Part C clinics provide treatment and care to more than 300,000 people each year. Ryan White Part C clinics often are the only means by which many persons receive HIV testing and care. Part C also is the primary method for delivering HIV care to rural communities—approximately half of Part C providers serve rural communities.

The comprehensive, HIV care model that is supported by the Ryan White Program has been highly successful at achieving positive clinical outcomes with a complex patient population.¹ In a convenience sample of eight Ryan White-funded Part C programs ranging from the rural South to the Bronx, retention in care rates ranged from 87 to 97 percent. However, estimates from the Centers for Disease Control and Prevention (CDC) show that only 40 percent of all people living with HIV are engaged in care nationally.² Once in care, patients served at Ryan White clinics do very well—more than 83 percent of Ryan White patients achieved viral suppression in 2015. The Ryan White Part C clinic at Washington is beating this national average—in 2016, our patients had an 86 percent viral suppression rate, and 81 percent were retained in care.

Investing in Ryan White Part C Programs Saves Both Lives and Money

Early and reliable access to HIV care and treatment both helps patients with HIV live relatively healthy and productive lives and is more cost effective. One study from the Part C Clinic at the University of Alabama at Birmingham found that patients treated at the later stages of HIV disease required 2.6 times more healthcare dollars than those receiving earlier treatment meeting Federal HIV treatment guidelines. On average it costs \$3,501 per person per year to provide the comprehensive outpatient care and treatment available at Part C funded programs. The comprehensive services provided often include lab work, STD/TB/Hepatitis screening, ob/gyn care, dental care, mental health and substance abuse treatment, and case management. This is a bargain when compared to the high cost of hospital and emergency care visits.

Fully Funding and Maintaining Ryan White Part C Programs Is Essential

Because of both the inadequacy of insurance coverage for people with complex conditions, such as HIV, and the fact that some individuals will remain uncovered, fully funding and maintaining the Ryan White Part C Program is essential to providing comprehensive, expert and effective HIV care nationwide. At this critical time in the HIV/AIDS epidemic, when research has confirmed that early access to HIV care and treatment not only saves lives but prevents new infections by reducing the risk of transmission to near zero for patients who are virally suppressed, it is essential to maintain overall funding levels for the Ryan White Part C Program. Increas-

¹ See Improvement in the Health of HIV-Infected Persons in Care: Reducing Disparities at <http://cid.oxfordjournals.org/content/early/2012/08/24/cid.cis654.full.pdf+html>.

² See CDC's HIV in the United States: The Stages of Care, <http://www.cdc.gov/nchhstp/newsroom/docs/HIV-Stages-of-Care-Factsheet-508.pdf>, November 2014.

ing access to and successful engagement in effective, comprehensive HIV care and treatment is the only way to lead the Nation to an AIDS-free generation and reduce the devastating costs of—including lives lost to—HIV infection.

Continue to Permit the Use of Federal Funds for Syringe Access Programs that Help to Advance Public Health and Address Drug Use

RWMPC and HIVMA commend Congress for modifying the ban on Federal funding for syringe access programs, and the fiscal year 2018 Trump Administration budget request for proposing to continue this effective policy. In 2015, 54 percent of individuals who inject drugs reported using a syringe services program in the past year, compared to only 36 percent in 2005.³ While syringe access programs remain technically illegal in St. Louis, injection drug users seek syringe access services over the border in Illinois, and opioid use continues to be a critical problem in our State. In Missouri, hospital utilization for prescription opioid overuse (not the use of illicit opioids, such as heroin) increased 137 percent between 2005 and 2014, with the highest statewide rates of hospital utilization in the St. Louis metropolitan area.⁴ In 2014, uninsured patients accounted for 30 percent of all hospital visits for opioid overuse—this was a 10-year, 268 percent increase.⁵

RWMPC and HIVMA are committed to evidence-based public health interventions that both increase access to healthcare and decrease transmission of HIV, viral hepatitis, and other blood-borne pathogens. Injection drug use is a major transmission route for these infections, and increasing access to syringe access programs through Federal funding will help decrease the spread of hepatitis C and HIV, as well as connect individuals to critical healthcare and support services, including overdose prevention, substance use treatment, and medical care for hepatitis C, HIV, and other life-threatening infections. I urge the Subcommittee to maintain appropriations language that allows access to syringe services in jurisdictions that are experiencing or are at risk for an increase in hepatitis infections or an HIV outbreak due to injection drug use as a key element of infectious disease prevention and as a way to identify and engage individuals in critical medical care, including substance use treatment.

Thank you your time and consideration of these requests. RWMPC, HIVMA, and I urge you to fully fund the Ryan White Program, including the Ryan White Part C Program, to effectively treat and prevent HIV infection and to optimize individual and public health outcomes, as well as maintain access to Federal funding for syringe access programs to help stem the tide of the opioid epidemic and its devastating impact on individuals and families nationwide.

[This statement was submitted by Ernie-Paul Barrette, MD, Medical Director, Barnes Jewish Hospital and Director, Ryan White HIV/AIDS clinic.]

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 2018 Budgets and matters for consideration for Health and Human Services and Education. Inasmuch as we do not have an fiscal year 2018 President's Budget on which we can speak, this testimony represents the level of need for programs identified. 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 to be reflected in the fiscal year 2018 Budget, 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.

³Centers for Disease Control and Prevention. Vital Signs: HIV and Injection Drug Use, November, 2016. Online at: <https://www.cdc.gov/vitalsigns/hiv-drug-use/index.html>.

⁴Reidhead, M. (2015, October). Alarming trends in hospital utilization for opioid overuse in Missouri. HIDI HealthStats. Missouri Hospital Association. Hospital Industry Data Institute. Online at <http://web.mhanet.com/hidi>.

⁵Reidhead, M. (2015, October). Alarming trends in hospital utilization for opioid overuse in Missouri. HIDI HealthStats. Missouri Hospital Association. Hospital Industry Data Institute. Online at <http://web.mhanet.com/hidi>.

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. EDUCATION REQUESTS

\$5 Million for the State-Tribal Education Partnership Program (STEP) Increase in Funding Directly to Education Departments to Leave 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.

\$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. ESSA’s authorization for fiscal year 2017 is \$15 billion. However, 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.

II. HEALTH AND HUMAN SERVICES REQUESTS

\$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 accounts for its success rate. Current funding dollars provide less for Native populations as inflation and fiscal constraints increase, even though research shows that there is a return of at least \$7 for every single dollar invested in Head Start. Congress should increase funds to Head Start and Early Head Start 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.

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 2018, we recommend the following:

—*Restore \$280 Million to Child Welfare Services Program.* Tribes need to have access to increased flexible Child Welfare Services Program funds for their child welfare programs. Of the 567 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.

- 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.
- 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.
- \$50 Million for Tribal Behavioral Health Program.* The Substance Abuse and Mental Health Administration (SAMHSA) funded Tribal Behavioral Health Grants (TBHG) at \$30 million in fiscal year 2016 (\$15 million for Mental Health and \$15 million for Substance Abuse Prevention). 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.

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.

Thank you for allowing me to submit these requests on these fiscal year 2018 Education and Health and Human Services Budgets.

[This statement was submitted by Hon. Kay Rhoads, Principal Chief, Sac And Fox Nation.]

PREPARED STATEMENT OF THE SCLERODERMA FOUNDATION

THE FOUNDATION'S FISCAL YEAR 2018 L–HHS APPROPRIATIONS RECOMMENDATIONS

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- \$7.8 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 2018 funding increase for CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP).
 - At least \$36 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 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 2018 L–HHS Appropriations Bill.

ABOUT SCLERODERMA

Scleroderma is a chronic connective tissue disease affecting approximately 300,000 Americans. The word "scleroderma" means hardening of the skin, which is one of the most visible manifestations of the condition. The cause of this progressive and potentially-fatal disease remains unknown, there is no cure, and treatment options are limited. Symptoms vary greatly and are dependent on which organ systems are impacted. Prompt diagnosis and treatment by a qualified physician may improve health outcomes and lessen the chance for irreversible damage. Serious complications of the disease can include: pain, skin ulcers, anemia, pulmonary hypertension, and disorders of the digestive system.

ABOUT THE FOUNDATION

The Scleroderma Foundation is the national organization for people with scleroderma and their families and friends. It was formed January 1, 1998, by a merger between the West Coast-based United Scleroderma Foundation and the East Coast-based Scleroderma Federation. 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.

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. Unfortunately, budgetary challenges at CDC have pushed the agency to focus resources on combating a narrow set of "winnable battles." 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 has worked 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 has recently formed 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.

ONE FAMILY'S STORY

Cheyenne Cogswell is an 8-year old third-grader living in the poverty-stricken town of Falmouth, Kentucky. Cheyenne was diagnosed at age six with a severe case of systemic scleroderma. The disease has caused kidney failure and significant damage to her digestive system, making it difficult for the body to receive the proper nutrition needed for a growing child. She has undergone several life-saving operations and numerous hospitalizations. Her skin and other internal organs, such as the heart and lungs, are also affected. Cheyenne's treatment first consisted of hospitalization and intense chemotherapy. She continues with daily chemotherapy injections, now given by her mother, to help suppress her immune system and slow the progression of the disease. Cheyenne is being raised by a single mother who has faced extreme consequences from the financial burden created by scleroderma, losing her job in the economic downturn, as well as the family's home. Doctors doubted if Cheyenne would survive beyond her seventh birthday, but she continues to beat the odds. Chronic diseases like scleroderma are unpredictable in their course, and

the family—together with their close circle of friends—continues to fight and hope for the best. Their road is uncertain and illustrates why funding for NIH and its research programs are vital to so many people whose lives are impacted by chronic illness such as scleroderma.

[This statement was submitted by Mr. Robert J. Riggs, Chief Executive Officer, Scleroderma Foundation.]

PREPARED STATEMENT OF THE SLEEP RESEARCH SOCIETY
FISCAL YEAR 2018 APPROPRIATIONS RECOMMENDATIONS

- SRS joins the broader medical research community in thanking Congress for providing a \$2 billion funding increase for NIH for fiscal year 2017 and in requesting a subsequent \$2 billion funding increase for fiscal year 2018 to bring NIH's budget up to \$36.1 billion (consistent with the necessary level of funding identified through the Cures effort).
- 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 Neurological Disorders and Stroke (NINDS); the National Institute of General Medical Science (NIGMS); the National Institute on Aging (NIA); and the National Institute of Mental Health (NIMH). Sleep and related research activities impact many conditions and nearly every body system and, as a result are studied across various Institutes and Centers at NIH.
- SRS joins the broader public health community in thanking Congress for providing the CDC with a modest funding increase for fiscal year 2017 and in requesting a subsequent increase of about \$550 million in fiscal year 2018 to bring CDC funding up to \$7.8 billion annually.
- Please provide proportional funding increases for the various Centers at CDC, including Chronic Disease Prevention and Health Promotion and promote stability in funding in regards to resources made available through the Prevention and Public Health Fund.

Chairman Blunt, Ranking Member Murray, and distinguished L–HHS Subcommittee members, thank you for considering the views of the Sleep Research Society as you begin work on fiscal year 2018 appropriations for NIH, CDC, and related sleep, sleep disorders, and circadian programs, including research training and career development activities for young investigators.

ABOUT THE SLEEP RESEARCH SOCIETY

SRS was established in 1961 by a group of scientists who shared a common goal to foster scientific investigations on all aspects of sleep 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.

ABOUT SLEEP DISORDERS

- 50–70 million Americans across all demographic groups chronically suffer from a sleep disorder; however, studies show that minority populations suffer at a disproportionate rate.
- Adults who do not get enough sleep on a regular basis are more likely to suffer from chronic conditions, including obesity, hypertension, diabetes, poor mental health, and injuries.
- Adults 18–60 years old need seven or more hours of sleep regularly per day for optimal health. Sleep-disordered breathing, including obstructive sleep apnea, is a detrimental condition affecting 15 percent of the population.
- Studies show that 85 percent of 725 troops returning home from Afghanistan and Iraq had a sleep disorder and the most common was obstructive sleep apnea (51 percent).

- Insufficient sleep impairs cognitive performance, which can increase the likelihood of motor vehicle and other transportation accidents, loss of work productivity, and medical errors.
- Each year, sleep disorders, sleep deprivation, and sleepiness add an estimated \$15.9 billion to the national healthcare bill.

NIH RESEARCH ACTIVITIES

Due to the central role of sleep to nearly every system of the body and the progression of various diseases and conditions, most NIH Institutes and Centers are involved in sleep research. Sleep related activities and programs across NIH are coordinated through the National Center on Sleep Disorders Research (NCSDR) housed within NHLBI. Annual \$2 billion funding increases for NIH are consistent with the funding plan for implementation of the “Cures” Act and such a meaningful infusion of discretionary funds across all Institutes and Centers will allow for a reinvigoration of NCSDR and implementation of critical research activities outlined in the 2011 Sleep Disorders Research Plan:

- Advance the understanding of sleep and circadian functions and of basic sleep and circadian mechanisms, in both the brain and the body, across the lifespan.
- Identify genetic, pathophysiological, environmental, cultural, lifestyle factors, and sex and gender differences contributing to the risk of sleep and circadian disorders and disturbances, and their role in the development and pathogenesis of co-morbid diseases and disability.
- Improve prevention, diagnosis, and treatment of sleep and circadian disorders, chronic sleep deficiency, and circadian disruption, and evaluate the resulting impact on human health.
- Enhance the translation and dissemination of sleep and circadian research findings and concepts to improve healthcare, inform public policy, and increase community awareness to enhance human health.
- Enable sleep and circadian research training to inform science in cross-cutting domains, accelerate the pace of discovery, and the translation of enhanced therapies from bench to bedside to community.

The emerging Precision Medicine Initiative also holds notable opportunities for scientific advancement related to sleep research, particularly related to phenotyping. Ensuring adequate support for this program consistent with the funding identified in the “Cures” Act would allow emerging activities to move forward.

Finally, NIH support critical research training and career development activities for young investigators. This ensures the next generation of scientists is adequately prepared and that the pipeline is robust. Meaningful funding increases are needed to reduce the troubling pay-lines and rising age of investigators that receive their first grant, which undermines the field.

CDC PUBLIC HEALTH ACTIVITIES

CDC gathers important data on sleep disorders through their surveillance efforts under the Chronic Disease Prevention and Health Promotion program. More specifically, CDC engages in the National Healthy Sleep Awareness Project which conducts research on prevalence and incidence of sleep disorders, and raises awareness on the importance of healthy sleep through the production of State fact sheets, updating the CDC website, and disseminating information on sleep related topics. Currently population-based data on the prevalence of circadian disruption and its relationship to disease risk is relatively limited. Please fund CDC at \$7.8 billion including an express ongoing support for funding sleep awareness and surveillance activities within the Chronic Disease Prevention and Health Promotion program, so that progress can continue in the areas of sleep disorders and disturbances, sleep awareness, and education to the public community.

TIMELY APPEAL

Recent fiscal year 2016 and fiscal year 2017 investments in NIH are already demonstrating progress in key areas of disease progression and health promotion. These gains would be undone though if deep funding cuts proposed by the administration were adopted (or any funding cuts). At this crucial time, please continue the investment in important and valuable medical research and public health activities.

Thank you for your time and your consideration of this request.

[This statement was submitted by Sean P.A. Drummond, Ph.D., Sleep Research Society.]

PREPARED STATEMENT OF THE SOCIETY FOR NEUROSCIENCE

Mr. Chairman and members of the Subcommittee, I am Eric Nestler and it is my honor to present this testimony in strong support of a \$2 billion increase in funding for the National Institutes of Health (NIH) for fiscal year 2018. I am offering this testimony in my capacity as President of the Society for Neuroscience (SfN). I am the Dean for Academic and Scientific Affairs at the Icahn School of Medicine at Mount Sinai, where I am also the Director of the Friedman Brain Institute and professor of neuroscience, pharmacological sciences, and psychiatry. My laboratory studies the molecular mechanisms of drug addiction and depression in animal models—a critical topic given the current crisis around opioid addiction across the U.S. and stress-related disorders and suicide among our Nation's Veterans.

SfN believes strongly in the research continuum. Basic science leads to clinical innovations, which lead to treatment advances that impact the public's health. Basic science is the foundation upon which all health advances are built. The Society stands with many others in the biomedical research community in support of an increase in NIH funding of not less than \$2.0 billion above the fiscal year 2017 level, supplemented (not supplanted) by releasing the full funding for the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative in the 21st Century Cures Act that passed Congress with overwhelming bipartisan support.

We commend this Committee for your leadership in passing a bipartisan, bicameral fiscal year 2017 Omnibus Appropriations package and urge you to build upon this success by enacting a \$2.0 billion increase for NIH in the fiscal year 2018 budget this year. The commitment of Congress to sustained, robust funding for NIH maximizes the impact of every dollar appropriated and is the fastest way to move from discoveries to treatments and cures.

SfN counts nearly 37,000 members world-wide, most of whom are U.S.-based scientists, teachers, and clinicians. We are dedicated to advancing the understanding of the brain and spinal cord. That is why we are deeply appreciative of Congress's efforts in fiscal year 2016, which broke a streak of nearly 13 years where funding failed to keep pace with the annual rate of biomedical research inflation. During these years there was a nearly 25 percent loss of purchasing power of NIH-funded science throughout the U.S. Now, it is critical to maintain the new pace in the fiscal year 2018 bills you are now formulating.

We are also grateful for your support of the BRAIN Initiative. While only one part of the research landscape in neuroscience, BRAIN has been critical in promoting future discoveries across neuroscience and related scientific disciplines (see an example below). By including part of the funding in 21st Century Cures—and note that it is only part of the annual funding that BRAIN will require—Congress helped maintain the momentum of this endeavor. Please remember, however, using those funds to supplant regular appropriations would be counterproductive. There is no substitute for robust, sustained, and predictable funding for NIH.

The deeper our grasp of basic science, the more successful those focused on clinical and translational research will be. We use a wide-range of experimental and animal models that are not used elsewhere in the research pipeline. These opportunities create discoveries—oftentimes unexpected discoveries—that expand knowledge of biological processes at the molecular, cellular, and brain circuit levels. These levels of discovery reveal new targets for research to treat brain disorders of all kinds that affect nearly a billion people worldwide.

As the leading scientific society dealing with the brain and nervous system, SfN hosts one of the largest annual scientific meetings and publishes two highly-rated scientific journals. We are also committed to educating the public about healthy and unhealthy brains and, of course, engage policymakers regarding the tremendous progress we have made and the potential that lies ahead for brain research. Some recent, exciting advancements include the following.

THE IMPACTS OF NEUROSCIENCE RESEARCH

Understanding the Relationship Between Genes and the Brain

My own NIH-funded research investigates the links between neuropsychiatric disorders and the changes in gene expression that occur over a lifetime (epigenetics). These epigenetic changes can be influenced by life experiences, including exposure to stress, drugs of addiction and natural factors like hormone cycles. My lab seeks to understand how these epigenetic mechanisms lead to life-long changes in brain function in disorders such as depression and drug addiction, and provide new routes of investigation for possible treatment. For example, my work looks at how the regulation of key genes in single brain regions affect the expression of a network of other genes, which underlie an individual's susceptibility versus resilience in neuropsychiatric disorders. In particular, we study how gene regulation changes

susceptibility in response to chronic stress or drug exposure in mice and depression or addiction in humans. In identifying new molecular and genetic mechanisms that underlie these complicated disorders, we are now working to advance these discoveries into new and more effective treatments.

Recording the Brain Without Damage

The BRAIN Initiative, now in its fourth year, continues to bring together researchers from the life sciences, physical sciences and engineering to create new tools and technologies that allow neuroscientists to expand our understanding of the brain and nervous system. One BRAIN Initiative project produced a flexible and ultrathin electrode grid (NeuroGrid) that records the activity of single neurons on the surface of the human brain without damaging the brain itself. In addition to NeuroGrid's potential use in clinical settings, such as determining areas of the brain causing severe epilepsy, it is also a powerful tool for more basic research.

Because the NeuroGrid causes no damage to the brain, it can record in areas, such as those involved with language, where even the most minor lesion could lead to a loss of function. NeuroGrid is a critical tool for understanding the connections between neuronal activity and human behavior, one of the seven key principles that underlie the BRAIN Initiative.

Identifying Individual Cell Signatures

While neuroscientists often think of the brain in terms of groups and networks of neurons and non-neuronal cells working together, NIH's Single Cell Analysis Program takes a different approach. The Program funds research investigating individual cells and cell types to understand how these cells affect everything from response to disease treatments to their function in a larger network. In this program, researchers have been able to create long-lived, healthy cell cultures of human brain tissue. Scientists then analyzed these cultured brain cells to determine their cell type, and were even able to find epigenetic effects of medications taken by the patients from which the samples originated. In addition to providing information about the unique properties of the tens of thousands of cell types that make up the human nervous system, this technique also provides a new and powerful model for testing the molecular and epigenetic effects of drug treatments, and for understanding how these different cell types interact to form the basis of the functioning human brain in health and disease.

THE IMPACT OF NEUROSCIENCE INVESTMENT

In addition to physical health, there is a significant impact of this research on the economic health of our communities and Nation as well. Funding for NIH supports roughly 400,000 jobs and \$58 billion in economic activity throughout the fifty States. As you may know, nearly 83 percent of NIH's budget goes directly to universities, research institutes, and hospitals. Another 9 percent funds cutting edge research by NIH's world class scientists.

Congress's commitment to fund basic and translational neuroscience created the essential foundation for developing a deep and thorough understanding to address diseases that strike more than 100 million Americans every year, more than a quarter of our population. Perhaps the most frightening number to consider, however, is \$760 billion. This is the current estimate of the economic impact on American families and the economy of neuro-related diseases. This number will only grow into the trillions as our population ages in the years ahead, unless we act.

The U.S. has long been the world leader in biomedical research related to neuroscience and many other fields. But other nations, particularly in Asia and Europe, are investing heavily to catch up with—and pass—us in the near future. Much of the research done at NIH cannot be accomplished in the private sector or with philanthropic support. 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 the future will see progress in the development of cures, treatments, and methods of prevention that will assure a better, healthier future for all Americans.

On behalf of the scientists and physicians of the Society for Neuroscience, we thank this Subcommittee for its past support and we look forward to working with you in the months and years ahead to provide health and economic benefits to your constituents. The opportunity to create previously unimaginable progress is knocking at our door. We just need the courage and the wisdom to answer it, welcome it, and implement it with great foresight.

[This statement was submitted by Eric J. Nestler, MD, PhD, President, Society for Neuroscience.]

PREPARED STATEMENT OF THE SOCIETY OF NUCLEAR MEDICINE AND
MOLECULAR IMAGING

The Society of Nuclear Medicine and Molecular Imaging (SNMMI), headquartered in Reston, Va., is a nonprofit scientific and professional organization that promotes the science, technology and practical application of nuclear medicine and molecular imaging. SNMMI strives to be a leader in unifying, advancing and optimizing molecular imaging, with an ultimate goal of improving human health. With 18,000 members worldwide, SNMMI represents nuclear and molecular imaging professionals, all of whom are committed to the advancement of the field.

We thank you for increasing the National Institutes of Health (NIH) budget and to encourage you to do the same in 2018. We recommend that the NIH be funded at the level recommended by the Ad Hoc Group for Medical Research—a coalition of more than 300 patient and voluntary health groups, medical and scientific societies, academic and research organizations, and industry. The coalition recommends that NIH be funded at \$2 billion more than its 2017 level in addition to funds included in the 21st Century Cures Act for targeted initiatives.

As the President noted in his Joint Address to Congress millions of Americans in every community await new or improved treatments and diagnostics for a wide range of diseases. Medical research supported by the NIH plays an irreplaceable role in achieving their hopes of a healthier future. For this reason, the investment in NIH has long been prioritized by leaders of both parties as a key responsibility for the Federal Government.

The National Institute of Biomedical Imaging and Bioengineering (NIBIB) is funding studies using advanced imaging techniques and radiopharmaceuticals has advanced the diagnoses and treatment of imaging patients should continue to be supported. NIBIB funding has also supported local and regional economies by creating jobs and catalyzing new industries. For decades, the Federal commitment to scientific discovery has strengthened our country's competitiveness as the leader in healthcare research.

Thank you for your time and consideration.

[This statement was submitted by Sally Schwarz, President, Society of Nuclear Medicine and Molecular Imaging.]

PREPARED STATEMENT OF SOLVE ME/CFS INITIATIVE

Dear Chairman Blunt and Ranking Member Murray,

On behalf of the Solve ME/CFS Initiative (SMCI) and as a patient with myalgic encephalomyelitis (ME), I am writing to applaud your leadership at today's hearing to examine treatments and services in America's mental healthcare system. One area in particular that I request you further examine is the current Center for Disease Control (CDC) recommendations including Cognitive Behavioral Therapy (CBT) and Graded Exercise Therapy (GET) for patients with myalgic encephalomyelitis (ME), commonly known as chronic fatigue syndrome (CFS) which is a biological illness yet misdirected into mental health.

ME/CFS is a complex disease with an array of debilitating symptoms including extreme exhaustion, orthostatic intolerance, unrefreshing sleep, memory loss, joint pain, inflamed lymph nodes, severe headache, sore throat, neurological abnormalities, and even complete organ system shutdown. The cause of ME/CFS is unknown, and there is no existing cure nor FDA-approved treatment for the disease. It is estimated that the burden of ME/CFS costs our economy up to \$24 billion a year.

I bring these items to your attention because "many healthcare providers are skeptical about the seriousness of ME/CFS and mistake it for a mental health condition,"¹ despite definitive scientific evidence that ME/CFS is a biological disease. In 2006, Dr. Anthony Komaroff, a senior physician at Brigham and Women's Hospital and professor of medicine at Harvard Medical School observed:

"There are now over 4,000 published studies that show underlying biological abnormalities in patients with this illness (ME/CFS). It's not an illness that people

¹"Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness," Institute of Medicine of the National Academies Final report brief, May 2015, http://www.nationalacademies.org/hmd/-/media/Files/Report%20Files/2015/ME/CFS/ME/CFS_ReportBrief.pdf.

can simply imagine that they have and it's not a psychological illness. In my view, that debate, which was waged for 20 years, should now be over."²

Yet over 10 years later, practicing physicians and even information provided by government agencies misdirects patients with ME/CFS into the mental healthcare system.

The CDC website recommends treatment options for this illness including Cognitive Behavioral Therapy (CBT), despite numerous concerns expressed by the patient and medical communities. While we are encouraged by the CDC's efforts (such as the technical development working group) to address these concerns, these inappropriate CBT references persist even after the Agency for Healthcare Research and Quality (AHRQ) downgraded CBT in an addendum published in July 2016.³

As a result of this information being communicated by the CDC, between 1 million and 2.5 million patients⁴ with ME/CFS are being encouraged to seek mental health treatment options that are unlikely to assist their condition and could even potentially cause harm. This influx of misdirected patients creates additional strain on our mental healthcare system which is already struggling to accommodate patient needs. It would save our country billions of dollars if patients with ME/CFS were correctly and promptly diagnosed by fully-educated medical professionals and directed into appropriate and robust systems of care instead of into our heavily impacted mental healthcare system.

As you examine the treatments and services available in the American mental healthcare system today, please keep in mind the patients with ME/CFS and how a small correction at the CDC can ease the burden on our existing mental healthcare treatment system.

I hope this information and insight into the lives of those with ME/CFS has been helpful. Please feel free to contact myself or my staff if have any questions or if there is any additional information we can provide. I look forward to continuing to work with you and your colleagues to improve the lives of patients with ME/CFS in the future.

Sincerely,

[This statement was submitted by Carol Head, President & CEO, Solve ME/CFS Initiative.]

PREPARED STATEMENT OF THE STUDENT SUPPORT AND
ACADEMIC ENRICHMENT GRANT PROGRAM

The undersigned organizations on behalf of the Title IV, A Coalition 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 2018, is the result of Congress' decision to consolidate more than 20 existing programs, most of which were competitive, into a single formula-funded flexible block grant program that has the potential to benefit millions of students by allowing districts to choose how to spend their dollars to support safe and healthy schools, well-rounded education, and the effective use of technology. The critical education programs meant to be supported by SSAE funds include: 1) safe and healthy students activities, such as providing mental health services to students; 2) increasing student access to STEM, computer science and accelerated learning courses, physical education, the arts, music, foreign languages, and college and career counseling; funds for an effective school library program; and, 3) providing students with access to technology and digital materials and educators with technology professional development opportunities.

We strongly urge Congress to fully fund the SSAE program in fiscal year 2018, as the fiscal year 2017 allocation of only \$400 million is wholly inadequate to provide the flexibility at the local level or to run the program as Congress intended. Funding this program at less than 25 percent of its authorized level in its first year

²Professor Anthony Komaroff, MD. "Chronic Fatigue Syndrome Awareness Campaign." Center for Disease Control Press Briefing, November 3, 2006, The National Press Club, Washington DC, Press Conference.

³"Diagnosis and Treatment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome" Agency for Healthcare Research and Quality Evidence Report/Technology Assessment #219, Addendum July 2016.

⁴"Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness," Institute of Medicine of the National Academies Final report brief, May 2015, http://www.nationalacademies.org/hmd/~/media/Files/Report%20Files/2015/ME/CFS/ME/CFS_ReportBrief.pdf.

has already presented serious implementation issues, including the need to allow States to allocate funds to districts competitively, contrary to what is authorized in ESSA. States electing to run a competition will incur significant burdens as they grapple with creating, initiating, and judging a competition. Altering the structure of the program in this manner also negates the Congressional intent of increasing access to SSAE programs for all students and instead is likely to continue to benefit those districts already adept at winning competitive grants.

As a result of the low funding and the confusion around a competition, we are deeply concerned that many States might ignore the competitive option altogether and choose to allocate the money by formula for the sake of ease and fairness to all districts. While our groups ultimately want these dollars to go to every district, electing to distribute the money by formula at this low funding level has its own potentially negative consequences. For instance, many States or districts might choose to simply transfer the dollars for another purpose, as the amounts received by formula may simply not be enough to make meaningful investments in these areas, thereby leaving districts with no Federal funds to support Title IVA's abovementioned activities.

In addition to the financial challenges of such a low funding level, the amount allocated for SSAE does not allow States and districts to make meaningful investments in a range of programs that, when combined, improve conditions for learning and help students receive a well-rounded education. It will force school districts to choose between high- quality programs that positively impact students in different ways—trading off school counseling services for Advanced Placement programs, for instance, thereby jeopardizing the greater flexibility for districts and schools that Congress intended.

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 2018 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,

AASA, The School Superintendents Association	National
Action for Healthy Kids (AFHK)	National
Advance CTE	National
AESA	National
Alliance for Excellent Education	National
American Association of School Librarians	National
American Council on the Teaching of Foreign Languages	National
American Counseling Association	National
American Dance Therapy Association	National
American Federation of School Administrators	National
American Heart Association	National
American Music Therapy Association	National
American School Counselor Association	National
ASCD	National
Association of School Business Officials	National
Campaign for the Civic Mission of Schools	National
Campaign for the Civic Mission of Schools	National
Coalition for Community Schools	National
Collaborative for Academic, Social, and Emotional Learning (CASEL)	National
College in High School Alliance	National
Committee for Children	National
Committee for Children	National
Communities In Schools	National
CoSN	National
Council of Administrators of Special Education	National
Edgenuity	National
Girl Scouts of the USA	National
In Reach, Inc.	National
International ACAC	National/International
International Society for Technology in Education (ISTE)	National
Jobs for the Future	National
Learning Disabilities Association of America	National
MACUL	National & Michigan
Music for All, Inc.	National
National Alliance of Concurrent Enrollment Partnerships	National
National Association for College Admission Counseling	National

National Association for Music Education (NAfME)	National
National Association of Elementary School Principals (NAESP)	National
National Association of School Nurses	National
National Association of School Psychologists	National
National Association of Secondary School Principals (NASSP)	National
National Association of State Directors of Special Education (NASDSE)	National
National Center for Learning Disabilities	National
National Center for Technological Literacy at the Museum of Science, Boston	National
National Center for Technological Literacy at the Museum of Science, Boston	National
National Council of Teachers of Mathematics	National
National Interscholastic Athletic Administrators Assoc. (NIAAA)	National
National PTA	National
National Rural Education Association	National
National Science Teachers Association	National
National Summer Learning Association	National
Noodle Markets	National
Organization of American Kodály Educators	National
Recording Academy	National
Safe Routes to School National Partnership	National
School Social Work Association of America	National
SETDA	National
SHAPE America—Society of Health and Physical Educators	National
Society for Public Health Education	National
Software & Information Industry Association	National
STEM Education Coalition	National
STEM LA3—Girls Collaborative Project	National
Students4STEM	National
Trust for America’s Health	National
Alabama Educational Technology Association (AETA—ISTE Affiliate)	Alabama
Pacific Northwest Association of College Admission Counseling (PNACAC)	Alaska, Idaho, Montana, Oregon, & Washington
Arizona Association of School Psychologists	Arizona
RMACAC	Arizona, Colorado, New Mexico, Utah, and Wyoming
California Association of School Psychologists	California
California Educational Technology Professionals Association	California
The Joyful Child Foundation	California
The Joyful Child Foundation	California
Winters Joint Unified School District	California
CUE	California, Nevada
Canon City School District Fremont RE-1	Colorado
Colorado Society of School Psychologists	Colorado
Garfield County School District 16	Colorado
Innovative Education Colorado (InnEdCO) (ISTE)	Colorado
Pikes Peak BOCES	Colorado
Delaware Association of School Psychologists (DASP)	Delaware
Delaware Association of School Psychologists (DASP)	Delaware
Florida Association of School Psychologists	Florida
Georgia K–12 CTO Chapter of CoSN	Georgia
Illinois Association for College Admission Counseling	Illinois
Illinois School Psychologist Association	Illinois
Westfield Washington Schools	Indiana
Indiana Connected Educators	Indiana
Kentucky Association for Psychology in the Schools	Kentucky
LACUE (ISTE Affiliate)	Louisiana
Louisiana Association of Computer Using Educators	Louisiana
Kent County Public Schools	Maryland
Maryland Society for Educational Technology (MSEA)	Maryland
MassMEA	Massachusetts
Michigan Association for College Admission Counseling	Michigan
Michigan Music Education Association	Michigan
Missouri Association of School Psychologists	Missouri
Montana Educational Technologists Association	Montana
JML Strategy—Montana Afterschool Alliance	Montana
Montana Education Partnership	Montana
Nebraska School Psychologists Association	Nebraska
Nevada Association of School Psychologists (NVASP)	Nevada

New England Association of College Admissions Counselors	New England
New Hampshire Music Educators Association	New Hampshire
New Hampshire Society for Technology in Education (NHSTE)	New Hampshire
NHCTO Council	New Hampshire
School Administrative Unit #6	New Hampshire
New Jersey Association of School Psychologists	New Jersey
NJMEA	New Jersey
Albuquerque Public Schools	New Mexico
Explora	New Mexico
New York State Association for Computers and Technologies in Education	New York
New York State Association for Computers and Technologies in Education (NYSCATE)	New York
New York State School Music Association	New York
New York State Association for College Admission Counseling	New York State
North Carolina CoSN	North Carolina
North Dakota Music Educator's Association	North Dakota
Ohio Music Education Association	Ohio
Salem Keizer Education Foundation	Oregon
Association of School Psychologists of Pennsylvania	Pennsylvania
Marine Advanced Technology Education (MATE) PA	Pennsylvania
Parkland School District	Pennsylvania
Progressive Music	Pennsylvania
PAECT	Pennsylvania
Southern Association for College Admission Counseling (SACAC)	Regional
RISTE	Rhode Island
South Dakota Music Education Association	South Dakota
The Fitting Room Educational Media Corporation	State
TETA—Tennessee Educational Technology Association	Tennessee
Texas K–12 CTO Council	Texas
Virginia Society for Technology in Education (VSTE)	Virginia
Washington Music Educators Association	Washington
Washington Music Educators Association (WMEA)	Wisconsin
WEMTA Wisconsin Educational Media & Technology Association	Wisconsin
Wisconsin Educational Technology Leaders (CoSN)	Wisconsin
Wisconsin Music Educators Association	Wisconsin
Wyoming School Psychology Association	Wyoming

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 2018. The Centers for Disease Control and Prevention (CDC) play a pivotal role in educating the public. To that end, the Tourette Syndrome Public Health Education and Research Program at the CDC is critically important to the TS and Tic Disorder community. We respectfully request that you continue funding the \$2 million appropriation for the program in the fiscal year 2018 Labor, Health and Human Services (LHHS), Education and Related Agencies Appropriations. The program on Tourette Syndrome is administered within the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the CDC, in partnership with the TAA. This program was established by Congress in the Children's Health Act of 2000 (PL 106–310 Title 23) and is the only such program that receives Federal funding for Tourette Syndrome. 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 treatment for Tourette Syndrome and Tic Disorders.

The TAA is the premier national non-profit organization working to make life better for all people affected by Tourette and Tic Disorders. We have served in this capacity for 45 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 many 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 that roughly 50 percent

of children and teens with Tourette Syndrome are not diagnosed. Studies that included children with undiagnosed TS and children with diagnosed TS have estimated that 1 out of every 162 children (0.6 percent) have TS. These numbers do not include children with Chronic or Provisional Tic Disorders. 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. Diagnosis is often complicated by the fact that among children diagnosed with TS, 86 percent also have been diagnosed with at least one additional mental, behavioral, or developmental condition according to the CDC website. These co-occurring conditions include Attention Deficit-Hyperactivity Disorder (ADHD), Obsessive Compulsive Disorder (OCD), Autism, Oppositional Defiance Disorder, anxiety, depression and learning difficulties. Primary care, family physicians and pediatricians do not learn a significant amount about TS and Tic Disorders in medical school so consequently may diagnose the co-occurring condition(s) and not the TS or Tic Disorder. Pediatric neurologists study significantly more about TS and Tic Disorders in their specialized training. The CDC TS Program works to ensure these 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. 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, educators can refer students for assessment by their physician or a pediatric neurologist for potential diagnosis and treatment. This will allow these medical providers to work with the educators to develop individualized education plans for the child to accommodate the TS and Tic Disorders.

Delayed diagnosis or the lack of diagnosis can increase healthcare costs with additional doctors visits and assessments, can increase education costs and can delay important treatment and therapy for the patient. The CDC Tourette Syndrome Public Health, Education and Research Program strives to increase the understanding and awareness of TS among these critically important medical and education professionals to increase the percentage of school aged children with TS who are diagnosed and improve the timeframe from symptoms to diagnosis.

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 educates the public and parents of newly diagnosed patients on Tourette Syndrome and Tic Disorders to ensure a better understanding which can lead to better diagnosis and earlier treatment.

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 2018 for the Tourette Syndrome Public Health Education and Research Program at CDC's NCBDDD at the previously enacted level of \$2 million.

PREPARED STATEMENT OF TRiO STUDENT SUPPORT SERVICES

From 2009 to 2016 I worked for the TRiO Student Support Services program at University of Wisconsin—Superior. UW-Superior is fortunate to host three TRiO programs: Upward Bound, Student Support Services, and the McNair program.

UW-Superior is the only public 4 year university in northern Wisconsin, and serves an area that has been economically depressed for decades. In 2011 when Governor Scott Walker enacted Act 10 he set off a cascading series of administrative changes and budget realignments that undermined the UW system's ability to serve its students. Over the next 5 years UW-Superior programs were cut, positions went unfilled, and faculty and staff morale plummeted. The secure funding of the UW-

Superior TRiO programs made them a refuge for at-risk students in the turbulent environment. So many UWS students qualify for these services the appropriate reaction would be to expand them.

At UWS we considered Upward Bound, Student Support Services, and McNair to be our academic pipeline from high school to graduate school. Our offices worked in concert to ensure that students from low income backgrounds, with disabilities, and the first in their families to attend college received the advocacy and guidance they needed to succeed in their education.

The desire to eliminate TRiO programming wholesale is a slap in the face to the most vulnerable of American students. These students often times are unsure if they deserve an education. To eliminate programs like McNair and EOC is a crude insult to these students. If Secretary DeVos and those of her persuasion are not, in fact, out to intentionally undermine the ability of at-risk students to improve their circumstances, then she (and they) are doing everything in their power to make it look as if they are.

I've seen first generation college students from poverty stricken backgrounds show me their acceptance letters to graduate school with tears in their eyes. I've watched rooms full of parents beaming with pride to watch the first person in their family gain a 4-year degree. I've read cutting edge research from McNair Scholars that would never have been produced without the encouragement and support that McNair provided them. I have seen these same students crying in my office because they did not have \$40 for a textbook. I once helped an evicted, homeless, disabled, senior citizen, Native American student find a tutor to help her with the classes she never stopped attending. I would have happily introduced this student to Representative Sean Duffy, whose office was across the street from UW-Superior, but he declined the offer to celebrate TRiO Program with us. Seven years in a row.

Eliminating TRiO programming is obscene. It is an inexpensive program that does immeasurable good. TRiO works.

Sincerely,

[This statement was submitted by Dr. Jess A. McCullough, TRiO Student Support Services.]

PREPARED STATEMENT OF TRUST FOR AMERICA'S HEALTH

Thank you Chairman Blunt and Ranking Member Murray for the opportunity to submit testimony on behalf of Trust for America's Health, a nonprofit, nonpartisan organization dedicated to saving lives by working to make the prevention of illness and injury a national priority. I am honored to have the opportunity to highlight the importance of investing in prevention and public health programs at the Department of Health and Human Services in the fiscal year 2018 Labor-Health and Human Services-Education appropriations bill.

Every American should have the opportunity to be as healthy as he or she can be. Every community should be safe from harmful threats to its residents, and all individuals and families should have services that protect and support their health, regardless of who they are or where they live. But right now, communities across the country face serious, ongoing health problems. In the past decade there has been a significant increase in death rates among middle-aged White men and women (ages 45 to 54), and death rates remain significantly higher among Blacks and other people of color. Key contributing factors are drug overdose, liver disease, suicide, and chronic conditions such as heart disease and diabetes—all conditions that are preventable if we prioritize stronger prevention and public health efforts.

Public health departments are on the front lines, charged with protecting citizens from health threats like these. Unfortunately, the Nation's public health efforts have been chronically underfunded for decades, leaving Americans unnecessarily vulnerable to preventable health problems, ranging from major infectious disease outbreaks and bioterrorism threats to diabetes to opioid misuse. The United States spends \$3.36 trillion annually on health, but only 3 percent of that spending is directed to public health. That equates to an average of around \$255 per person. By contrast, total healthcare spending is \$10,345 per person.

The Centers for Disease Control and Prevention (CDC) is the world authority for public health and the Nation's first defense against epidemics, but its funding has remained relatively flat for several years. Adjusting for inflation, CDC's budget has actually declined by more than 15 percent (more than \$1.5 billion) over the past decade. The fiscal year 2018 President's budget would dramatically worsen this problem, with a proposed \$1.2 billion cut to the CDC that would be perilous for the health of the American people. The budget proposes enormous cuts throughout the agency, including to programs that protect the American people from infectious dis-

eases, environmental contaminants, exposure to tobacco and much more. If these budget cuts were to occur, they would cripple CDC's operations and result in increased illnesses, injuries and preventable deaths.

Additionally, the American Health Care Act (ACHA, H.R. 1628) would further exacerbate these budget cuts by repealing the Prevention and Public Health Fund (Prevention Fund). In the current fiscal year, 20 percent of CDC's budget (\$890 million) comes from the Prevention Fund. Of that investment, \$625 million directly supports State and local public health efforts. Among the essential public health activities supported directly by the Prevention Fund are grants to States for infectious disease control, the Preventive Health and Health Services Block Grant, which allows States to address their most pressing health threats, the 317 immunization program, tobacco cessation and other core public health programs. Eliminating this funding without a plan to replace that loss to the CDC's budget combined with the cuts proposed in the President's budget would decimate public health in every State and lead to an unprecedented elimination of public health and prevention activities that save lives every day. I urge you to work with your colleagues on the authorizing committees to avoid the dire consequences that would come with elimination of critical public health funding.

CDC's core budget supports a wide range of essential public health programs to improve health, prevent diseases and injuries, and prepare for major health emergencies. The combined impact of the proposed \$1.2 billion fiscal year 2018 budget cut and the AHCA's \$890 million cut would put all of that at risk. It is important to note that approximately 75 percent of CDC's budget is distributed to your States and districts in the form of grants and contracts to State and local public health departments and community partners to support critical services and programs.

Millions of Americans become unnecessarily sick or die every year from infectious diseases, which cost more than \$120 billion a year. Every day, public health and healthcare must respond to foodborne outbreaks, outbreaks of vaccine-preventable illnesses like measles and mumps and the flu. In addition, we have seen an increase in the number of emergencies due to new infectious diseases and other threats to the public's health. Last year we saw State and local public health departments struggle to respond to the Zika virus; the year before we faced an Ebola epidemic. And every year there are natural disasters, extreme weather events, and manmade events like terror attacks.

Preparedness for these events requires a steady, reliable funding stream—cities and States cannot hire and train staff overnight after a crisis happens. CDC-supported Public Health Emergency Preparedness (PHEP) cooperative agreements provide grants to every State to develop and maintain core capabilities to respond to emergencies. These investments have saved lives, and mean that communities can often respond to an emergency without additional help from the Federal Government. Congress has provided short-term emergency funding to address the Ebola and Zika outbreaks and that funding has already or will soon expire, although the threats do not. We must build and maintain long-term capacity to address emerging and reemerging health threats and to prevent a manageable threat from becoming a major disaster.

A sustained investment in public health and prevention is also essential to reduce high rates of disease and to improve health in the United States. Chronic diseases such as cancer, diabetes, lung disease, heart disease and stroke, are responsible for seven out of 10 deaths and cost \$1.3 trillion in treatment costs and lost productivity every year. More than one-third of adults and 17 percent of children are obese, putting them at increased risk for a range of health problems. Obesity costs the country \$147 billion in direct healthcare costs each year.

Tobacco remains the leading cause of preventable death, costing \$170 billion in preventable health costs. And teenagers are increasingly using new tobacco products which increase their likelihood of nicotine addiction. We are concerned that the President's budget would eliminate funding from CDC's Office on Smoking and Health (OSH), which coordinates surveillance, laboratory, and evaluation activities related to tobacco use and its effect on health. OSH also educates the public about the harms of tobacco use, most notably through the successful Tips from Former Smokers campaign. Since 2012, Tips has helped at least 5 million Americans attempt to quit smoking, while at least 400,000 smokers have quit for good. Funding for tobacco cessation and quitline services in all 50 States, the District of Columbia, and two territories would also be jeopardized.

There is a growing evidence base that demonstrates that the majority of chronic disease is preventable by addressing common risk factors. In recent years, the CDC's Division of Nutrition, Physical Activity, and Obesity has granted 4-year cooperative agreements (known as the State Public Health Actions to Prevent and Control Diabetes, Heart Disease, Obesity, and Associated Risk Factors and School

Health), to all 50 State health departments and the District of Columbia. However, due to limited funding, only 32 States are currently funded to deploy enhanced strategies, including those related to obesity prevention. This Division also supports the Good Health and Wellness in Indian Country program, which currently supports 12 American Indian tribes and 11 Tribal Organizations in their efforts to address chronic diseases, including mental health, suicide and substance abuse.

This Division supports set-aside funding for high-obesity rate counties, with obesity rates higher than 40 percent, funding programs via land grant universities and colleges in dozens of counties across 11 States. We appreciate the increase you provided in fiscal year 2016, which allowed CDC to expand support to five existing and two additional grantees in Louisiana and Arkansas. But the need outweighs the funding level—only one quarter of eligible counties (33 of 135 counties) in less than half of States (11 of 17 States with eligible counties) have received grants.

To turn to another public health epidemic, around 21 million Americans are struggling with a substance use disorder, which is contributing to rising death rates among middle-aged White Americans, which I mentioned earlier. More than 2 million people have a prescription painkiller dependence, which has contributed to a related rise in heroin use. According to the CDC, 45 percent of people who used heroin were also addicted to prescription painkillers. Overall, misuse of prescription painkillers contributed to more than 14,000 deaths in 2014, and deaths from heroin more than tripled from 2010 to 2015. We need an integrated and balanced strategy to address both chronic pain and substance use disorder, and the CDC, SAMHSA, NIH and a range of other agencies have a role to play. We urge you to provide adequate funding to the CDC to promote prevention and early intervention programs; to fully disseminate safe prescribing guidelines; ensure patients with prescription drug misuse disorder have access to treatment they need to turn their lives around; strengthen Prescription Drug Monitoring Programs (PDMPs) so that they are real-time and can communicate across State lines; expand access to “rescue drugs” such as Naloxone; and increase safe storage and take-back programs.

Finally, I want to express our concern that the President’s budget proposes a more than 16 percent cut to CDC’s National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP), which prioritizes cost-effective programs and policies to reduce some of the Nation’s most dangerous and costly infections. About 85 percent of NCHHSTP’s budget supports extramural funding, so State and local health departments and community-based organizations will face devastating cuts to their ability to detect and fight these diseases. The opioid epidemic has made these programs especially crucial, as the crisis has fueled a nationwide epidemic of viral hepatitis and HIV—in fact new hepatitis C infections nearly tripled over 5 years.

America’s economic well-being is inextricably tied to the health of its communities and people. Keeping Americans healthier would significantly drive down trips to the doctor’s office or emergency room, reduce healthcare costs, and improve overall productivity. Public health funding is already insufficient to meet existing needs, and public health departments struggle every time a new epidemic emerges. Without a strong investment in prevention, the country will never advance in the fight to prevent diseases and curb epidemics. Achieving a healthier Nation is a goal all Americans share—and greater investment in the Nation’s public health system is a sound and powerful approach. Thank you.

[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 2018 RECOMMENDATIONS

-
- Provide \$36 billion for the National Institutes of Health (NIH)
 - Support the NIH hereditary angioedema research portfolio
 - Encourage the Centers for Disease Control and Prevention (CDC) to advance hereditary angioedema education and awareness
-

Thank you for the opportunity to present the views of the U.S. Hereditary Angioedema Association (U.S. HAEA) regarding fiscal year 2018 funding for the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC). On behalf of U.S. HAEA, I urge Congress to support hereditary angioedema research and public awareness.

U.S. HAEA is a non-profit patient advocacy organization dedicated to serving the estimated 6,000 HAE sufferers in the U.S. We provide a support network and a wide range of personalized services for patients and their families. We are also 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

U.S. HAEA recommends that Congress provide an overall funding level of \$36 billion for NIH in fiscal year 2018. In addition, U.S. HAEA urges Congress to include recommendations in accompanying committee reports emphasizing the importance of advancing HAE research per the findings of the October 2014 scientific conference, Expanding Boundaries of our HAE Knowledge.

In October 2014, the NIH National Institute of Allergy and Infectious Diseases (NIAID), the National Center for Advancing Translational Sciences (NCATS), and U.S. HAEA partnered on the state-of-the-science conference, Expanding Boundaries of our HAE Knowledge. This conference brought together top HAE researchers as well as other medical researchers across disciplines in order to identify promising avenues for future research. NIH should capitalize on this conference by issuing requests for applications or other opportunities for HAE research based on the findings of the conference.

As a rare disease community, HAE patients are also stakeholders of the Office of Rare Diseases Research (ORDR) and may benefit from programs like the Therapeutics for Rare and Neglected Diseases (TRND) program. U.S. HAEA also urges Congress to robustly support NCATS and the NIH rare disease portfolio in fiscal year 2018.

CDC PUBLIC AWARENESS AND EDUCATION TO PREVENT HAE DEATHS

In order to prevent deaths, eliminate unnecessary surgeries, and improve patients' quality of life, it is critical that CDC pursue programs to educate the public and medical professionals about HAE in fiscal year 2018.

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 help patients lead a productive life. Education and awareness is needed to reach patients and providers with this message.

Thank you for the opportunity to present the views of the HAE patient community. I hope Congress will support research and education on HAE.

ADDITIONAL MEDICAL RESEARCH ACTIVITIES

For many years (including fiscal year 2017), Congress has included HAE as a condition eligible for study through the Department of Defense Peer-Reviewed Medical Research Program. This opportunity has led to many researchers successfully competing for funding with meritorious research projects that have advanced our scientific understanding of HAE. Further, emerging research has linked HAE episodes to Post-Traumatic Stress Disorder (PTSD) and general anxiety disorder, both of which have a higher prevalence in military service member populations. To capitalize on recent progress and opportunities in this area, please work with your col-

leagues on the Appropriations Committee to ensure HAE is once again recognized as a condition eligible for study in fiscal year 2018.

PATIENT PERSPECTIVE

HAE Patient Testimony

—*John Williamson from Texas*

My name is John Williamson and I was diagnosed with HAE as an infant by physicians at the U.S. Navel Hospital in Jacksonville FL where my mother was stationed at the time. My story illustrates HAE's profoundly negative impact on patients and their families.

Our HAE journey began with my grandmother who, due to the lack of knowledge about HAE, was subject to numerous unnecessary exploratory surgeries. Several of her organs were removed because surgeons did not understand that HAE was the cause of her severe abdominal pain.

Tragically, my mother has experienced altogether too many nearly fatal swelling attacks. On one occasion, she went to the local E.R. with throat swelling, but was misdiagnosed as having an allergic reaction, turned away, and sent home. Less than an hour later her throat closed completely, she stopped breathing and lost consciousness. Luckily a family friend was there to call 911. Her situation was so grave that paramedics had to preform an emergency tracheotomy in the ambulance. As a result, my mother was on a breathing machine for several weeks, and doctors told my grandparents that that she was dying and, ". . . not likely to make it."

Her severe HAE was the primary reason my father left us. Having met many others with HAE, I notice an unfortunate trend in broken families due to a spouse not being able to deal with the turmoil causes by frequent and severe HAE symptoms.

I began having attacks about the third grade. My symptoms involved extreme abdominal pain and vomiting along with swelling in my hands and feet. I endured many hospitalizations due to these horrific and debilitating swelling attacks. At age 14, I began taking anabolic steroids—the only treatment available at the time. This severely toxic medicine did little to alleviate my symptoms, but brought on severe side effects.

Growing up I never made plans for the future, thinking, "What's the point, I am always sick and I am likely to die from throat swelling." School was always a challenge because I would inevitably fall behind after frequent absences due to HAE attacks. Later in life, maintaining a steady job was also difficult. I lost jobs because painful and disfiguring HAE attacks forced me to miss work. All in all, I spent a good part of my life in fear of the next HAE attack, while fighting to maintain a positive attitude.

I am pleased to report that recently approved therapies have led to some improvements in the quality of life experienced by my family and me. Nevertheless, so much remains to be done! On behalf of my family and the HAE community, I encourage to the Committee to fund public education, awareness and research initiatives outlined in this testimony.

[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 48 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 2018 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 \$1.7 million above the fiscal year 2016 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.

—\$30 million in discretionary funds as requested by the American Indian Higher Education Consortium for Title III–A (Section 316) of the Higher Education Act, \$2.4 million above the fiscal year 2016 level.

—Support the recommendations of the House and Senate Appropriations Committees in fiscal year 2017 to provide sufficient funding to the Pell Grant program which, when combined with the mandatory funding, would provide the maximum Pell Grant award of \$5,935. We also support the Senate Committee recommendation to allow students to receive Pell Grants year-round.

—*Section 117 Perkins Funding.*—Trially Controlled Career and Technical Institutions. We appreciate the \$500,000 increase for Section 117 Perkins in fiscal year 2016. This funding level finally brought Section 117 Perkins back to its fiscal year 2012 pre-sequestration level. Funding for other programs authorized under the Perkins Act were restored several years earlier. Perhaps Section 117 was overlooked as a source of career readiness and job training because these funds had been moved to the Higher Education portion of the budget, rather than staying in the Career and Technical Education account. 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. The hospital facilities in the regions were unable to hire certified Medical Coding & Billing personnel so we developed and currently offer this certificate as one of our online offerings. We are now able to train students for good paying in-demand employment with a focus on career rather than just a job. Finally, upon receiving approval by the Higher Learning Commission to offer a Bachelor's Degree in Environmental Science, we began this 4-year program in the Fall of 2016, thus providing experiential research opportunities for our students.

Funding for United Tribes Technical College is a good investment. We have:

—Renewed unrestricted accreditation from the Higher Learning Commission for July 2011 through 2021. We offer 1 diploma, 4 certificates, 16 Associate degrees, and 4 Bachelor degree programs of study (Criminal Justice; Elementary Education; Business Administration; Environmental Science). Business Management, Criminal Justice, Medical Coding and General Studies are fully available and offered 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).

—A semester retention rate of 66 percent and a graduate placement rate of 73 percent.

—Students from 49 tribes represented at UTTC.

—Our students are very low income, and 70.4 percent of our undergraduate students receive Pell Grants.

—An unduplicated count of 524 undergraduate degree-seeking students and 4 non-degree seeking students; 1,114 continuing education students; and 29 dual credit enrollment high school students for a total of 1,671 students for 2016–2017.

—A critical role in the regional economy. Our presence brings at least \$34 million annually to the economy of the Bismarck region. 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.

Title III–A (Section 316) Strengthening Institutions.—The Title III–A Strengthening Institutions funding is very important for all the tribal colleges and we sup-

port the American Indian Higher Education Consortium's request of \$30 million for discretionary funding, \$2.4 million above fiscal year 2016. 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. New buildings are actually cheaper than rehabilitating the old buildings that now house students. We are hopeful that a shovel ready 32-unit housing project estimated at \$6.8 million will be considered as an infrastructure project in the upcoming year.

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 has 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 2017 Appropriations Committees recommendations to provide the maximum Pell Grant award of \$5,935 and the Senate Committee proposal to reinstate year-round Pell Grant eligibility, 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.

The Duplication or Overlapping Issue.—As you know in March 2011, the Government Accountability Office issued two reports regarding Federal programs which may have similar or overlapping services or objectives (GAO-11-474R and GAO-11-318SP). Funding from the Bureau of Indian Education and the Department of Education's Carl Perkins Act for Tribally Controlled Postsecondary Career and Technical Education were among the programs listed in the reports. The full GAO report did not recommend defunding these programs; rather, it posed the possibility of consolidation of these programs to save administrative costs. We are not in disagreement about possible consolidation of our funding sources, as long as program funds are not cut.

The Perkins funds supplement, but do not duplicate, the BIE funds. Both sources of funding are necessary to the frugal maintenance of our institution. We actively seek alternative funding to assist with academic programming, deferred maintenance, and scholarship assistance, among other things. The need for career and technical education in Indian Country is so great and the funding so small that there is little chance for duplicative funding. United Tribes Technical College and Navajo Technical University, who focus on career and technical education, received combined only \$15.1 million in fiscal year 2016 Federal operational funds (\$8.2 million from Perkins; \$6.9 million from the BIE). That is not an excessive amount for two campus-based institutions who offer a broad array of programs geared toward the educational and cultural needs of their students and who teach job-producing skills.

We invite the Chair, Ranking Member and all members of this Subcommittee to visit United Tribes Technical College—we are in close proximity to the Bismarck airport. We would be honored and pleased to arrange such a visit.

Thank you for your consideration of our requests.

[This statement was submitted by Leander “Russ” McDonald, PhD, President, United Tribes Technical College.]

PREPARED STATEMENT OF THE VIRGINIA YOUNG DEMOCRATS

The Virginia Young Democrats—the statewide organization for Democrats under the age of 36 in Virginia representing 44 chapters and over 10,000 members—appreciates the opportunity to submit testimony to the Senate Labor, Health and Human Services, Education, and Related Agencies (LHHS) Appropriations Subcommittee.

VAYD encourages the subcommittee to fully fund Title IV-A: Student Support and Academic Achievement Grants at the \$1.65 billion authorization level. These grants provide unprecedented flexibility for States and districts to identify their students’ unique needs and to address these challenges in a well-rounded and holistic manner. At the current fiscal year 2017 Funding level, Virginia districts and schools will be forced to choose between vital programs including STEAM courses, college counseling, and mental health services. When schools and districts are put into these positions, students will ultimately lose out.

VAYD encourages the subcommittee to maintain funding for the Carl D. Perkins Career and Technical Education Act. Virginia is a national leader in workforce development and we take pride in providing all students with opportunities to find a fulfilling career pathway. Beginning with the class of 2017, all high school graduates in Virginia will be required to have earned a career and technical education credential setting them off on a solid footing before they even graduate. Teachers, districts and schools depend on Perkins CTE funding to be able to provide adequate training for these credentials; therefore, it is absolutely essential that these funds are maintained in the coming fiscal year.

VAYD urges the committee to reject the proposal from the President’s budget to eliminate Federal subsidies for student loans. Subsidized student loans benefit students with demonstrated financial need by covering the cost of their interest payments while they are enrolled in college. In 2016, students attending colleges and universities in Virginia took out over \$2 billion in student loans. If this change were enacted, it will significantly increase the cost of student borrowing and create perverse and unacceptable disincentives for students to attend college or university.

VAYD encourages the committee to maintain funding for TRIO and GEAR-Up funding. TRIO programs are housed at [XX] colleges and universities in Virginia and they provide counseling, advising and support services to hundreds of low income or first-generation students across the commonwealth. We now have 17 school districts that have partnered with GEAR-UP to offer college prep and skill development to cohorts of students from grade 7 through their first year of college. The President’s budget proposal threatens the success of TRIO and GEAR-UP by cutting their funding by 15 percent and 34 percent respectively. This would disproportionately impact students of color, students whose first language is not English, students from low-income backgrounds, and first-generation college students—precisely the groups that need the most support.

[This statement was submitted by James Lewis, President and Cristina Diaz-Torres, Education Caucus Chair.]

PREPARED STATEMENT OF THE WASHINGTON STATE LONG-TERM CARE OMBUDSMAN PROGRAM

Thank you for your ongoing support of the State Long-Term Care Ombudsman Programs (SLTCOPs) and for vulnerable adults served by them. I’m submitting this testimony on behalf of thousands of Washingtonians who live in licensed long-term care settings, which include our State’s residential habilitation centers and State operated Veteran’s Homes, and in collaboration with the National Association of State Long-Term Care Ombudsman Programs (NASOP). This statement and the following funding recommendations are respectfully submitted for the fiscal year 2018 for the State Long-Term Care Ombudsman Programs administered through the Administration for Community Living, within the Department of Health and Human Services, and include:

- \$5 million authorized under the Elder Justice Act for Long-Term Care Ombudsman Program (LTCOP) services and training to fight elder abuse, neglect, and exploitation;
- \$16.6 million authorized under Title VII of the Older Americans Act for LTCOPs to partially restore funding back to the fiscal year 2011 level; and
- \$20 million for LTCOP services to be provided in assisted living facilities.

I am requesting your assistance to further our progress toward achieving the goal of assuring access to long-term care ombudsman services for all who need them.

As you know, the Long-Term Care Ombudsman Program was established by Congress under the Older Americans Act of 1965 as a first line of protection for the health and welfare of elders and individuals living with disabilities who live within nursing homes. Enacted by Congress in 1978, the SLTCOP is the only program in the Older Americans Act that specifically serves residents of long-term care facilities.

- SLTCOPs provide direct advocacy services to help stop elder abuse and neglect.
- We resolve complaints and problems before they escalate, working for an improved quality of life and improved care. We also save States, Medicare and Medicaid money by resolving problems at the lowest level, keeping them out of the expensive regulatory system and legal system.
- SLTCOPs go directly to the “bedside” of residents, informing them and their family members of their legal rights, options in care and helping them maneuver through the complicated health and long-term care systems.
- We also gather data about our work, and about how our long-term care system is doing. We track complaint data to inform the public, the licensing oversight system and lawmakers.
- SLTCOPs collaborate with the Department of Justice, the Centers for Medicare and Medicaid Services, State licensing and regulatory agencies, the Area Agencies on Aging, State Adult Protective Services, local lawmakers, providers, and others to advocate for a quality long-term care system for all vulnerable adults.

It is a well-known fact that our aging population is growing, and we see the need for ombudsman services growing too. Most SLTCOPs harness the strength of volunteers to deliver ombuds services. Many of our volunteers are retirees who want to give back to their local communities. We are very proud that the Washington State LTCOP boasts 350 volunteers strong! But to meet the growth, we need more volunteers and more staff to support their work and we respectfully request the following funding as an investment in all State Long-Term Care Ombudsman Programs.

We request \$5,000,000 under the Elder Justice Act (EJA). This appropriation would allow States to hire additional staff to recruit and support ombudsman volunteers. Although the funds have been authorized since 2010, to date no EJA funds have been appropriated to State Long-Term Care Ombudsman Programs.

Second, we request \$16,621,101, which is authorized by Congress in Title VII of the Older Americans Act. Title VII programs already receive limited funding, and the impact of sequestration and inflation has drained services further, which is evidenced by an overall decline in ombudsman case work. The request of \$16,621,101 is less than the fiscal year 2011 appropriation level of \$16.83 million.

Third, we request \$19,980,000 to support SLTCOP work with residents of assisted living and similar community-based long term care settings. While the mandate to serve residents in assisted living was added to our mission by the 1981 amendments to the Older Americans Act, there were no new appropriations for the needed expansion of the program. Since 1981, assisted living and similar community based homes have boomed in size, but SLTCOP funding has not increased to meet the growth and the needs of residents living in these settings. For example, in 2015, while long-term care ombudsmen visited 67 percent of nursing homes on a quarterly basis across our Nation, only 27 percent of assisted living facilities received a quarterly visit. The health profiles of assisted living residents have also changed over time. Assisted living facilities serve frail elders similar to those living in nursing homes. They also serve individuals who have complex medical needs, persons with dementia, and individuals who have chronic mental health issues. Current funding levels preclude SLTCOPs from responding to complaints and monitoring facilities adequately and promptly.

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. LTC Ombudsmen are required to inform residents and their family members of less restrictive (often less expensive) options in care and services available through Medicaid and Medicare. Further, in 2015, nearly 7,734 volunteers served in the SLTCOP. For every one staff ombudsman, six volunteer ombudsmen serve residents. Using volunteers keeps program costs to a minimum and reaches more residents, more often. Ombudsman staff and volunteers investigated 199,238 complaints made by 129,559 individuals. Ombudsmen were able to resolve or partially resolve 74 percent—or three out of every four complaints investigated. In addition, ombudsman representatives provided information on rights, care, and related services approximately 520,000 times.

In 2016, Washington State had 3,543 licensed long-term care facilities with approximately 69,288 licensed beds. The Washington State LTC Ombudsman Office

has a team of three full-time staff, 12 local subcontractors who employ 15 certified ombudsmen and 350 volunteers. Last year we received 4,480 complaints, resolving nearly 90 percent of all complaints “in house” and keeping them out of the regulatory and court systems. Our volunteers donated 39,222 hours to the program and 56,448 consultations were provided to consumers, providers of care, and others. Because of budget constraints we are only able to visit 52 percent of all licensed homes over a year’s time across our State. In King County, where the majority of adult family homes are located, we are only able to visit 25 percent of existing homes. Unfortunately, nearly half of long-term care residents in our State will never receive a routine visit from an ombudsman.

Currently, Federal Older Americans Act funding comprises about 32 percent of the total funding required to maintain the Washington State program at its current level. Additional funding would support ombudsman elder justice work, help us recruit cost-saving volunteers, and help the growing number of assisted living residents get the quality of care and dignity they deserve.

Demand for our services is growing. The number of complex and very troubling cases that long-term care ombudsmen investigate has been steadily increasing. As more vulnerable adults are served in the community, we see an increase in complex care to include mental healthcare being delivered in less restrictive and “lower” cost settings, which is overall a good thing for consumers. However, the “age wave” coupled with more complex care demands, and limited resources places additional pressures onto our long-term care system. Ombudsmen are needed now more than ever as a constant presence and as the first line of protection in our nursing homes, assisted living, and similar care facilities.

Thank you for your ongoing support and consideration of our request.

[This statement was submitted by Patricia Hunter, Member, National Association of State Long-Term Care Ombudsman Programs.]

PREPARED STATEMENT OF THE ZIKA COALITION

The Steering Committee of the Zika Coalition, a group of nearly 100 organizations representing patients, healthcare providers, persons with intellectual and developmental disabilities, public health, and businesses, respectfully submits testimony regarding fiscal year 2018 funding related to combating Zika virus. More information on the Zika Coalition, including membership, can be found at <http://www.marchofdimes.org/advocacy/zika-coalition.aspx>.

We urge you to include ample funding to combat the Zika virus in the fiscal year 2018 appropriations bills. We commend Congress for providing supplemental funding for fiscal year 2017, but it is imperative that Congress sustain that investment in fiscal year 2018 and beyond.

Zika virus remains a significant public health threat. Over 200 individuals have been infected with Zika through local transmission in two states, while nearly 5,000 Americans across the country have travel-related infections. Among these are roughly 1,800 pregnant women, whose pregnancies are at risk for the serious birth defects Zika can cause. These numbers are dramatically higher in the US territories, where more than 36,000 people and roughly 3,800 pregnant women, mostly in Puerto Rico, have been infected locally.

We are disappointed that the President’s Budget Request does not provide adequate resources to combat this ongoing public health threat. Therefore, it is imperative that the Subcommittee fund the following programs at the recommended levels specified below in the fiscal year 2018 Labor, Health and Human Services, Education, and Related Agencies (Labor-HHS) Appropriations Bill.

National Institutes of Health

The Coalition recommends \$34.1 billion for the National Institutes of Health (a \$2 billion increase over the fiscal year 2017 enacted level), with a proportionate increase for the National Institutes of Allergy and Infectious Disease (NIAID) and the Eunice Kennedy Shriver National Institute for Child Health and Human Development (NICHD).

Thanks to previous Federal investment, NIAID is making significant progress toward developing a Zika vaccine. However, much of this research is at a critical stage and can only progress with adequate funding. NIAID predicts that, given appropriate resources, a Zika vaccine will likely become commercially available within the next few years.

An effective Federal response must include research, prevention and treatment. NICHD is investigating how Zika virus infection affects reproductive health and pregnancy, along with the development and health of children exposed to Zika virus

in the womb. This work is critical in understanding the impacts of the Zika virus, and how they may be mitigated.

Within NIH, we specifically request \$10 million for the Zika in Pregnancy (ZIP) Study, which is being conducted as a partnership between NIAID and NICHD. The study follows women from their first trimester throughout their pregnancies to determine if they become infected with Zika virus and, if so, health consequences for both mother and child. Infants are followed for at least 1 year after birth to track their development. In only the first year of operation, the study has provided valuable information on this rapidly emerging disease and its impacts.

Title V Maternal & Child Health Services Block Grant

The Zika Coalition recommends that the Title V Maternal and Child Health (MCH) Block Grant at the Health Resources and Services Administration be funded at \$650 million, an increase of \$300,000 over fiscal year 2017.

The Title V MCH Block Grant is distributed to 59 States and jurisdictions to address the health needs of mothers, infants and children, which includes children with special healthcare needs and their families. From the onset of awareness about the Zika virus, Title V programs have been supporting the response to Zika through activities including: disseminating public health information and prevention tools and supplies to providers and the public; providing the 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 Zika Coalition urges that funding for the Title V MCH Block Grant be increased in order to assist State, territorial and tribal programs in meeting the increasing demands of Zika prevention and the expected increase in affected families who will require additional services.

Centers for Disease Control and Prevention (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD)

The Coalition requests \$152.61 million (\$15.1 million over fiscal year 2017) for this Center.

NCBDDD is the lead Federal agency tasked with supporting vital surveillance, research, and prevention activities aimed at birth defects and developmental disabilities. Given the center's expertise, NCBDDD staff are playing a key role in the international and domestic response to the Zika virus. With reprogrammed funds and supplemental funding provided in fiscal year 2017, NCBDDD has helped build 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 that has improved our understanding of the impact of Zika virus on pregnant women and infants. These funds are critical to support ongoing Zika-related birth defects prevention, surveillance and research activities

CDC National Center for Emerging and Zoonotic Infectious Diseases (NCEZID)

The Coalition recommends \$630 million (\$98 million over fiscal year 2017) for NCEZID.

NCEZID is the CDC's core infectious disease program, charged with detecting and responding to infectious disease outbreaks. NCEZID has played a pivotal role in responding to the Zika virus, including supporting local surveillance and vector control programs, providing guidance on laboratory testing for Zika virus, and operating the Zika Pregnancy Registry. Within NCEZID, the Epidemiology and Laboratory Capacity cooperative agreement is pivotal in ensuring State, local, tribal, and territorial governments can strengthen public health workforce, disease detection systems, laboratory capacity and health information capacity to react to this threat. We ask that a substantial portion of these funds be directed toward activities to strengthen epidemiologic surveillance and investigation, improve mosquito control and monitoring, and bolster laboratory capacity in State, territorial, tribal, and local public health departments.

CDC Public Health Emergency Preparedness Cooperative Agreements (PHEP)

The Coalition requests \$705 million (\$45 million over fiscal year 2017) for CDC's Public Health Emergency Preparedness Cooperative Agreements (PHEP).

PHEP supports State, local, tribal and territorial public health departments' ability to respond to public health crises. Increased funds will enable communities to maintain new systems created with the supplemental funds, including the capacity to identify and investigate a potential or ongoing 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 sup-

plies. The Zika Coalition requests \$705 million for PHEP to sustain current Zika response efforts.

Conclusion

The Zika Coalition looks forward to working with you throughout the appropriations process to ensure that our country's resources to fight the Zika virus and to mitigate its impacts are adequately funded.